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A Life Disrupted: Still Lived

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A life disrupted: Still lived

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Abstract

This research illustrates the experience of living with hallucinations from the perspective of being, and sought to answer the questions: what is the meaning of hallucinations and how do hallucinations connect to one's sense of self?

A phenomenological Heideggerian hermeneutic approach was used to guide data collection and analysis. In this study, 12 individuals with schizophrenia or schizoaffective disorders were asked to describe their experience of hallucinations within the context of being. An overarching constitutive pattern emerged with four themes. The constitutive pattern, "A Life disrupted: Still lived," described a pattern of survival and perseverance on one's own terms; a common thread that emanated throughout the other themes. For these participants the four themes that epitomized living a life with hallucinations were: (a) Are they who they are? (b) A not so certain life, (c) Finding strength in the broken places, and (d) I am still me. *Are they who they are* described both a cognitive search and emotional appraisal of the structure of the hallucinatory experience. Who and what is it? The confusion and fear participants articulated, and attempting to make some sense out of the experience bore a close resemblance to the mechanism of order emerging from chaos. *A not so certain life* illustrated a picture of living with a chronic illness. Participants described the same waxing and waning of the disease, the lifelong picture of living with a disease, and the same ambiguous perspective of treatment. Participants also spoke of living a life of loss. This loss and subsequent grief in the face of stigma and self-

perceived stigma were analogous to disenfranchised loss. Nonetheless, participants

referred to making small and daily gains as a way of deriving meaning from this

experience. *Finding strength in the broken places* was this process of lending a different

kind of meaning to this experience as integral to surviving mental illness. There was

some disparity with the literature concerning the usefulness of language that emphasized

mastery and self-empowerment. This language served to be more overwhelming than

helpful and clients visualized "getting better" in small ways with small daily gains.

Heidegger's language of care as *leaping in* and *leaping ahead* more closely depicted

nursing's goal of intervening in the day-to-day needs, as well as the long-range goal of

self-empowerment. Additionally, despite literature that conceptualizes a lost or

disintegrating self, almost all participants agreed that hallucinations were not expressive

of their intrinsic being, rather, "who they were" their "being" remained separate from

their hallucinations. *I am still me* described a *persistent sense of self*, defined as a sense

of being that remained consistent throughout.

CHAPTER 1

Introduction

"Many things come out of my lovely blue eyes...bedsteads, commodes, baskets,

thread, stockings, of all colors, clothed from the plainest to the most elegant; and finally

people fly out, fortunately, not naked but completely dressed" E. Bleuler (as cited in,

Saas, 1950/1991, pp. 111-112).

Behrendt (1998) defined hallucinations as "perceptions that occur without an

object" (p. 236). Hallucinations may occur in any one of the five senses. The word

hallucination is derived from the Latin word allucinari-"to wander," and in a sense, there

is a kind of wandering within the mind (*Oxford English Dictionary*, 1989, p. 1047).

Hallucinations are further described by the *Oxford English Dictionary* as "an apparent

perception of an external object, when no such object is actually present" (1989, p. 1047).

Hallucinations are associated with psychiatric symptoms, and in the *Diagnostic and*

Statistics Manual (DSM IV-TR, 1994) the diagnosis of schizophrenia requires a

frequency and severity of hallucinations and delusions that are present for a significant

portion of time. *DSM IV* further defines hallucinations as "a sensory perception that has

the compelling sense of reality, but occurs without external stimulation" (1994, p. 769).

Historically, hallucination research has traditionally been etiology-based, and

subsequent intervention and treatment have been driven by psychobiological theories.

Psychodynamic theorists propose that hallucinations occur in response to id desires to

regulate anxiety, overcome traumatic experiences, or maintain id, superego, and ego

balance (Schneck, 1989). The psychodynamic treatment response has been therapy to

explore id desires and maintain balance with the ego. Freud (1924) held that voices were meaningful, the result of intra-psychic conflict and a return to the defensive functioning of early childhood. Accusatory voices were seen as a response to a harsh superego expressing criticism toward the drives of id, and advisory voices were viewed as a response from both the ego and the superego. Some psychoanalytic theorists draw attention to the similarity between hallucinations and dreams. Jung suggests that hallucinations symbolically express wishes that may be unacceptable to the conscious mind. Jungian theory views an emotional complex (a set of feelings) as overpowering, breaking away from the psyche and taking the form of visions or voices that speak to the person (Jung, 1939).

Cognitive behaviorists propose that hallucinations are one means of alleviating unwanted or excessive stimuli (Read, 1999). Beck and Rechtor (2003) believed that excessive stimuli may cause one to cross a perceptual threshold and therefore experience hallucinations. Beck and Rechtor (2003) hypothesized that hypervalent *cognitions* or hot spots exceed a previously low threshold for hallucinations. In other words, hallucinations may occur when the internal or environmental demands exceed the threshold level, i.e., fatigue, isolation, stress. Hallucinations are thus maintained by basic core beliefs (delusions), and the relationship the individual has with the hallucinations. Additionally, Beck and Rechtor (2003) suggest that there may be a neurological predisposition to this phenomenon. The authors posit that excessive cortical pruning during adolescence lowers the ability to reality test and impairs reasoning to the extent that the individual uses primitive reasoning strategies. For example, emotion-based reasoning

predominates--"I feel I know this voice, therefore it must be real." Additionally the
authors suggest "cerebral flooding of dopamine and other transmitters (possibly in
response to neuronal loss) starts to hyper prime the salient cognitions (self-evaluative,
intrusive or obsessive) and leads to their crossing the person's perceptual threshold to
hallucinations (p. 19)." In effect, as the individual entertains false beliefs, is predisposed
biologically, possesses deficiencies in reality testing and reasoning, and without the
normal restraints (e.g. stress, fatigue) the result is a "progression of hot thoughts to voices
(p. 19)."

Other cognitive theorists state that hearing voices may be a meaningful response
expressing emotionally unprocessed events (Haddock, Bentall & Slade 1993; Honig et al.
1998; Romme & Escher, 1989). This is consistent with the experience of hallucinations
subsequent to trauma, and as experienced by victims of torture (Ensink, as cited in
Romme & Escher, 1993). Treatment that is driven by this theoretical perspective
includes therapy and learned interventions for the patient (cognitive restructuring).
Recent studies (Read, 1999; Ellenson, 1986) suggest a relationship among hallucinations,
the onset of schizophrenia, and physical and sexual abuse. Incest, in particular, has been
related to the likelihood of hallucinations and the onset of schizophrenia (Read, 1999).
The findings of Perry and Pate (1994) further suggest neurodevelopmental sequlae as a
result of childhood trauma. The advent of the "decade of the brain" has created a renewed
focus on neurobiological etiology arising from genetic, chemical, and structural changes.

Neurobiologists theorize that hallucinations may be caused by arrested cortical
development or "cortical pruning" of synapses thus reflecting a reduction in cortical

connections (Feinberg, 1983; Hoffman & McGlashan, 1997; Huttenlocher, 1979).

Hoffman and McGlashan further posit that it is the synaptic pruning during adolescence (which would explain the initial diagnoses in adolescence or early adulthood) that reflects abbreviated neuron connectivity as a cause of hallucinations. Additionally, theorists hypothesize that auditory hallucinations are due to an abnormality affecting inner speech. The idea is part of a general theory that identifies a defect in self-monitoring in schizophrenia. Apparently persons with schizophrenia fail to recognize their own inner speech as self-generated, and therefore, experience speech as outside themselves (Brebion, Amador, David, Malaspina, Sharif, & Gorman, 2000). Still, other theorists have suggested that auditory hallucinations may be caused by dysfunction in the language areas of the brain, specifically the auditory cortex in the temporal lobe, or increased blood flow in Broca's area (McGuire & Shah, 1993). With these theoretical perspectives in mind, the ultimate treatment modality has become medication management.

However, treatment that is etiology-focused underestimates the totality of the hallucinatory experience for the individual. Treatment that incorporates multiple theoretical approaches and the human experience may address more fully a phenomenon that is still only partially understood. The management of hallucinations may include individual therapy, cognitive restructuring, and stress management, as well as medication management by a health care team. Evidence of premature cortical pruning may require fresh approaches such as early detection and intervention, particularly in late adolescence. While neurobiological approaches predominate, few studies address the meaning of hallucinations or the relationship of hallucinations to the individual sense of

being or self-concept. In fact, exploring voices apart from diagnostic purposes is discouraged and rendered unimportant from a neurobiological perspective (Jones, Guy & Omrod, 2003; Leudar & Thomas, 2000). Haddock, Bentall & Slade (1996) relate that professionals have been traditionally trained to avoid discussing the content and characteristics of hallucinations with their clients under the belief that doing so will "encourage" either the voices or the client's false beliefs regarding the voices. This stance disallows a true investigation into the meaning hallucinations have for clients. Rather than encourage the voices, it is possible that a dialogue with clients regarding their hallucinations can enhance our understanding of this experience. Additionally, empirical, reductionist research perspectives do not touch on the personal nature or value hallucinations may have for the person who hallucinates. The goal of treatment is often to minimize or erode the experience of hallucinations when the more important question may be "What is this experience like for the individual?" Finally, to effect personalized coping strategies requires an understanding of both the content and the meaning hallucinations have for persons who hallucinate.

Gaps in the literature suggest that there is limited research related to the meaning hallucinations have for the individual, and while there are current studies focusing on hallucinations and personhood, these do not specifically address the relationship between being and hallucinations. Hallucinations often interfere in the daily lives of people with schizophrenia. Hallucinations may be voices or visions that criticize, denigrate, comfort, or support; therefore, it is important to gain a better perspective of how closely these hallucinations are tied to the client's sense of self or being. Although recent studies

explore belief systems and self-esteem, the question remains, "What is this experience like for the client?" An appropriate beginning, therefore, requires a qualitative study that would elicit the nature and extent of that experience for the individual who hallucinates. Research is also needed to explicate the intensely personal nature of hallucinations and to consider the experience of hallucinations within the context of being.

Statement of the Problem

The onset of hallucinations generally predicts worsening psychotic symptomatology (Bustillo, Lauriello, Horan, & Keith, 2001). As a result, mental health professionals continue to deal with repeated and increased number of hospitalizations, recurrence of other psychotic symptomatology, and an increase in the population of the mentally ill within the homeless population (who may not avail themselves of services or are too ill to seek services). Despite advances in neuroleptic medications, a sizable proportion of psychotic clients do not respond to medication, and are likely to relapse, (Heinsen, Lieberman & Kapelowicz, 2000; Bustillo, Lauriello, Horan & Keith, 2001), and up to 23% experience persistent positive symptoms that are resistant to medication (Sheperd, Meiijen, Dean, & Cooney, 1996). Also, symptoms of depression or comorbidity are found in 25-40% of clients with psychosis (Johnston, Owens, Frith, & Leavy, 1991) and there is a concomitantly high risk of suicide (Briera, Schreiber, Dyder, & Packard, 1991). While psychiatric interventions with auditory hallucinations voices are more varied and demonstrate improvement, the results have been disheartening (Bouchard, Vallieres, Roy & Maziad, 1996). The contemporary picture among

disciplines is one of numerous theoretical models and close attention to neurobiological etiology and empirical outcomes.

Research regarding the multiple aspects of hallucinations looks at the quantity, quality, and severity of hallucinations, as well as outcomes resulting from the experience of hallucinations i.e., projected isolation. However, an understanding of the nature of hallucinations is needed. Understanding is needed, in light of a phenomenon that often directs the course of action individuals choose, whether that course of action is to isolate, escape, or respond to commands. The significance for nursing science is that this research builds on a perspective of the client, as an individual with unique and different needs, perspectives and outcomes.

Significance for nursing science

If nurses do not know what the experience of hallucinations is like for the individual how can meaningful interventions be chosen? For the individual, the hallucination, by itself, may have a personal or relational significance; and to that extent our knowledge of that experience is limited. Additionally, if hallucinations challenge core concepts of one's being, knowledge and insight regarding this phenomenon may tell us how hallucinations affect the individual's sense of self. Conversely, hallucination research that focuses on pathology, dangerousness, or the actions resulting from hallucinations may miss important aspects regarding what hallucinations are really like for the individual. Perhaps what is needed is an approach to the phenomenon of hallucinations using multiple perspectives, including, attentiveness to what is happening with the client, what that experience of hallucinations is like for the client, and how

hallucinations affect and impact their sense of being? In doing so, nursing science can

move toward a more complete understanding that lends not only a richness to our

knowledge base, but enables nurses to be better able to assess, decide when to intervene

(if indeed intervention is desired), then, develop interventions to assist the client by

developing a plan of action.

Purpose

The purpose of this qualitative study is to explore the meaning hallucinations have

for the individual within the context of their sense of being. Being is defined as: "the state

or quality of having existence; One's basic or essential nature" (*The American Heritage*

Dictionary, 1985, p.169). Human existence is the experience of the individual presence

and participation in the world. The individual understands existence in terms of the

experience of self-within a defined background of the whole of self and the world (Laing,

1960). The "self" has a need to find purpose and meaning (Erikson, 1962).

Therefore, being cannot be made the subject of an objective inquiry. One of the

aims of this study is to explore the relationship between self and hallucinations. In a

qualitative interview the questions the researcher asks, and the interpretation of the

interaction, are dependent on the philosophical underpinnings of the study.

Theoretical perspective

The philosophical grounding of this study is a Heideggerian hermeneutic

perspective based on the works of the German existentialist Martin Heidegger. Carper

(1978) reminds us that epistemology (the way of knowing) must fit the ontological search

(p. 67). A hermeneutic (interpretive) inquiry revolves around the concept of being. A

philosophy that explores being and is at the same time a research method fits the nature of knowledge sought in this study. A Heideggerian hermeneutic research perspective inherently investigates the meaning of being, and, to this extent lends itself to research that explores hallucinations within the context of being. *The research questions derived from this focus are*: 1) What is the meaning of hallucinations? 2) How do hallucinations connect to one's sense of self?

In summation, this study has multiple goals of enlarging our understanding of the experience of hallucinations, discovering if there is a link between the perception of hallucinations and self and if the link exists, the impact of hallucinations on the individual sense of self or being. This chapter provides an overview of the background, significance and research questions to be explored in this dissertation. Chapter two is a review of current literature and chapter three outlines the method and research design of this study. Chapter four summarizes the findings of this study and chapter five provides analysis of the aforementioned findings.

CHAPTER 2

Literature Review

Introduction

This research project centers on the experiential view of hallucinations from the client's perspective and as related to being. Previously, there has been an accepted view of hallucinations as an entity or phenomenon requiring intervention or treatment. Therefore, the movement in hallucination research has been directed toward development of interventionist research with a gradual focus on distress and belief systems attributed to hallucinations (Farhall & Gehrke, 1997; Birchwood, Meaden, Trower, Gilbert & Planestow, 2000), and in the end, perspectives that view the entirety of the experience. The intention of this review is not to cover the gamut of hallucination research, but rather, to illustrate the progression of our perception and understanding of this phenomenon. The quantitative review of literature studies the efficacy of cognitive-behavioral therapies (Farhall & Gehrke, 1997), clients' coping strategies (Bucherri, Trygstad & Dowling, 1997), clients' beliefs about their voices (Birchwood, Meaden, Trower & Planestow, 2000), and connections between clients' beliefs about their voices and their coping responses (Sayer, Ritter, & Gounay, 2000).

More recently, ownership of voices is a continuing theme as studies indicate value in acknowledging giving voice to hallucinations both individually and in a group context (Hayne & Younge, 1997; Martin, 2000). A qualitative mode of inquiry fits the exploration and hence the understanding of this phenomenon. Understanding of the lived experience (Hayne & Younge, 1997), moving into the client's world, and using

the client's voice become our epistemological tools; whether narratives highlight…

"making sense of hallucinations"… (Casey & Long, 2002), the waking/sleeping

interaction of dreams and hallucinations (Levin & Daly, 1998), or demonstrate that

hallucinations can be both a source of stress and a means of coping (Shaw, McFarlane

& Bookless, 1997). In reviewing both quantitative and qualitative studies, it is my

intention to emphasize the differences between studies that focus on what nurses can do

about hallucinations and studies that investigate the client's personal experience of

hallucinations.

Quantitative research studies

These studies were chosen from research literature that concentrates on clients'

beliefs and attitudes about their hallucinations and management of those hallucinations.

Additionally, these studies highlight interventionist approaches directed toward the

effectiveness of strategies aimed at diminishing or reducing hallucinations. Specifically,

cognitive-behavioral approaches are the current focus of nursing interventions, and

accordingly, are the focus of this review of quantitative studies.

Recent research is beginning to look at relationships between the client and the

voice, particularly in terms of the client's belief system regarding their voices.

Birchwood, Meaden, Trower, Gilbert, and Planestow (2000) suggested that distress and

behavior are shaped by beliefs about the voices' status, identity and purpose. The

authors investigated the distress associated with these voices. Birchwood et al.

concluded that distress associated with voices was linked not so much to voice content

but to the individual's beliefs about those voices. In this study, the authors (Birchwood

et. al., 2000) examined the client's relationship with the voice within the larger framework of social relationships. Additionally, the researchers hypothesized that perception of the client's own social ranking influences beliefs about voices, measures of power, and social rank, thus, participants were asked to identify their dominant voice. The authors assumed that the dominant voice would create the most distress. The sample size consisted of 59 clients, 39 males and 20 females, who had heard voices for at least two years. The authors predicted that those individuals who are of lower rank or perceive themselves to be of lower rank on the social scale would "be more entrapped by their voice, will be significantly more depressed than those who do not, and that such autocratic subordination will also be apparent in the client's wider social relationships" (p.338). Instruments used in this study were the Hustig and Hufner (1990) scale measuring voice topography; the Beck Depression Inventory, Belief about Voices Questionnaire (BAVQ), the Social Power Differential Scale (SPD, the Voice Power Differential scale (VPD) and the Social Comparison Scales (SCS).

Results supported the authors' hypothesis that "the difference in rank between voice and voice hearer is mirrored in social rank differences between self and others" (Birchwood, Meaden, Trower, Gilbert & Planestow, 2000, p. 343). That is, power attributed to the voice is related to the voice-hearers' own sense of personal status within a larger social context. The authors suggested "treating the psychosis alone does not guarantee the alleviation of symptoms, feelings of depression, sense of marginalization, or loss of self-esteem" (Birchwood, Meaden, Trower, & Planestow, 2000, p.343).

While the beliefs verbalized still require further investigation, the significance lies in the purported relationship the client has with the voice and their personal history of social ranking and social relationships. The view that clients' voices are a separate component appears less rigid, and there exists the possibility that clients' relationship with, and response to, their voices may be dependent on past social schemata. That is, clients' beliefs about their voices also affect the relationship with the voice, consistent with their own personal schemas. The researchers concluded that the client's belief system and the relationship with their voices are an ongoing concern for mental health professionals.

Bucherri, Trygstad, and Dowling (1997) evaluated the effectiveness of behavioral management strategies in individuals who experienced persistent auditory hallucinations. Using an experimental design with randomization of subjects, individual differences in the experience of hallucinations, their responses, and the use of management strategies were noted. Twelve veterans with a diagnosis of schizophrenia were study participants. The mean age was 50.25 within a range of 30-77 years. The age at which participants first heard voices ranged from 17-37 years. Two participants were female and ten were male. Six participants were African –American, five were Caucasian and one was Asian. Two groups were followed. Subjects in the experimental group attended a weekly class for 12 weeks on symptom management, in which 11 strategies of self-management were practiced. Control participants attended a weekly day treatment class for 12 weeks.

Those who attended the experimental symptom-management class were followed at three, six, nine, and 12 months. Follow-up data of individual variations in the experience of auditory hallucinations and response to behavioral management strategies were collected during scheduled meetings. A hallucination scale (Auditory Hallucinations Follow-Up Questionnaire) was used to determine the extent, type and severity of the hallucinations. Follow-up questionnaires were sent to those unable to attend. At each data collection point, participants completed the Hustig and Hustig (1990) Auditory Hallucinations Follow-up Questionnaire (AHFQ) designed for the study. Subjects were asked to rate the characteristics of their hallucinations and indicate strategies they are currently using.

Weekly diary scores for the experimental and control groups demonstrated no statistical differences in frequency, loudness, or intrusiveness at the end of the twelve weeks. However, 75% of the participants in the 12 week class related that they found help in coping with persistent auditory hallucinations. Participants also reported a reduction in symptom severity (the mean score dropped from 4.0 for clarity, 3.8 for tone and 3.0 for distractibility to 2.75, 2.6 and 2 respectively). The eleven strategies included: reading aloud, talking with someone, wearing an earplug (left ear), wearing an earplug (right ear), humming, self-monitoring, watching television, listening to music, relaxation tapes, saying "no" and saying stop and go away." Bucherri et al. discovered that while behavioral strategies did not change the hallucinations themselves, or the quality of the hallucinations, many of the strategies were still being used as a means of coping by clients at the one-year follow-up. Even participants who reported using very

few strategies reported using more at the one year follow-up. However, at the end of 12 months participants reported using fewer strategies then at six and nine months. Participants also appeared to creatively use a variety of strategies that included some of those taught in the weekly class, as well as their own strategies. As a result, seven new strategies emerged in this study as by products of participant input. The authors concluded that although the classes appeared helpful, effective treatment for persistent auditory hallucinations is contingent upon the individual.

Farhall and Gehrke (1997) applied a stress and coping framework to the experience of hallucinations. They predicted that coping strategies used by the general population in response to stressful situations would be used by individuals who hallucinate, in addition to strategies reported in the literature in studies of psychosis (p. 259). Eighty-one participants were interviewed in structured interviews regarding their coping response to hallucinations. Ninety-six percent of the clients interviewed had a DSM IV (Diagnostic and Statistical Manual IV TR) diagnosis of schizophrenia. In structured interviews the authors compared passive-coping strategies to resistance-coping strategies used by the clients. Resistance-coping strategies, which are those strategies aimed at eliminating hallucinations and taught by professionals i.e. shouting or ignoring, were less effective. Strategies the clients incorporated on their own, over a period of time (passive-coping), appeared to be more practical. However, the authors were supported in their findings that clients used both general and hallucination-focused strategies. Farhall and Gehrke (1997) also suggested that active acceptance coping may be adaptive (Romme & Escher, 1989).

Sayer, Ritter, and Gounay (2000) also investigated client coping mechanisms as correlated between attribution styles and coping strategies. The authors collected data using Beliefs About Voices Questionnaire (Chadwick and Birchwood, 1997) to distinguish the processes by which individuals identify the characteristics of their voices, and the subsequent coping mechanism used. The sample consisted of 26 people with schizophrenia who were receiving in-client treatment from a London hospital with a psychiatric center attached to the district hospital. The mean age of the sample was 37.6 years ranging from 19 to 65 years. The mean age of the onset of schizophrenia was 22.9 and the mean duration of illness was 15.1 years. The number of male and female respondents was evenly split. The investigator used a 30-item questionnaire (Beliefs About Voices Questionnaire) verifying the dimensions of malevolence, benevolence, engagement, and affective response. Key workers and selected nurses administered a standardized information questionnaire. The same staff then re-administered the questionnaire to the same respondents after an interval of four weeks to assess whether attributional styles had changed over time. The relationship between attribution and coping was measured by categorizing malevolent and benevolent beliefs as attribution styles and resistance and engagement with voices as coping strategies. Scores for each category were calculated at times one and two. Investigators analyzed results using cross-lagged panel analysis of the data. Pearson correlation coefficients were used to calculate correlation.

As the authors predicted, clients identified positive relationships between a resistive coping style and an attribution of malevolence, and between an engaging

coping style and an attribution of benevolence to voices. The relationship between
benevolence and engagement showed the strongest correlation (r=.87 x 1, p< .001;
r=.72 x2, p<.001).

However, attribution and coping styles did not remain static over time, and some
individuals sometimes believed their voices to be both benevolent and malevolent at the
same time. Conversely, other respondents did not believe their voices to be either
benevolent or malevolent.

In times one and two the strongest relationship occurred with benevolence and
engaging. Sayer et al. (2000) infer that a "benign attribution of voices is strongly
associated with coping strategies which encourage involvement with voices" (p. 2003).
The authors suggest that individuals with a malevolent attribution style were more
likely to have an engaging coping style than people with a benevolent attribution style
were to have a resistance coping style.

Similar to the findings of Chadwick and Birchwood (1994) these findings imply
that the relationship between beliefs about voices and the coping style used may
indicate a certain coping pattern, but the predictability of how individuals will respond
is less certain, especially within the element of time. Individuals with hallucinations
may significantly change their coping pattern, not necessarily in response to their
attribution or perception of the malevolence or benevolence of the voices. The results
indicate that in a sample of inpatient and outpatient clients with schizophrenia who hear
voices, there are strong correlations between types of belief systems and coping

strategies. This is particularly true of people who hear benevolent voices and attempt to engage them.

Therefore, the interventions nurses apply may have no bearing on how the client perceives their hallucinations, what strategies clients already use and how those strategies change over time. The researchers suggest that what is needed is a careful assessment and systematic reassessment to determine changes in coping styles, not necessarily connected to the attribution, but rather to the individual.

Additionally, health professionals may be undervaluing the strategies clients already have in place. Currently, professional expectations of what succeeds may not be based on research. While clients appear to be more responsive to voices they identify as benevolent, and appear to resist malevolent voices most of the time, health care professionals cannot assume that coping and attributional styles are either predictable or remain stable over time.

Perhaps, the role of nursing has been so infused with developing strategies aimed at diminishing or eliminating hallucinations that nurses often fail to listen to our clients to ascertain what strategies work and what the desired goals are. Strauss (1989) suggests that mental health professionals "fail to hear details of the subjective experience of clients or to recognize the interrelationship between subjective experience and illness" (1989, p. 181). Voices may tell the client to stop taking their medications or refrain from talking to health care professionals. How the client views the voice and the relationship with the voice may predict the coping strategies that are used (Chadwick & Birchwood, 1994). These studies underscore the role clients have in developing coping

strategies that diminish voices. Therefore, the conceptual view of clients as having "little control" is gradually changing to one of clients having greater self-sufficiency and in-place coping patterns. In fact, clients' integration and preference for self-developed strategies over strategies taught by professionals demonstrates a kind of self-sufficiency and self-empowerment that professionals may have overlooked.

Qualitative research studies

Listening to the subjective experience of our clients is a prerequisite of qualitative research. Qualitative research emerged from a postmodern perspective that saw a growing discordance with empiricist paradigms. Postmodern perspectives challenged the concept of a single reality, an absolute truth. Watson (1988a) writes:

Nursing is undergoing a questioning process as to whether it should continue to align itself with traditional science to improve practice or to abandon science in favor of some other approach to reality. It would be inappropriate and irresponsible to discard science and discount scientific progress, but at the same time, science, as traditionally viewed and presented must be questioned and challenged in nursing and human sciences (p.9).

Listening to what clients tell us can of itself be a coping strategy. Martin (2000) established a group in Manchester with the purpose of providing an opportunity to explore clients' experience of voice hearing. The facilitator's role was the maintenance of a safe and nonjudgmental environment. Using the framework of Romme's Hearing Voices Network was established in the United Kingdom. The goal of the Hearing Voices Network was to establish an environment in which clients shared experiences of auditory hallucinations and developed skills to manage auditory hallucinations. Romme and Escher's protocol was used:

1) To accept the client's experience of the voices

2) To try and understand the different language clients use to

describe their frame of reference as well as the different language

the voices use for communication

3) To consider helping the individual communicate with the voices

to stimulate the client to meet with other people with similar

experiences and to read about hearing voices to diminish the taboo

and isolation (1993).

The group named itself "Harvey" to maintain confidentiality. Participants all

heard voices. They were told that they would have the opportunity to discuss their own

experience of hallucinations. They were also reminded that the group did not offer

therapy, training, or factual information. The group met for 45 minutes weekly on a

voluntary basis.

Evaluation of Harvey's group was a reflective and ongoing process. An evaluative

group session met every three months. Parse's theory of human becoming (1995) and

Romme and Echer's (1993) work with "Hearing Voices" provided the framework for

interpretation. All group members contributed their individual perspectives. A

consensus report was negotiated and agreed upon by group participants. Recurring

themes included:

"I am more sure of myself because it helps you to understand the voices."

"It makes you realize that you are not alone."

"The group has given me a lot of support; it is the closeness that makes it work."

"Talking to other people makes you realize that each person is different; that your own experience of voices are unique." (Martin, p. 139)

While Martin (2000) acknowledged that the process of evaluating Harvey's group did not reflect a high degree of quantitative rigor, and thus the method is open to criticism, the author's hope is that group progression will lead to more formal evaluation approaches. However, the study used components of a qualitative, phenomenological research perspective, including use of subjective narratives and member-checking in the evaluation that disallowed the need for quantitative rigor. Martin also viewed structuring of the experience of the illness by the client (group process) as inherently empowering (2000, p.140). Martin encouraged nurses to be more concerned with empowering the client to verbalize his or her experience and thus impact on both the clients' and nursing's understanding of this phenomenon. While this group may not be suitable for all clients who hear voices (the author acknowledges this), the value of this group lies in coherence and ownership for the clients as participants and evaluators of their own group. Additionally, the uniqueness of a group setting to verbalize aspects of this experience can be at once supportive and a coping resource.

It appears that clients may have coping strategies that work, whether individually or in a group, regardless of the interventions of mental health professionals. While nurses are often confronted with the frightening, persistent qualities of hallucinations, client's attitudes toward their hallucinations may not be an entirely dismal one. In fact, hallucinations may have intrinsic meaning for the client. It is perhaps, because of the

meaning hallucinations have for clients, that in recent years, conceptual thinking of

hallucinations as supportive, protective, or friendly has emerged. Miller, O'Conner, and

Di Pasquale (1993) explored clients' attitudes towards their hallucinations. Miller et al.

conducted a qualitative study of 50 inpatients and examined the course of client

attitudes before and after treatment. Fifty-two percent of clients reported positive

aspects of their hallucinations and of those, 12% stated they would like to continue

hallucinating. The authors also noted that those clients who valued their hallucinations

before treatment, were also more likely to be hallucinating after treatment. The findings

of this study were unique in that they give voice to a more complete experience of

hallucinations for the mentally ill. The study also underscored why treatment adherence

or medication is a difficult regimen for the mentally ill to maintain, particularly, when

hallucinations may not pose that much of a problem to the client. If clients value their

voices to what extent is treatment necessary? This research study provokes certain

questions i.e., at what point do health professionals intervene. Do health professionals

(nurses) intervene at all when clients tell us their hallucinations are comforting or

friendly? The authors suggested that the predictable nature of hallucinations might

make them a viable coping mechanism.

The conceptual view of hallucinations as symptoms indicative of illness or from a

purely medical model may be broadened to include a perspective of hallucinations as

intrinsically meaningful for the client (Berendt, 1995; Chadwick, 1994; Romme, 1998).

In a recent study Romme (1998) compared two patient groups of voice hearers

(individuals who experience auditory hallucinations) and one non-patient group who

heard voices. One group was composed of 18 patients diagnosed with schizophrenia, in the other group there were 15 patients with a disocciative disorder and the final group was composed of non-patients (no reported number). All participants experienced auditory hallucinations. The two patient groups were recruited from a local community mental health center. The non patients were recruited by television and press advertisements. Information about voices was gathered in semi-structured interviews. Pivotal points of interest included questions regarding the criteria differences for hallucinations among the three groups, the involvement and influence of the voices on the three groups, and lastly, differences between the life history of the individuals and their involvement with their voices (Romme, 1998). The interview format included the following guidelines: aspects of the experience itself, characteristics of the voices, circumstances surrounding the initiation of voices, triggers, identity of voices, interpretations of voices, coping strategies, present social network, and experiences in childhood.

The researchers reported that formal criteria for hallucinations as identified by the World Health Organization (WHO, 1974) were essentially the same among all three groups. In terms of the influence of hallucinations on the individual, the nonpatient group found the voices predominantly positive, while the patient groups did not. Finally, life history and the experience of voice hearing demonstrated some real differences among the three groups. In all three groups the author discovered that the onset of voices coincided with a traumatic life event. This life event had greater long-term impact on patients than non- patients. Additionally, the childhood stability and

security of the individuals in the non-patient group appeared to make these individuals

less vulnerable to the negative aspects of hallucinations. Romme (1998) proposed that

hallucinations may be the result of stress and, more importantly, suggests that "it is not

the hearing of the voices that indicates psychopathology, but the way a person copes

with it that create it" (p.43). Romme further considers the symptoms of psychosis,

namely hallucinations, as a way of dealing with life's experiences in a way that has

meaning for the client.

Understanding hallucinations also means understanding the lived experience of

the individual with schizophrenia. An understanding of the lived experience of

individuals with mental illness allows health professionals, an impression of this "life of

craziness." Mental illness is more than a break from reality, or disruption of normal

functioning. There is a growing body of phenomenological literature that describes the

lived experience of the individual with mental illness. Hayne and Younge (1997)

studied the lived experience of individuals with schizophrenia using a hermeneutic

phenomenologic mode of inquiry. Using a convenience sample, forty published first

hand accounts from men, women, and children living with mental illness served as the

data for this study. Ten accounts were narrated by family members and included in the

thematic analysis. Accounts came from journals in the subject areas: *Schizophrenia*

Bulletin, Hospital and Community Psychiatry, The Journal of the California Alliance

for the Mentally Ill. An integral aspect of this study was the recognition that each

individual's experience with persistent mental illness is unique to that individual. Notes

were made and organized around emergent themes. Several readings were undertaken to

further identify and specify themes. Significant statements were extracted using a cut

and paste method. Disclosures of meaning were established through a

phenomenological perspective. Four life worlds (corporeality, spatiality, relationality,

and temporality) provided the framework for discovery. Corporeality denoted the bodily

experience; spatiality referred to the experience of lived space; relationality to

interpersonal relationships; and temporality highlighted a" temporal frame of reference"

(Hayne & Younge, 1997, p. 320). Hayne and Younge discovered that corporeality

referred to a bodily pain, "pain that is expressly palpable" (p.317). Corporeality

included seeing the self as a "body belonging to someone else," "a presence," or "casing

that used to be a body" (p. 317). Clients appeared to view the body as somehow not

belonging to them-as something outside themselves. The authors discovered spatiality

referred to an ill defined self "the absence of self-agency... likened to being swallowed"

(p.318). Clients revealed relationality as a theme and voiced feelings of betrayal and

lack of trust. Clients further expressed "feeling empty" and "in turmoil" (p. 319).

Temporality is expressed as "time unfolds in sick cycles" (p. 323). It is the reality of

chronic illness and a certain acceptance. The authors acknowledge, "the internal

struggle is not always in the forefront, but never does remit entirely either" (p. 323).

Hayne and Younge discovered that in schizophrenia, the primary relationship exists

between the individual and their mind, i.e., "my mind fights against itself" (Ruocchio,

1989, p. 163).

The mind fighting against self is a depiction of self against self. This

fragmentation of self as seen in both nightmares and the hallucinating experience was a

focus of the research conducted by Levin and Daly (1998). Levin and Daly speculated that understanding nightmares, and testing the two experiences of nightmares and hallucinations may reflect more accurately the phenomenological experience for the person who hallucinates. They further suggested "that extreme levels of annihilation, fragmentation, usually accompanied by a strongly kinesthetic component may represent and express phenomenologically the dissolution of self during the onset of a psychotic break" (1998, p.218). That is, the breakdown of individual identity and the feelings associated with the disintegrating self result in psychotic symptomatology. Therefore, Levin and Daly (1998) speculated that dreams serve as reparative functions to stabilize a fragmented self-representation. When these efforts become inadequate, the sensory experiences are no longer contained during REM sleep, and begin to dominate the bulk of the individual waking experience.

Levin and Daly (1998) also theorized that nightmares or dreams could presage or predict schizophrenic decompensation, and also extend the dream (nightmare) period into daytime experiences. The authors presented a case study of a woman who experienced chronic paranoia with two witnessed psychotic relapses in the hospital. These relapses were immediately preceded by vivid nightmare attacks. The content of her nocturnal dreams were consistent theme-wise with waking hallucinations, suggesting a link between these experiences.

The authors (1998) admit their theory is" highly speculative" and difficult to verify and it is worth noting that nightmares may be a continuation or reenactments of daytime hallucinations, or that hallucinations are so fixed as to represent reality for the

individual. There are numerous explanatory scenarios that may be responsible for the onset of nightmares or hallucinations, such as: medications sleep deprivation, stressful events, and current physiological conditions. However, the authors provided an approach to understanding the phenomena of hallucinations, through the use of dreams and nightmares that could provide some insight regarding the etiology of waking hallucinations. The phenomenological description of dreams and the link between wakeful hallucinations is worth investigating in terms of continuing to gather data regarding the experience of these phenomena.

Shaw, McFarlane, and Bookless (1997) investigated the trauma of psychotic illness, more specifically, the trauma of psychotic symptoms and hospitalization as criteria for post traumatic stress disorder. The experience of psychotic symptoms was compared to the symptoms of PTSD (post traumatic stress disorder). The researchers (1997) interviewed subjects recovering from an acute psychotic episode. The age range of subjects was between 16-65 years and follow-up continued for one year. The interview process required that psychotic symptoms had abated at the time of the interview. A senior psychiatric resident collected data within a semi-structured interview format. The severity of the psychotic symptoms was measured by a modified BRPRS (Brief Psychiatric Rating Scale). The severity of PTSD symptoms was measured by the CAPS questionnaire (Clinician Administered PTSD Scale). The results of the hospital and treatment experiences were perceived as distressing by clients. Patients recovering from psychotic illness indicated a high prevalence of symptoms of acute distress such as: loss of control, enforced treatment and feeling psychologically

out of control. Twenty-two of 42 clients met the criteria for PTSD. In a design that

combined qualitative and quantitative methodology the authors suggest that symptoms

of PTSD may be similar to those of schizophrenia such as withdrawal and hyper-

vigilance. Also, distinguishing between delusions and intrusive memories can further

complicate assessment. Therefore, some confusion may exist as to whether health care

professionals are identifying the symptoms of PTSD or a psychotic illness.

Previously, psychotic symptoms have been suggested both as a source of stress

and a means of coping. It is, however, a novel concept to propose psychotic symptoms,

including hallucinations, as a predictor of further illness (PTSD), primarily in terms of

the trauma of both the psychotic symptoms and the hospitalization experience. In these

ways, the challenge of mental illness questions basic assumptions of identity, relational

experiences and the existential reality of the person.

Casey and Long (2002) studied the experience of mental illness and how clients

make sense of this experience. The study focused on the narrative analyses of clients

who were hallucinating and their experience of mental illness.

Six clients diagnosed with mental health problems were selected. Unstructured

interviewing techniques were used to generate narratives. The initial question was:

"Tell me about the time when you first experienced mental health problems and what

sense you made if it at the time?" Participants were also asked for their present day

interpretations of past events. Interviews were tape-recorded and transcribed verbatim.

The authors selected Polkinghorne's (1988) approach to narrative analysis to produce

explanatory stories. A specific type of narrative analysis, paradigmatic analysis was

selected to group explanations for mental illness across the six stories. The transcribed narrative of one man, Gary, is the focus of the study. Gary's struggle with his understanding of his diagnosis becomes a source of tension as he concludes, "…I just have a problem in life, getting on in life, and as a result of not getting on in life, I have isolated myself, and as a result of isolating myself from other people, I hear voices, and as a result of hearing voices, I talk to myself" (Casey & Long, 2002, p. 609). A recurring theme is one of reconciliation. Reconciling the "high" of the experience with the "structured reality" that he has a mental illness. Reconciling his sense of personal importance "I'm under the false impression that I'm somehow important in the scheme of things" with his own diminished self-esteem (p. 607). Reconciling the difficulties in listening and engaging with voices with choosing to isolate and become less informed about reality. One resonating theme this story underscores is that positivist paradigms minimize the astuteness and personal experience of our clients. The authors succinctly conclude, "The same challenge and responsibility is inherent in nursing research as in nursing practice; that of listening to and upholding the voices of the persons in our care" (Casey & Long, 2002, p. 609).

Summary

Quantitative studies can expand our understanding of hallucinations. The link between voices and distress (Birchwood, Meaden, Trower, Gilbert, and Planestow, 2000), the perception of what voices mean in light of personal schemas (Bucherri, Trygstad & Dowling, 1997), the usefulness of learned coping strategies versus self-held strategies (Sayer, Ritter & Gounay, 2000), and the type of coping skills

(Farhall & Gehrke, 1997) provide an understanding of how clients respond to and manage hallucinations.

Conversely, rather than viewing hallucinations as an entity affecting clients, qualitative studies offer a glimpse into this private world of hallucinations. Clients finding support and a sense of empowerment in the group process (Martin, 2000), feeling comfortable with voices (Miller, 1993), and the recognition that each person's experience with mental illness is unique to that person (Hayne &Young, 1997, Casey & Long, 2002) provide us with a different type of understanding. Also, without a qualitative framework, obscure aspects of a phenomenon may not be investigated. It is unlikely that investigators would concern themselves with dreams and hallucinations (Levin & Daly, 1998), or the trauma associated with psychotic symptoms similar to the symptomatology of post traumatic stress disorder (Shaw & McFalane, 1998).

Conceptually, a shift in thinking has occurred. Historically, clients have been viewed as victims of their own symptomatology, whereas currently, clients are suggested as owners of their voices, who have at their disposal, workable means of coping, and indeed, hallucinations themselves may be a form of coping (Chadwick & Birchwood, 1994; Farhall & Gehke, 1999; Romme, 1998). Furthermore, hallucinations may serve as support or feedback regarding self-held beliefs (Chadwick & Birchwood, 1998, Miller et al., 1993) and predictors of further illness (Levin & Daly, 1998). In the end, hallucinations are a phenomenon as unique as the individual, a phenomenon that changes reality, and changes how an individual looks at the world (Casey & Long, 2002). Making sense of mental illness, and of hallucinations, requires listening to the

client and a research perspective that combines understanding with a readiness to

explore. While there is an increasing focus on the experience of hallucinations, little

research is directed at *being* or the individual sense of self and the experience of

hallucinations. The following chapter outlines the research perspective this researcher

will use in addressing this gap.

CHAPTER 3

Research design

Introduction

The purpose of this qualitative study was to explore the meaning hallucinations have for the individual within the context of their sense of being. The design of the proposed study was a Heideggerian hermeneutic phenomenological method developed in congruence with the philosophy of Martin Heidegger. Heideggerian hermeneutics was the methodology suitable for conducting this research because "hermeneutics seeks commonalities in meanings, practices and bodily experiences in the depiction of the lived experience" (Owens, 1998).

Martin Heidegger was a student of Husserl, who developed phenomenology, but each differed significantly in their views of research and scholarship. Husserl introduced the notion of the "lived experience," presupposed the mind-body duality of Cartesian philosophy and sought to use "bracketing" as a way of removing presuppositions (Koch, 1995). Koch (1995) further described Heidegger's concepts of the hermeneutic circle, preunderstanding and co-constitution as direct contrasts to Husserl's views of bracketing. Heidegger was inherently ontological; Husserl was interested in knowledge–seeking. Heidegger proposed hermeneutic or interpretive phenomenology as the method of inquiry fitting for the study of human action. In this chapter the philosophy that served as the underpinnings of this research are described and the specific processes of the design are presented. A Heideggerian hermeneutic phenomenological design was chosen as the

framework for this study to address two research questions: *What is the meaning of hallucinations? How do hallucinations connect to one's sense of self?*

The first section of this chapter presents an overview of Heideggerian hermeneutics. The second section discusses the study of being (self) as a focal point of this study and the third section discusses the methodological process of Heideggerian hermeneutics.

Heideggerian hermeneutic inquiry

What is the goal of addressing self or being in a study that focuses on the experience of hallucinations? Being and hallucinations reinforce each other in that, for the person who hallucinates, hallucinations may define a state of being for that person at that moment. Using a Heideggerian perspective has value, for central to this philosophy, is the acknowledgment of being. In the aforementioned studies, hallucinations may define being for that individual at one point in time. Hallucinations and delusions are often the driving force, in terms of motivation and thinking, for the individual with schizophrenia. Understanding how these hallucinations affect the individual can assist health professionals in strategizing interventions.

Concepts that direct and inform this study are being (self), and meaning. The basis of a Heideggerian hermeneutic perspective is that individuals who hallucinate are human beings who are situated in their worlds, yet engaged in day-to-day living, sharing the same human concerns.

Conceptually, hallucinations have been viewed as a distinct entity separate from the overall psyche of the client. Hallucinations have been regarded as a symptom

necessitating treatment or removal, rather than as an inherent part of the individual (Brown, 1989; Bouchard et al., 1996; Bucherri et al. (1997). While hallucinations may be a symptom of a psychotic process that requires treatment, the hallucinations also become part of the individual, a part of the individual sometimes not differentiated by the individual. In this same way, hallucinations may be entwined with one's being.

For Martin Heidegger (1927/1962) the guiding philosophical question was, "What is being?" He returned to the Greek philosophers, Plato, Socrates and Aristotle, to answer the questions, "What is being?" and "What does it mean?" The distinction that Heidegger offers is both ontic and ontological. The ontic *being* (seiendes*)* entities, is simply the fact of existing on a daily basis. *Being* (sein*)* asks the ontological question, "Who am I?" Heidegger (1927/1962) uses the term Dasein, the entity that is in each one of us. Dasein asks the ontological question and seeks to understand the meaning of being; in order to arrive at the ontological meaning of being, we must first come to understand our own being and how we live in our world.

According to Heidegger (1927/1962) the lives of human beings are situated with activities and relationships that are meaningful. Situated-in-the-world means that we understand who we are through our lived experience. This understanding of who we are is seen and understood in everyday experiences. Heidegger believes there is commonality in this understanding with all other human beings. Some of these understandings may be culturally specific, or specific to the community or the individual's family. Being situated also means being situated at a specific point in history (1927/1962).

Hermeneutics

Palmer (1969) traces hermeneutics to the Greek word *hermios* a reference to the messenger god Hermes. Hermes was also the god of understanding, known for his ability to uncover meaning and clarify understanding for human beings. Polkinghorne gives the origin of the term *hermeneutic* as the Greek word *hermeneuein* meaning "to interpret" (1983, p. 218). Weinsheimer (1989) links the origins of hermeneutics to rabbinic interpretations of the Talmud, and allegorical interpretations of canonical texts. Weinsheimer illustrates hermeneutics as the "practice of interpretation" (1989, p.117). Polkinghorne (1983) describes hermeneutics as the interpretation of experience (p.218). Polkinghorne further describes *Understanding* with a capital "U" as separate from comprehension. "It is a process which embodies all of the capacities of the mind operating together. It involves a to-and fro movement from part to whole and back to part again" (1983, p. 217).

Schleiermacher is credited with developing and redefining hermeneutics. He redefined the process as dependent on the ability of the reader to discern the sentence itself and the readers' knowledge of the experiences and historical context of the author (Palmer, 1969). Therefore, the meaning of the text is not understandable without knowing the author's intended meaning. This is Scheiermacher's principle of reconstruction. This process of reconstruction has evolved into the hermeneutic circle (Palmer, 1969). The core principle of hermeneutics is that understanding is a process that is achieved by comparison. The researcher compares a part of the text with the whole. The meaning of

the text is compared with the historical context or situatedness of the participant. The

text is also compared with the researcher's own background or preunderstanding.

Dilthey (1944/1976) named the movement from whole to parts to whole as the

hermeneutic circle. Understanding therefore has a circular nature. Polkinghorne states

that the movement is "not really a circle, but, more of a spiral in which each movement

increases the depth of understanding" (p. 227). Dilthey established hermeneutics as the

preferential methodological basis for the study of the human sciences.

Philosophical background of being and self

Being, self

Integral to this study is an understanding of being for the person who hallucinates.

Being and the numerous words that suggest being (identity, self, self-concept,

personhood, self-affirmation) call for a definition. Yet definitions are elusive and even

Heidegger refuses to define being other than to suggest *ways* of being. Just as Heidegger

explored the meaning of being, the representation of being as self, identity, self-concept,

personhood and self-affirmation is viewed from sociological, psychological, and

philosophical perspectives.

Mental representations of who I am and how I am perceived are identified in the

philosophies of Descartes, Locke, Kant, Hume, and Heidegger. The 17th and 18th

century view was of the "self" as an individual capable of reasoned judgment. Descartes

(1596/1977), in his pivotal 17th century treatise *Discourse on Method* underlined this

stance in the phrase "Cogito ergo sum," "I think therefore I am." In other words, by

reason of my ability to think, I exist, because I cannot exist without thinking. That is,

there exists a detached self who is a thinking entity. Thus, Descartes reinforced the dualism of mind and body. This dualism exists between two spheres of reality; the mental, myself as thinker, and the body, which occupies space.

Locke (1894; 1954) differed from Descartes in that he viewed the mind and body as an inseparable entity. He defined self as *essence*. Moreover, self is not so much the substance or make-up of the individual, but rather, how that person can be identified. If an individual occupies the same time and space, and is constant i.e., the person remains the same, then, that is the same person (1894/1954, p.175). Kant, in *Critique of Pure Reason* (1781/ 1929) distinguished two aspects of self: the "I" subject and the "me" object. The subjective, how do I feel about the world and the objective what does the world do to me? However, Hume (as cited in Gaskin, 1988) questioned the very existence of self and viewed self as a sequence of perceptual experiences. Hume states that the idea of self as permanent must be derived from an impression that is permanent, however, there is no impression that is constant, all impressions are transient. In Hume's (as cited in Gaskin, 1988) "bundle of self" theory, the self is no distinct entity, but rather a mass of perceptions.

Psychology and sociology

A shift in the way self is viewed occurred with the emergence of the social sciences of psychology and sociology. Gergen (1991) describes this movement as the shift from the individual as a created being versus the individual as socially created. Structural viewpoints of identity (Freud, 1924, Erikson, 1962) focus on the introspective self. Freud (1924) conceptualized the ego ideal as the child's conception of what is reality. In the

battle between the id and superego the ego defines self and plays the role of mediator.

Harry Stack Sullivan (1962) describes personification as part of the subject self-system

for emotionally divided selves. If self-appraisals are negative then the self-system is one

of self-doubt (p. 11). Erickson (1962) viewed self within a larger socio-cultural context.

Specifically, personal identity is based on the individual's place in time and space, and

how the individual is recognized by others (1968, p.50).

Symbolic interactionists (Mead, 1934/1970; Jaynes, 1996) view identity as a

symbolic social construction. According to Mead, "The individual experiences himself

...not directly, but only indirectly from the particular standpoints of other individual

members of the same social group, or from the generalized standpoint of the social group

as whole to which he belongs"(1934/1970, p.138). That is, the self is a byproduct of the

social world we live in and therefore, how we view ourselves is symbolic of that world.

Behaviorists view identity as self/identity tied to action or consequences of action

(Skinner, 1971). In other words, behavior is dependent on the environment and events

that occur (Hattie, 1992, p.31). Cognitivists link self to self-schemas which are

generalized views about self (Beck, Emory, Rush & Shaw, 1987). How individuals

respond to daily experiences is dependent on assumptions based on schemas. Self is a

system of self-schemas (Beck, et al.1987).

Constructionists describe self as psychological processes that support individual

activities. Baumeister (1998) describes self in terms of self-control and self-regulation.

Social cognition theorists seek to understand and explain, "...how the thoughts, feelings,

and behavior of individuals are influenced by their real, imagined or implied presence of

others" (Allport, 1985, p.3). Bem's (1972) self-perception theory states that external cues are used as self-references. Self perception theory further suggests that attribution processes for the self and others is essentially the same. Bem (1972) defines the differences between self-perception and other perception: self-perception as opposed to other perception can respond to internal cues, has knowledge of the past and can assess those aspects of a situation that has meaning to self.

Therefore, being and self are defined in terms of an individual essence, a mind/body dualism, subject-object representation, a stream of perceptions, a socially created human being, self-schemas, and self as influenced by the world and socially created. Essentially, Heidegger's perspective of self as inherently ontological, invested in a search for meaning, and part of culture both departs and rests on these same views. Heidegger is not restricted to a mind-body split, and, although being is integral to his philosophical stance, Heidegger refuses to define being or self explicitly. Heidegger chooses to view being as entities existing and responding differently. Daisen is concerned with the meaning of self, but there is the self that is simply *being-there*, that exists on a day-to day basis. In a Heideggerian hermeneutic research perspective, discovery rests on how we come to understand being.

Meaning (the revelation of truth)

Dilthey maintains that meaningfulness is always a matter of reference to the contexts of relationships (1944/1976). Heidegger expands on this. Heidegger (1927/ 1962) believes that our existence is one of meaning. He believes our life presents itself in terms of possibilities, and that one can choose any of these possibilities.

When Heidegger addresses meaning he uses the Greek word for truth, *althea,* which Heidegger interprets as "uncovering." Heidegger's conception of truth is in the revealingness of what is concealed as opposed to an idea of truth as one correct understanding (1954/1968, p.205). It is *everydayness* that creates meaning or truth. Meaning is interpretation from the beginning, an involvement with the individual at a certain intellectual level, an everydayness level. Heidegger uses the phrase "letting it lie before you" (1954/1968, p. 205). In other words, allowing meaning to happen as a means of arriving at meaning or truth.

Meaning also has an authentic/inauthentic mode. Heidegger states that humans can remain in an authentic mode most of the time. We can move from authentic to inauthentic, but what makes this meaningful is that I own it. "Authentic moments are those moments when we are most at home with ourselves" (Heidegger as cited in Moran, 200, p. 271). Furthermore, meaning is sustained when something is revealed in its hiddenness (1972). An example Heidegger (1927/1962) uses, is when he speaks to our use of tools and uses the example of the hammer whose meaning is dependent on its functionality.

Preunderstanding

Preunderstanding is used to describe meaning and the structure of culture. Human beings come to a situation with a story or a preunderstanding. These stories are already within our common background and are brought to focus in order to be understood. Preunderstanding is our structure of being in the world; it is not something we can bracket. Heidegger (1927/1962) claims that as we live in the world, or live a life

at a cultural level, everything we do is an act of interpretation. We are self-interpreters. There is not an outside or detached point in which we suddenly become ourselves, or are, more ourselves. Therefore, a researcher in a Heideggerian hermeneutic study does not sit outside to collect data, rather, preunderstanding or background becomes part of the research.

Meaning is conceived of as not only a way of knowing, but as a way of being in the world. Initially, Heidegger's goal was to uncover the true meaning of being. For Heidegger (1927/1962) uncovering the true meaning of being does not mean finding out all we need to know about human existence, but rather, to understand what it means to be human. And the human being reveals self in his or her situatedness. Essentially, meaning and being are part of the conceptual framework outlined by this researcher. This philosophical background undergirds the exploration of self, being and hallucinations. Definitions of self, perspectives of self are **thinking** ways of looking at self. Phenomenology is an experiential, viewing and sitting-still approach to understanding self. A phenomenological study, specifically a Heideggerian hermeneutic study looks at the phenomenon in conjunction with the person-the lived experience. Heideggerian hermeneutics then seeks to understand not only the lived experience, but also, the meaningfulness of the lived experience.

Research Design

Research was conducted using a Heideggerian hermeneutic phenomenological research design. Heideggerian hermeneutics is both a philosophy and a research method. Heideggerian hermeneutics is an interpretive research approach that seeks to understand the experience of the individual within multiple contexts: the individual, the environment,

and culture. The goal of Heideggerian hermeneutics is not theory formation nor does this approach seek answers to a problem. The task of a Heideggerian hermeneutic researcher differs in that there is an explicit direction of ontological self-interpretation (Benner, 1994). In this study, the goal of a Heideggerian hermeneutic researcher was to:

1) understand the situatedness of the person who hallucinates within their own personal world

2) explicate shared meanings of hallucinations among other participants who hallucinate

3) understand the ontological significance of hallucinations

Interviewing was the primary means of generating themes. Data collection and analysis occurred over a time frame of two months. The researcher's background or preunderstanding is not bracketed, but rather, the researcher's historicity, experience and understandings were made explicit as part of the method.

A modified version of the Diekelmann, Allen, and Tanner (1989) method was used. The researcher read the transcripts in their entirety. MARTIN (1995) software was used to initially encode data. The researcher read the transcripts as a whole, developed a written interpretation of revealing meanings discovered within the text, met and discussed similarities and differences with peer experts, and identified emerging themes through the hermeneutic circle.

The Hermeneutic circle

The hermeneutic circle is based on a Heideggerian mode of inquiry that seeks understanding rather than the development of theory. The hermeneutic circle "is an approach to scholarship that acknowledges the situatedness of both the researcher and the

participant" (Diekelmann & Ironside, 1998, p. 243). Heidegger states that we are all in a "circle of understanding" (Heidegger, 1927/1972). That is, human beings are circular beings, and in this circle, we come to understand and interpret things. Because we come from a background of shared human practices, even research takes part in this circle (Dreyfus, 1991).

In this study, the hermeneutic circle was a working team whose members have experience in the field of interest. The research team consisted of six professional colleagues who had expertise in the phenomenon or methodology and agreed to participate as team members in this research endeavor. The team was comprised of six members selected by the researcher, three advanced practice psychiatric nurse clinicians and three interpretive researchers, whose goal was to provide written interpretations without knowledge of the identity of participants, for whom confidentiality was maintained.

The selection criteria for the three advanced practice psychiatric nurse clinicians included Master's preparation with an extensive psychiatric nursing background. The selection criteria for the three interpretive researchers included successful completion of the Heideggerian Hermeneutic methodologies course (2005, George Mason University) for interpretive researchers. Communication among team members consisted of face-to-face meetings, phone calls, and e-mail. An incentive was provided to the research project team members in the form of a $100 donation to Sigma Theta Tau International.

This research team delineated themes through discussion of the various interpretations. As work progressed, each text was read against the preceding text. In this

way new themes were identified and old themes clarified or refined. Team members explored discrepancies and identified unwarranted assumptions. Implicit in this team approach was the understanding that there is no single "correct" or absolute interpretation (Diekelmann & Ironside, 1998).

Individual researchers also brought to the circle background that incorporates culture, family and preunderstanding. For this team background included expertise in nursing, counseling, and psychology. The team members also brought aspects of their particular cultures, work and understandings to the hermeneutic circle. The team members brought to the hermeneutic circle their preunderstanding or background in terms of their own psychiatric nursing practice, experience within different cultures, understanding of the interpretive approach and their unique insights. Background was therefore essential in ascribing meaning to the texts through being-in-the world.

Coconstitution is the recognition that there is no implicit separateness between the texts, participants and researchers. Every aspect of this research represented a whole. Interpretive research considered those meanings that were not revealed in the intricacies of the phenomena; meanings that were simple, hidden and overlooked, the "splendor of the simple" (Heidegger, 1971, p.7).

As previously mentioned hermeneutic researchers worked within a team bringing to the circle their unique insights, backgrounds and knowledge. The rigor lies in the team identifying common themes or underlying themes that may be missed by a single researcher. The team dialogued and analyzed, reading each text against previous texts. Texts were analyzed and differences were brought forward. Patterns that emerged during

these sessions were woven together to represent the constitutive whole. Critiques were written by team members so that "a review process exposes unwarranted and unsubstantiated interpretations that are not supported by the texts" (Diekelmann & Ironside, 1998, p.243).

Assumptions

Assumptions implicit in this qualitative research included the following: that understanding is achieved through the individuals' expression of their experience, that commonalities cross the realm of human experience, and, in interpretive research, obscure or less obvious meanings have significance. In interpretive research, the researcher interprets the texts through their preunderstanding. The end result is then a blending of the interpretations of multiple team members. The ultimate aspiration is to seek understanding of the participant's experience within multiple contexts; the individual, the environment and their culture. Finally, there was no single correct interpretation (Diekelmann & Ironside, 1998).

Participant selection

Inclusion and exclusion criteria

Sampling was purposive. Participants selected were of both genders, varying ages, somewhat diverse cultures, and multiple levels of acuity to increase the variability of the sample. A varied sample increases the variability of themes and provides opportunities to uncover less obvious themes. A varied sample was obtained by strategizing sites for recruitment. Recruitment took place in two urban locations, in

diverse, multi-ethnic neighborhoods. An original sample size of 13 participants was obtained, with a drop-out rate of one participant, the final sample size was 12.

Nancy Diekelmann stated that a sample size of ten participants is sufficient to meet the needs of a Heideggerian hermeneutic research study. Heideggerian research focuses on individual stories sufficient to garner themes (personal communication, 2000). Polkinghorne states that the "choice of sample for descriptive studies of an ongoing organizational structure is based on the usefulness of a particular example in uncovering the pattern" (Polkinghorne, 1983, p.271). Benner (1994) reiterates that the "Sample size is projected at the beginning of the study, but this is often adjusted depending on the quality of the text and the way that the lines of inquiry are reshaped by the clients" (p. 107). An initial sample size of 13 was considered sufficient in acknowledging Benner's caveat that numerous observations and interviews with the same study participants will generate a large volume of text (Benner, 1994). In other words, in interpretive research, it is the richness of the text, not the size of the sample that is critical. Benner relates that the overall goal is one of richness and redundancy (1994). Redundancy or saturation occurred after the eighth participant.

Inclusion criteria included individuals who had experienced hallucinations related to mental illness or an emotional disorder not associated with delirium tremens of alcohol use or the perceptual phenomena of drug use. An experience of mental illness or emotional disorders makes it possible to yield faithful accounts that are not transitory descriptions of hallucinations i.e., hallucinations caused by sensory deprivation or medical etiology. Inclusion criteria also encompassed English-speaking adults 18 years or

older who were able to articulate their personal recollection of the hallucinatory experience, and who were willing to have their conversation recorded. Exclusion criteria excluded individuals who were unable to verbalize their experience of hallucinations. The initial sample size of 13 dropped to 12 when one participant was unable to clearly articulate his experience.

Recruitment

Participants were selected from their communities in the southeastern Virginia area using three recruitment methods. The first recruitment method included newspaper advertisements in local community newspapers in Norfolk, Richmond and Virginia Beach requesting volunteers, with a short description of the study and contact phone numbers. The second recruitment method used flyers affixed to bulletin boards of business and community centers, outpatient psychiatric facilities, Alliance for the Mentally Ill (AMI) meetings, and Community Service Board's (CSB) clubhouses. These flyers included a short description of the research study and contact phone numbers. Interested participants personally contacted this researcher. A final recruitment method encompassed an information session. An information session, approved by the site, was offered at the CSB clubhouses and NAMI meetings at their weekly or monthly meetings. In the information session, flyers were made available on a nearby table. This researcher explained the nature of the study; and individuals had the opportunity to ask questions. This researcher left the meeting and potential participants volunteered for the study by seeking out the researcher and calling the number on the flyer. Individuals who expressed interest and who met criteria determined the meeting time and date. Interviews took place

at mutually agreed convenient locations (secluded cubicle in the library, back room of a coffee shop and an interview room) that facilitated confidentiality for the participant and privacy. A $20 gift certificate to a local store (Target or Wal-Mart) was offered as compensation for the time and effort participants give to the study.

Data collection

Data sources

Narrative accounts accessed through the interview process were the primary source of data. Data sources consisted of post-interview written observations and transcripts of tape-recorded interviews. Post-interview written observations included the researcher's observation of individuals' facial expression, posture, activity and other non-verbal's as source of nonverbal communication. Written notes (field notes) were reviewed as well as an ongoing reflective journal as an adjunct to ongoing analysis. A transcriptionist was used to ensure verbatim transcription.

Interviews were conducted for a time span of 45 minutes to one hour. Transcriptions were spot checked to validate accuracy. Notes were generated after the interview. Interview questions were open-ended, broad-based and designed to encourage self-reflection and the unfolding of the individual's personal story. Orienting interview questions were:

> *Tell me what it is/was like for you when you hallucinate/ed?*
> *How does this experience affect the way you think about yourself?*
> *How do you see yourself?*
> *If you did not have this experience would you think differently about*
> *yourself?*

Probes and exploring questions were used depending on the participant's response. Further inquiry was used to further the narrative so that the totality of the experience was

clarified. Phrases and interrogatives such as: "tell me more," "what is it like," and "how is it?" were used. Participants were also asked to *"Remember a specific time"* or *"give a for example"* or *"tell a story about the last time you hallucinated"?* Non-verbal communication, the environment, and the researcher's impressions were noted and recorded in the journal and field notes immediately after the interview.

Demographic material was obtained at the time of the interview (see Appendix A). Demographic information included gender, age, race, educational level, current medications, approximate date of first hallucinatory experience and date of last hallucinatory experience. Collected interview data were entered into a Martin software program (University of Wisconsin, Diekelmann, Lam & Schuster, 1995), and coded in the same program.

Interview process

The participant had ample opportunity to review and discuss the consent form with the researcher. The participant and the investigator signed the consent form to indicate reciprocal agreement. The participant also completed the Client Data Form (see Appendix A).

Allen (1994) reminds us "There is no hermeneutic interview. The interview approach may vary with the theoretical perspective" (p. 179). For each interview, the participant was interviewed at a date, time and setting of their choosing. Key to Heideggerian hermeneutic phenomenology is in understanding what it means *to be* and what it means to *live with the phenomenon.* The researcher clarified her understanding and interest in the phenomenon of hallucinations and outlined her interest in the study.

The researcher described to the participant her interest in understanding their lived experience.

In seeking a perspective of the lived experience of the individual who hallucinates and how this affects their lives, an interpretive style of interviewing was essential. Interpretive phenomenological interviews were circular, complete, never-ending, and attentive to content and situated in the moment. Dialogues were connecting as a way of being present with the participant.

Again, the initial question was: *Tell me what it was like for you when you hallucinate?* Heidegger (1927/1969) notes that "the very fact of posing a question is disclosure, for to question is to sketch in advance the context of meaning in which a particular inquiry will move" (p. 269). Therefore, the initial question was broad-based and neutral to allow the client's revelation of their experience to unfold naturally. However, to bring together the nature of the experience and ontological significance probes and questions emerged within the conversational mode.

Termination of the interview occurred when the participant or researcher indicated completion. Participants had been informed that they could terminate the interview at any time and, that they may drop out of the study at any time without penalty.

Data Analysis

Transcriptions of interviews, field notes, and memos were used as text to develop categories, topics and patterns from which analysis will be derived. Data were synthesized for themes that developed from the interviews using Martin software. The

following seven stages were used to organize and collect data, a method developed by

Diekelmann, Allen, and Tanner (1989).

1) Audio taped interviews (with the participant's permission) were read to gain overall

information. Notes written after the interview were also used.

2) Implicit and explicit meanings were extracted by the investigator.

3) A hermeneutic story was developed after every interview.

4) Themes were developed using Martin qualitative software (1989).

5) A comparison of interpretations, patterns and themes that go against the patterns were

identified and compared by the hermeneutic team. Patterns are those meanings or

compilation of "…things that go together in a particular way " (Benner, 1994, p.173).

Themes are commonalities or similarities in topics. Related themes are those themes or

topics garnered from interviews and notes that share common characteristics.

6) Constitutive patterns were justified. The constitutive pattern expressed the

relationships among themes and is reflected in the texts of the participants' audio taped

interviews.

7) Final written report was completed (Diekelmann, Allen, & Tanner, 1989).

 In this study participant review was added to the method to support identified themes

and as a way of enhancing rigor. Those participants who requested follow-up phone calls

were contacted for verification of themes. At this writing four participants have verified

the themes and constitutive pattern.

Data Analysis Procedure

This multi-staged method of analysis was modified (addition of participant review) to describe universal meanings. Shared meanings were identified and coded as themes and constitutive patterns. The qualitative software package, MARTIN (Diekelmann, Schuster & Lam 1995) was used as a tool for analyzing the narrative data. As data unfolded, the following outlines a further delineation of the previously stated seven "stage-by-stage" process of hermeneutic analysis.

Stage one Audio taped interviews were collected and transcribed. Post-interview notes (field notes) were used as well as an ongoing reflective journal. As suggested by Diekelmann (1989) the interview texts were read in their entirety, to obtain an overall understanding. Members of the team identified related themes within the interview. Interpretation, patterns and themes that went against the pattern was compared with the researcher's interpretations and the interpretations of the other team members.

Stage two The team identified implicit and explicit meanings from the interview texts. Fidelity to the participant's meaning was one aspect of the ongoing responsibility of team members. This means not simply the said and unsaid words and phrases, but the experience of the interview. In other words, what was the mood of the interview experience? How did the participant respond to the researcher? In this stage, biweekly sessions were held during which the written interpretations of the themes with supporting excerpts from the interview were read. Similar analyses by other members followed. Dialogue among team members clarified the analyses. Returning to the text provided evidence for the analysis. Group consensus was the ultimate goal.

Stage three A hermeneutic story was developed with each transcript. This stage involved further independent analysis of each document by team members. Independent analysis continued, and with each succeeding interview, themes were compared with interpretations of other team members and previous interviews. Again discrepancies of interpretation among team members are clarified by referring back to the interview text Diekelmann (1989). The goal was a written synopsis or hermeneutical story about each transcript.

Stage four As previously mentioned six experts (members of the hermeneutic team) were consulted who had been selected by the researcher: three psychiatric nurse clinicians, and three interpretive researchers. The goal in this stage was to identify relational themes. A relational theme is one that cuts across many contexts (Diekelmann, 1989). Interpretations generated in previous stages were reread and studied to see if similar or conflicting interpretations were present in the various interviews. Dialogue between the researcher and team members was ongoing. MARTIN organized themes and the investigator refined these themes into constitutive patterns. At this point, variance in interpretation was discussed and documentation from the texts were used to support the choice of relational themes.

Stage five The expert readers' interpretations were autonomously analyzed with the primary researcher's interpretations. The goal of this stage was to identify a constitutive pattern present in the interviews that also expresses the association of the relational themes. Interpretation, patterns and themes that go against the pattern were compared and discussed with members of the team.

Stage six Constitutive patterns were justified. The purpose of this stage was to validate the analyses. This study used participant validation due to the requests made by the participants recounting the experience. When data collection was completed participant review was carried out to better illustrate this experience as verbalized by participants. Additionally, at this stage, opportunity for review of the entire analysis was provided to members of the research team.

Stage seven The final research report was completed. A written analysis of constitutive patterns is the highest form of interpretive analysis and reflective of the relationships among all themes. Ample excerpts from the interviews were used to validate the reader's findings. While there is no single correct interpretation, continuous examination of the whole and parts of the document, and returning to the interview text, ensured that interpretations are valid (Diekelmann, 1989).

<center>*Rigor and trustworthiness*</center>

The goal in Heideggerian hermeneutic research is to understand the essence of the lived experience. To this extent the voice of the individual is paramount. Lincoln and Guba (1985) suggest that multiple methods of obtaining data increase the likelihood of building trustworthiness in qualitative research. Thus the use of interviews and observations as well as all written and transcribed materials enhanced trustworthiness. In this study texts were produced by both interviews and observations. Ricoeur (1991) reminds us that action can be regarded as text, and certainly attending to body language, (facial expression and behavior) is attending to the nonverbal aspects of language. In this hermeneutic study, other means of enhancing trustworthiness included: using participant

language verbatim and writing it down immediately after the interviews, using a tape'
recording device, recording precise descriptors (nonverbal language), using peer experts-
advanced-practice psychiatric nurses for corroboration, maintaining an ongoing record,
and the inclusion of a reflective journal.

Trustworthiness was also reinforced through the hermeneutic circle. Lincoln and
Guba (1985) viewed working with a research team as another means of building
trustworthiness by providing a mechanism to identify and counteract individual
preferences. In this study, understanding was viewed as circular and a variety of
meanings were brought to the text through the background of the interpreters within the
hermeneutic circle. Unlike most qualitative research which uses bracketing to maintain
objectivity or at least outline prejudices the researcher may bring to the research,
hermeneutics takes for granted that a certain background in the phenomena and
expectation of what the text will reveal, will be a part of what constitutes the
interpretation. Diekelmann states, "Hermeneutic researchers do not attempt to isolate or
bracket their presuppositions, but rather to make them explicit" (1998, p. 243). Therefore,
the background and understanding the team brings to the hermeneutic circle were integral
to the interpretive analysis. In this context I brought to the research team my experience
in teaching psychiatric nursing to potential registered nurses, my experience working
with runaway adolescents at Seton House, previous clinical experience in psychiatric
settings working as a member of the psychiatric emergency response team (PERS) and
clinical nursing experience at Obici Hospital. Additionally, I identified myself as an
Asian-American woman, middle-aged, and working in a setting that profits from illness. I

have had experience in hermeneutical research and attended the Advanced Nursing

Institute for Heideggerian hemeneutical Studies in July of 2000 at the University of

Wisconsin. Furthermore, I attended the Heideggerian hemeneutical Institute in July of

2005 at George Mason University. Therefore, the hermeneutic circle "is between my

mode of being beyond the knowledge which I may have of it, and the mode opened and

disclosed by the text as the world of the work" (Ricoeur, 1991, p. 178).

Process and consistency criteria are two categories of criteria specific to

interpretive research that were used to better identify interpretations. A process criterion

considers the political and power conditions under which the interpretations were first

produced (Allen, 1994; Fraser, 1989; Habermas, 1984; 1987). Ways this study

maintained process criteria were the conditions in which the participant was interviewed.

The participant selected the interview environment. Maintaining privacy and disclosing

narrative text only to the team ensured confidentiality. Consent forms were worded in

everyday language, and participants had ample opportunity to read and process the

consent documentation. Additionally participants were informed they could leave the

study at any time without penalty. Political and power conditions included the manner

and language of the interviewer. An engaging, warm and respectful attitude conveyed an

attitude of parity. Everyday language was be used. Additionally, Weber suggests that the

nature of the interview invitation is paramount. "If the invitation is genuine, the

interviewer turns to the participant as one human being to another" (1986, p. 65).

Process criteria also included establishing a measure of intersubjectivity (a client

and interviewer agreement) through subject review of the text. Subject review or

participant review of the text was part of this study. Although Allen (1994) relates that the participants' review may not be as methodologically essential in hermeneutic research due to the emphasis on meaning as interpreted through an intersubjective stance, the participant review was deemed important by participants themselves. However, clients wanted to know the study results and know that their voice "was heard." Summaries of the study results including themes and patterns was sent to study participants who provided an address to this researcher.

Consistency criteria were internal checks that included comparisons between interpretations of parts of the text with each other or comparing one text with another using comparison of language or the consistency of the author's interpretations. External consistency seeks to distinguish the linguistic and historical context within the text. External consistency asked the question "Is the meaning and structure of the text understood in ways that are consistent with the historical period in which it was produced?" (Allen, 1994). In this study, multiple stages of interpretation were provided as a means of bias control. "The purpose of multiple stages is to recognize inaccurate interpretations not supported by the interview text" (Diekelmann, 1989). Expert consensual corroboration (nurse researchers knowledgeable in interpretive methodology and mental health nursing) was also included in this process. As mentioned previously, continuous examination of the whole and parts of the document, and returning to the interview text, ensured external consistency. Sensitivity to the culture, to the historical context, and use of a reflective journal also contributed to external consistency. That is,

the inherent background of the interviewer becomes part of the cultural and historical understanding.

Faithfulness to the participants' meaning included identifying implicit and explicit meanings. Interpretation, patterns and themes that go against the pattern were compared with members of the team to ensure external consistency. The use of audio taped interviews made certain that texts studied by that team were accurate.

Another way to ensure faithfulness to the participants' meaning is to employ participant review. In the midst of this study many participants requested validation of themes. All but one participant requested to be contacted again. Participant review is a standard method of enhancing rigor in qualitative studies. Participant review includes returning to as many participants as possible and checking with them to validate meanings and themes the researcher has discovered are commensurate with their own understanding of the meanings and themes elicited from the interview. Themes were validated with four participants.

Human Subject Considerations

Before initiating recruitment strategies the Virginia Commonwealth University Institutional Review Board (IRB) approval was obtained. Prior to participation in the study, the purpose of the study was explained to prospective participants. Participants were provided with an in-depth description of the study, the interview format, and have an opportunity to ask questions. Participants were given a description of possible risks and discomforts. For example, this researcher introduced the interview experience by stating, "Several questions will be asked about your personal experience of

hallucinations. Sometimes talking about the experience of hallucinations can be uncomfortable. You do not have to talk about any subjects that you do not want to talk about, and you may leave the interview session at any time. If you become upset the study staff will give you the names of counselors to contact so that you can get help in dealing with these issues." The client may have had genuine concerns and self-doubt when recounting the memory of the hallucinations. While disclosing the memory or experience of the hallucinations is often therapeutic and positive, the experience can be potentially hurtful and traumatizing. Offering the client opportunity for counseling and follow-up was one means of ensuring protection of the client. Moreover, specific information regarding support groups were be made available for the client (See Appendix C)

Secondly, participants were provided with possible benefits of the study such as the opportunity to explore the meaning of hallucinations. In this study, there was no cost incurred for the participants. Clients received a $20 gift certificate for use at a local mall (Target or Wal-Mart)

Third, conducting the interviews in a safe, quiet room enhanced confidentiality and encouraged further self-disclosure. Clients were again reminded that they may interrupt, terminate or drop out of the study at any time without penalty. After data collection, audiotapes, transcripts, reflective journals and all written material were kept in a locked file cabinet accessible only by the primary researcher. Finally, to further ensure confidentiality, all transcripts were coded and did not contain names of participants. Clients were assured that consent forms, their words and information from the study will

be provided only to members of the research team, the nursing dissertation faculty and the IRB of Virginia Commonwealth University. I further stated, "Findings from this study may be presented at meetings or published in papers, but your name will not be used in these presentations or papers." I reminded the study participant that I am required by law to report disclosures that may cause injury to self or others. The study participants were informed that no names were recorded in the audio taped interview sessions. As mentioned earlier, the tapes and notes were stored in a locked cabinet. After the information from the tapes was typed the tapes were destroyed in accordance with the time line set in place by the IRB.

Ethical considerations, particularly ensuring confidentiality are a concern in an interpretive study. The participants chose their own pseudonyms as a way of making the interview session their own, and as another safeguard toward maintaining confidentiality. The team members (interpretive researchers) received only transcripts of the interview sessions that were indiscriminately coded by MARTIN software. The team referred to the interview texts by coded names or numbers. Finally, the consent form was reviewed, and signed by the study participant, a witness, and the investigator.

Limitations and strengths

Limitations included one unexpected drop out. This did not appear to impair the study, as saturation occurred with seven-eight participants. Unlike quantitative research in which the results are reproducible, predictable, and can be generalized to the population, the aim of qualitative research is to glean an understanding of experiences that are not always represented in a large sample size. A discovered strength of a Heideggerian hermeneutic inquiry was an enriched understanding of underlying themes.

The relationship between the interviewer and the client became the source of data, and the richness and depth of that relationship yielded more complete knowledge.

Polkinghorne observes that participation in phenomenological research has value for participants, "the process of engaging in the interview was itself helpful for the subjects in restoring their broken sense of community" (1988, p. 58). Polkinghorne (1988) acknowledges several potential consequences as a result of phenomenological research. Nursing science may: 1) gain knowledge of a phenomenon, 2) develop a deeper understanding of the lived experience, and 3) the descriptions may encourage others to share their experience or ask for support. A potential strength of phenomenological research is initiation of changes in nursing practice, and changes in public policy and social action (p. 58).

CHAPTER 4

"The love of our neighbor in all its fullness simply means being able to say to him, 'What are you going through?'"

Simone Weil (1951, p. 59)

Introduction

Findings: The Hallucinatory Experience

Through interpretive phenomenology, this research aimed to enrich our understanding of living life with hallucinations, explicate shared meanings of hallucinations among other participants who hallucinate and seek to understand the ontological significance of hallucinations. With the goal of improving nursing care to clients, these narratives contribute to scholarship in 1) exploring what it means to live a life with hallucinations, 2) identifying how this affects personhood and thus open up our thinking to a specific area of questioning, 3) explore the meaning hallucinations have for the individual within the context of their sense of being.

There is no single method for conducting interpretive phenomenology. The researcher holds closely to the following: "bringing forth the voices of the participants, not her own, holding herself open to new thinking through presenting interpretations to other scholars, rather than confirming her own preunderstanding , and challenging her thinking" (Diekelmann & Ironside, 1998, p. 244). Narratives provide a pathway for exploration through personalized, experiential perspectives (Kleinman, 1988; Morse and Johnson, 1991). Within the domain of the interview, the goal for the interviewer is to encourage the participant to tell their story. Narratives provide an opportunity to dialogue

using the language of the participants. Meaning is revealed through the conversations with the participant, at which point discovery occurs.

Thematic analysis

The initial readings of the verbatim transcripts and field notes were made available to the hermeneutic team via email. Different colored ink was used to differentiate the interpreters and to ease clarification of meanings among other team members. The interview texts were read in their entirety by the team, to obtain an overall understanding. Members of the team identified related themes within the interview. Texts were read and reread and organized into evolving themes. Some themes were dropped, while others were clarified. Interpretation, patterns and themes that went against the pattern were compared with the researcher's interpretations and the interpretations of the team. Emails, face-to-face conversations, and phone calls were generated to identify implicit and explicit meanings from the interview texts. Returning to the interview texts provided evidence for the analysis. Group consensus occurred as team members discussed themes and the fittingness of the themes with the text. The team consisted of six experts who were regularly consulted. Dialogue between the researcher and the experts was ongoing. MARTIN (a software computer program) was used to organize themes. Variances in interpretation were discussed and documentation from the texts were used to support the choice of relational themes. Another goal of this method is to identify a constitutive pattern present in the interviews that expresses the association of the relational themes. An opportunity for review of the entire analysis was provided to members of the research team.

As a result of the above steps four essential themes emerged; these are:

- Are they who they are?
- A not so certain life
- Finding strength in the broken places
- I am still me

The four themes represent aspects of the hallucinatory experience that were central to each participant's personal experience. Moreover, the themes are illustrative of an experience that is perceived as separate from the individual (voices, shapes or people that are not there), yet very much a part of who they are, how they make decisions, and how they assess their world. Participants were forthcoming in telling their story. The participants spoke of their experience against a backdrop of loss and missed opportunities, numerous hospitalizations, struggling with treatment, and for some, a renewed focus on the future. For many participants, "living through" the experience occurred in the past, yet time did not seem to change the impact or emotionality of the experience. Initially, participants viewed hallucinations as "something to be made sense of," and participants consumed time and energy lending meaning to the hallucinations. "Was there a message, what is the message, what is the impact on me and what should I do? Why is this happening to me? What is happening?" Among the participants there was an early questioning of the phenomenon. As participants responded to the compellingness of their hallucinations they reported their behavior frequently changed; they became fearful and isolated, abandoned self-care and attempts at intervention from others, and, often acted on hallucinatory messages. This behavior further served to disconnect them from family and friends, as well as opportunities for assistance. In addition, for some participants this behavior resulted in run-ins with the law, subsequent

incarceration, and frequent admissions to psychiatric faculties. Participants revealed treatment modalities which included medication management, electroshock therapy, and outpatient intervention. Thus they began a history of a chronic illness, with periods of wellness and connecting with others, interspersed with times of illness and loneliness. A significant aspect of the interview process was the participants' renewed perspectives in lending a different meaning to this experience. As a result, the focus of the interviews became how the participants had changed with their experience, what they had learned and how they planned to live life in the future. Participants disclosed freely a life that had been made unmanageable by this experience. Participants revealed how the hallucinations had changed their view of themselves, yet they were still glad to tell this researcher how they planned "to overcome."

Demographic data

After informed consents forms were signed, each participant completed a brief survey detailing demographic information containing personal data and information concerning themselves and the experience of hallucinations. Results of the survey are outlined in Table 1.

Table 1. *Demographic Information*

Survey item		Responses
Gender	Male	5
	Female	7
Age-Range		30-55
Mean		50
Race	African American	6
	Caucasion	6
	Other	0
Educational level	Highest level of education-two years college	1
	Some college	2
	High School graduates	7
	High School GED	2
Age of first experience of hallucinations		Range 3-37
Most recent experience of hallucinations	Currently experiencing hallucinations	6
	Last week	1
	Last year	1
	Past experience	4
Currently on medications		12
Class of medications	Neuroleptics alone	1
	Antidepressants alone	3
	Mood stabilizer and antidepressants	1
	Neuroleptic and mood stabilizer	5
	Neuroleptic and antidepressant	2

N=12

The participants were evenly divided among African American and Caucasian participants, with seven women and six men. Participants' ages ranged from 35 to 55 years, with a mean age of 50 years. At the time of the interview, all participants were on some type of neuro-psychiatric medication. Three clients recall experiencing hallucinations as children; the majority of participants recalled the inception of hallucinations sometime in adulthood. Seven participants possessed a high school diploma; one client related a reading disorder and two had some college experience. One client was currently taking college courses in pursuit of a degree. All but one participant attended a clubhouse or outpatient setting for the chronically mentally ill. From the initial sample of 13, one participant was unable to verbalize the personal experience of hallucinations, and therefore was excluded per exclusion criteria cited in Chapter Three in this proposal. The final sample consisted of 12 participants.

Context of the interviews

Participant #1-Akim

Akim is a young male in his early thirties. He engulfs the small space with his large frame. He is carrying all his bicycle accouterments with him. He has a serious demeanor; but what is most remarkable, is his deep, bass voice. Akim's first experience of hallucinations is fairly recent. This first experience was possibly nine years ago; he had been watching TV. He remembers the TV weather forecaster talking specifically to him. He recalls being "very scared." "I remember being scared, I can't remember specifics-I remember being very scared and paranoid." Akim's experience is also marked

by a progressive battle with depression and substance abuse. He bears in mind countless

episodes of ECT and periods of his life "when I have no memory."

There is an initial indistinctness about the quality or content of Akim's

hallucinations-they are visual- "seeing something out of the corner of my eye" they are

auditory-"voices, phone ringing." Akim wonders "is this due to memory lapses caused by

ECT, blackouts or the pain and sadness of schizophrenia." Akim becomes more explicit.

The voices attacked who he was. "It was a put down"; "It affected my self-esteem."

Hallucinations affected how he felt about himself, "felt like a screw-up"… scorned."

Subsequently, Akim remembers a long period of desolation marked by hospitalizations,

depression, drinking binges and memory gaps.

> …when it got to the point of hallucinations I become very depressed. Well…that
> would be…at least two…when it got to the point when I got depressed this has
> happened at least twice-and I say I think, because I had ECT and there are whole
> pieces where I have no idea what happened—I have a year when I don't know
> what happened. There's some gaps-I don't know what's going on. I remember
> one time, I quit my job, drinking. I hated my job-my friend and I were not going
> on too well-I remember being very paranoid it's like I can remember
> depression…

Today Akim states he "feels a lot better." Sometimes he wishes he could have

avoided the turmoil, the experience of hallucinations-but in a sense he is better for it. "I

am more confident now." This experience has benefited him unexpectedly. "I have a lot

of gratitudes." As Akim considers his world empathetically, he recognizes the experience

has made him more compassionate.

> I don't know-I can't put it into words-it sounds strange-but I'm glad it happened.
> One of the lessons I get out of it. It helps me to not judge people-because seeing
> people in the hospital-I learned to have compassion for people-and I don't have
> any proof of this-but I believe that there are some cases or sometimes when

people with mental health issues become themselves again-even if for a brief moment.

And more than that, Akim uses this experience to measure his world. "I need to face it-because pretty much it's a mirror image of me...." In the end, as Akim looks at himself today...he is a little surprised at himself. "I never thought I'd be doing what I'm doing today (attending the university)."

Participant #2-Catherine

Catherine is thirty-six years old. She is cautious and watchful. Catherine observes, and comments on the dress and behaviors of others as individuals walk through the entrance way. She herself is dressed carefully. There is a studied neatness, with special attention paid to brooches, jewelry, hair clips and all things ornamental.

Catherine talks about a dream she had the night before. There were three people standing over her–they were familiar people–she didn't know what they were doing, but she felt scared and nervous–she woke up smiling "because I didn't know what they were going to do to me." There is a dreamlike quality to her hallucinations, and it appears that differentiating hallucinations from the real world is difficult for Catherine. "And when I walk somewhere I be scared because I look behind me and in front of me to see who is walking behind me because they jumps and they scare me when they walk behind me and I jumps every time they walk behind me. My nerves are bad sometimes." Accompanying this fear is the unpredictable nature of the hallucinations, and, this unpredictability seems to compound her fearfulness. Sometimes the voices threaten to come to her place and kill her. At one point, she was hospitalized. As Catherine recounts this experience, "sometimes I wanted to commit suicide." Catherine is very much at the mercy of the

hallucinations, and of her illness. Catherine would like to be somebody else "... I don't want to live. I want to be like somebody else...like somebody different."

In this struggle to make sense of hallucinations, Catherine is not sure how she feels about herself. "Sometimes I don't feel good about myself, but, "most of the time I do." She imagines a different life if hallucinations were no longer a part of her life. "I'd learn how to read, go to school, drive a car, do all the things I want to do in my life." Catherine wonders if there is something inherently bad about her...that she is flawed since birth, "How come I was born this way?"

Catherine allows missed opportunities; however, it is the disconnectedness from her family that she regrets. As Catherine labors to stay close with her family...even taking a weekday with her sister (when her sister has the weekend with Mama) she always seems to be on the edges of her family. As much as she fears the hallucinations, the words and images; her greatest fear is really about being alone. And the disconnectedness is with people in general... "I be so bored to do something, wants to go out places, wants to hang out and I got nobody to hang out with." In the end, Catherine is not a picture of complete discouragement. There is an impression of self-preservation. Catherine tells us "I feel pretty good."

Participant # 3 Courtesy

Courtesy is in her 30's, and her very pseudonym, suggests who she is, courteous, kind, caring, and a mama to numerous clients at the clubhouse (a safe community, club-like setting in which participants socialize, attend groups, go on outings, and eat and work together). As the study is explained, she relates how anxious she is to help, and

how important it is that we know more about hallucinations. Courtesy's first memory of

hallucinations occurred in 1972, when her sister was killed in an accident:

> I ran because of the accident and I went through a whole lot. I couldn't, I didn't
> want to get out of bed. The only time I would get out of bed was when I would
> spend time with my (other) sister in different months. And I didn't want to get out
> of the bed and the only time I wanted to get out of the bed when she went, took
> me downtown in order to do some shopping and I wanted to stay in the bed all
> day. And I know everything I was doing but I just couldn't help it.

Courtesy recalls being hospitalized. "And then I took medication and I still had

problems. I couldn't, a lot of times; I couldn't make decisions on my own. I could not...I

couldn't make decisions, but I wanted to like stay or go; I will go and catch the bus two

and three times and come back and I couldn't make decisions whether I wanted to go or

stay too."

There's an aspect of feeling paralyzed that comes across as well as confusion.

Courtesy talks about her inability to think clearly, i.e., "In my hallucinations I thought

about, people out there, I couldn't think like I wanted to, I had a blockage like, I couldn't

think, like I couldn't think too clearly." The paralysis rests in her inability to make

decisions or feeling compelled, by feeling helpless to oppose the voices.

> It wouldn't ever tell me to kill myself, they would never tell me to hurt others, but
> I was, I mean I was always worried. I'm prone to worriness and sometimes I
> always but I am truly less worry because I pray a lot, I pray a lot and make the
> best could then. I couldn't make decisions for myself; I had a hard time. I didn't
> know whether, I couldn't make decisions at all at times.

However, Courtesy emphasizes a growing independence that is commensurate

with wellness. She now makes decisions on her own and "I try to enjoy life, I love

people."

When Courtesy talks about her self-concept she states, "I always put myself last."
She doesn't see this as necessarily negative... and, in fact, emphasizes her need and
enjoyment in being with people. It is a "being with" people that is not about dependency,
but instead a "being with," of connectedness. She shares her thoughts about loneliness
and the joy of being with others: "I won't boil a pot for myself, but I'll boil a pot for
someone else." While Courtesy does not use words such as loneliness and isolation, there
is still the underlying sense of loneliness in her very craving for time and attention from
others. Courtesy ends on an optimistic note. "I think I have improved a lot in mental
illness because I'm much more than what I was, a whole lot."

Participant #4 Harley

Harley is a thirty something young man with schizophrenia. He first experienced
hallucinations in the 10th grade and continues to experience them on a weekly basis.
Harley is shy and speaks softly. He seems somewhat depressed and his movements are
slow. He laughs readily and can see the humor in things. He attends the clubhouse daily
and takes his job as support staff very seriously. He enjoys motorcycles and currently
lives in a group home. Harley is paranoid and this is seen in his initial reticence. He
doesn't divulge the content of his hallucinations.

Harley talked about the scariness of living with hallucinations-particularly early
on- "The first time, it was kinda scary. It kinda had a bad effect on me. It was very
strong. It was all that." Harley remembers being isolated and choosing isolation.

> Well...when I was a kid. ..before I was 18...when it started...I was kinda
> withdrawn. I might do something...but I was a like I was someone who would go
> into a study and does his homework or something like that...it wouldn't be with a
> lot of people.

Harley sees a positive in his hallucinations and describes hallucinations as energizing. Hallucinations galvanize him: "well it kinda helps me in doing what I want to do." Harley, himself, denies being energetic, but maybe he can be perked up with his hallucinations; "Well it perks me up…you know kinda like a cup of coffee or something." On the other hand, not only does he use hallucinations to motivate himself, but he uses them as an excuse to not motivate "to get out of things." His hallucinations serve to motivate "to do," and 'to not do." While his hallucinations may serve to motivate or energize, he's never been able to make plans. In fact, Harley acknowledges hallucinations may keep him stuck in a rut. Well…I don't think I'm completely wasting my time. I guess there could be a better way to use of my time."

Participant # 5-Jimmy

Jimmy is a tall, lanky young man with a genial smile and an engaging demeanor. He is a mainstay at the clubhouse, volunteering to work in the kitchen, and assisting other members. He can always be discovered in this helpful capacity or, if not, he can be found sitting and chatting with other members.

Jimmy experienced a schizophrenic break when he was 18 years old. "I got sick in my mind when I was 18; I was scared when I got sick you know." He recalls feeling scared, "as if I was losing my mind"; "the voices told me to hurt myself." Jimmy would find glass on the street and cut himself. As he looks back he states, "I think that's crazy, when I think about it now, I think that's crazy-you know"…as if to say, I can't believe what I did. He recalls that his cutting became so bad that he "ended up in Eastern State." He remembers particularly when his father had a "hard time dealing with it," at his

father's home, and he acted bizarrely. Even retrospectively, Jimmy talks about the fear accompanying his hallucinations "yeaahhh-I'm just glad I'm through it-I was scared-sometimes. I still feel scared…" It's not only fear…but there is a sense of trepidation or worry that these symptoms may return unaccountably. Jimmy lived with his father who cared for him during his most psychotic periods." I used to get up in the middle of the night screaming…and my dad just couldn't deal with me. I used to walk up and down in the yard screaming…I'd yell AAAAAAhhhhh-and my dad would say "Jimmy, stop that now."

Although Jimmy doesn't directly state this, there is a sense of regret. His father had been taking care of him, Jimmy's behavior was peculiar and his father ultimately moved elsewhere, obliging Jimmy to live in an Adult Foster Care setting. At one point, Jimmy told himself that he needed to do better, that he needed to get better…and perhaps, it is at this point that he became serious about medications. The medication Clozaril has been a lifesaver for Jimmy… "when I took Clozaril, the voices were a lot less."

There is also a sense of loss when Jimmy talks about what he might have done with his life…"I'd have a job; "be master of my fate…" Jimmy feels powerless about the course of his life. He discusses missed opportunities about feeling connected to family, the community and the future. However, in making a choice about medications, he seems to have made a choice for wellness and he now uses this health to connect with others, "…if I can do this anybody can do it."

Participant # 6-Katrina

Katrina laughs readily as we engage in the interview room. As I explain the study, Katrina laughs again, barely suppressing her excitement. She still experiences hallucinations, and recalls her first experience as teenager. She is forty-something, with dark graying hair, parted in the middle and fanning out behind her. Her glasses are worn half-mast, parked on the bridge of her nose.

Katrina finds these (hallucinations) disturbing, "Well I was seeing things and I was seeing myself places, you know and seeing weird things and the devil and you know." Katina is scared, but then she " gets used to it "…it doesn't get me as much as it used to." "It's crazy at first-but then it starts to calm down." There is a sense of trepidation or worry that these symptoms may unaccountably return. They're there one minute-then they're gone-and the hallucinations may return when least expected. It's scary, but Katrina gets used to it. "Well, you know, when I first started hallucinating, you know like a child hallucinate they, or a teenager or somebody just having a mental illness, it's wow! You know crazy, but then it starts to calm down and so."

Katrina also relates how she has low "self esteem and low self-respect" and not attending to her hygiene when she is ill. "Well, I used to have a low self-esteem and I ah, less self-respect you know, but then I didn't comb my hair and all that you know…" At one point in all this, there seems to be an epiphany, a decision to walk out of the darkness, and to acknowledge her illness, "…well I'm gonna tell somebody, anybody could have a mental illness." This talking to somebody (during one of the hospitalizations) appeared to set in motion her follow-up with the local CSB (Community

Service Board) and her attendance at the clubhouse. She almost complains "... you're supposed to socialize with more than one person," she follows this with, "so I can get better," almost reluctantly acknowledging that this is part of the process.

While Katrina allows that she has "low self-esteem and low self-respect," on the other hand, the hallucinations have made her notice herself. Katrina continued that the hallucinations forced her to look in the mirror and at herself...

> Well the hallucinations, it seemed to improve it (self-esteem) because when I had the low self-esteem I would watch television and the television would just take over my whole world and then I started having hallucinations and it made me notice myself; then I start looking in the mirror and I said Lord, God, let me do something with myself, you know (laughs).

Katrina talks about God as good; that everything God sends is good, and hence hallucinations, despite their scariness, the hospital stays, even the missed opportunities, were a gift. As Katrina put it, "God is always good so He sends good things to everybody, and everything rounds out." Consequently, Katrina has found some positives in the midst of the sadness, loneliness and confusion. "Well, it's more interests in myself, and ah it involves more interests in helping myself like being more independent and responsible for myself."

Participant # 7- Louise

Louise is in her late 50's...she is very much a mother figure here at the clubhouse.. She helps considerably and is prone to offer advice. Her hair is graying and she wears bifocals ...which she frequently removes when she is concentrating. We review the consent forms and the study material as she focuses on the interview.

Louise has verbalized a late onset of schizophrenia. She began hearing voices sometimes after she had her children. Louise tells us it was "sometime in her forties." Louise has five children and she attribute stress with the onset of hallucinations.

> The thing came on me like when I started having children, stress, I was a mother-I had to raise five kids by myself-it took a lot of strength and courage to do that...but they've all gone their separate ways and all. And I'm still proud of them.

She is probably one of the few clients currently hallucinating...and that to some extent influences her responses. Her experience of hallucinations is twofold. The voices are at once irritating "I can't express myself too much, but it bothers me to hear voices...it bothered me; they want me to stop talking...say I talk too much," and helpful, "they're a guide." "They tell me to ask for help." The voices are clear and distinct, "they help me raise my children...they tell me what to do" and at other times the voices are mutterings, spirits that call her, "It's like spirits talking...but I don't hear what they say, but they're there."

The voices call her...as if she is powerless to resist. Louise at once appreciates the direction the voices give her, even if at times, she feels diminished, "I feel talked down to..."She recalls being a "happy, go lucky child" yet, now, she is filled with worry and premonition ("I suspect things"). Louise says she avoids the voices...yet also denies they're negative. "It takes a lot to raise five kids-a lot of strength and courage"...and the voices were there for her...it's as if she would have been directionless without the voices. What an exertion it must be to have voices with such a distinct ying/yang quality. That are helpful, but irritating; they call to her, yet she avoids them. Louise appreciates them, yet they diminish her and remind her to stop talking. The voices are vague, yet they are

clear and distinct and tell "her to get help." The voices have this parental quality that Louise attempted to resist, "Well in a way I did...I kind of avoid them if I can. If I couldn't, I'd take a nap. They come once in a awhile... so it bothers me...and umm...I don't know what to do sometimes with myself."

Louise also believes the advice just may be good, "I really appreciate it." Louise tells us that "I'm really a person who doesn't like to fuss. I'm quiet; I'm a good person." As if a good person is always quiet and doesn't stir things up. Is this Louise...or are these voices reminding her who she needs to be? Louise informs us that perhaps, if mental illness had not been part of her life, she would be "a very good person." "...I try to help people but they don't understand me. I try to comfort people and cooperate with people. I want to better myself, I'm trying to make myself better." The impression is Louise is trying despite or perhaps because of the voices. And deep down, she is still good...she is still there. "I believe about myself-I'm a good person and not a person who likes to fuss." Resonant in this interview is the premise "I'm still me." Louise tells us... "I'm just an old fashioned girl."

Participant # 8- Mack

Mack is in his thirties -he currently walks with crutches and his right leg is in a cast due to a recent fall. His details are vague. He is loud, expressing consternation that his new psychiatrist has decided to eliminate his benzodiazepine from his medicine regimen. He misses his previous psychiatrist who has recently retired. He turns to me saying, "This new doctor said taking this (medication) is like drinking a bottle of scotch. Did you ever hear of such a thing?" He continues in this vein, and with some redirection,

we talk. He frequently uses his arms and hands to make his point…sometimes his arms make large circling motions or his finger will "jab home" a central theme. At other times, during the conversation, he will close his eyes, and look down before continuing.

Mack reiterated that he's a decent guy, he cares about his family, and his friends…but he's disheartened. He has had numerous losses, run-ins with the law, his medicine isn't working, and he is alienated from members of his extended family.

There's never been anything good about living through this experience, Mack tells us "the hallucinations control my bad side"; they are scary, they are compelling, and, there is a violent component to their expectations. The "people" tell Mack to "shoot people," to do "bad things." "They come in the dead of night or early morning hours, and exist in a nightmarish realm.

> Scary, because there is no one that can help you. I've had strange ones…going back to my New York days…these people will come to me and say we have something bad for you to do and if you don't do it, we'll nail you…or something like that. I don't tell them I'm not going to do that. I'm not going back to those days.

There is a coercive feature to the hallucinations: "people that you wake up to are the people who are harming you. I see cars with somebody in them I see in a nightmare, and they want me to do this or do that ….I mean it gets scary."

So scary are the hallucinations that Mack closes his eyes as he remembered them. It is hard for him to distinguish nightmares from hallucinations. "I probably fell asleep, and I wake up, and I swear I see a figure in a cloud or something and I see a gun pointed at me. And it said go back where you belong…something I don't understand, the hallucinations are there when all the lights are out…"

If Mack were never to experience hallucinations again he tells us, "That would help my heart a lot." The only positive in this experience, is that Mack has become stronger; he has "learned to fight for things." "In some ways I think it made me stronger...you do have to fight for things...for me, this is hard to put it into words...I'm angry with myself...my family members don't even want to associate with me now, because of this...and my father's says...it's their loss...you know." Finally, he reminds us not to judge him, or to label him. "I have been judged all my life."

Participant # 9 Mary

Mary is a thirty-something female. She is abrupt, matter-of-fact in her manner and attitude. Her arms are crossed, she is initially hesitant, but relaxes as the interview is underway. She might alarm an onlooker with her short, staccato answers, large presence and defensive posture, but it is a posture honed by years of living with mental illness. She very much wants to be a part of the study, and very much wants to help others. We mutually relax as she mentally searches for a pseudonym and we both laugh at her choice.

Mary tells us a story about her life with hallucinations. Mary talks about living a life of confusion, stating "Hearing voices is strange. Is it, like, my voice, or is it a voice in my head? I know it's in my head-but I didn't know if it was a conscience voice or demons. You know what you call demons." Not only does she find the phenomena confusing, but discerning or "figuring out" the context of the hallucination is also confusing.

Mary further articulates feelings of sadness and "becoming suicidal" when she hallucinates. "Hallucinations were weird…they told me to hurt myself, to walk out in the street and get killed by a car." She remembers the commanding aspect of hallucinations "I hear voices –they tell me what to do. What not to do. Tell me to hurt myself when I'm really down. I'm suicidal when I'm not on my medication." She also talks about her self-esteem as "not existing." "I have no self-esteem … so it makes me feel down in the dumps-I isolate." Mary talks about her sense of self, herself as "not existing." While Mary talks about the freeing aspect of living without hallucinations, the converse also appears to be true, the bondage imposed by medications… that while medications free her from hallucinations, there is also bondage in being tied to taking medications. "If I could be free from my medications- I'd like be where I don't have to take medication. So if I don't take it every day it's hard-I have two pill boxes if I don't take it, I get suicidal." Noteworthy is the depth of sadness that Mary verbalizes. Mary uses the word "sorrow." "They gave me sorrow. I used to sit and watch cars go by. They'd tell me to go out and walk in the street and get hit by a car."

Additionally, Mary talks about hallucinations in terms of "giving me something" "Makes you more giving." Mary tells us she is "not shy anymore." She is happier. She is a different person when she does not hallucinate…she is now more assertive. Mary is more uninhibited in the sense of the joy and freedom she experiences living without hallucinations. "You could say the meds are working –it's been successful-while I haven't been hospitalized in a while…two years since August."

Mary looks back at her life and she announces a strength-giving aspect of hallucinations. "Made me strong- it really did. I was really doing things to hurt myself. I was in an apartment, and I turned the gas on, and I stopped the air in the doors. If it hadn't been for my roommate would probably have been dead, OD, tried to OD. Now I know those things are bad. I know I'm quite strong- if the voices come back."

Participant # 10-Paxy

Paxy is in her forties...she is involved in numerous activities at the center and is somewhat of a social butterfly. She is sporting bright orange–yellow hair that is either a wig or a new hairdo. I compliment her on her new look and she smiles and pats the curly do. She is careful with her dress and tends to dress somewhat formally. She looks a little stiff, hands folded primly on her lap.

Paxy indicates a long history of hallucinations, recalling childhood memories that disturb her, and impact on day-to-day living...even today. They interrupt her when she is trying to think, disrupt her conversations and in general, appear to be a nuisance. She describes the hallucinations initially as "not a good feeling." She remembers losing friends because of the voices ... and felt forced to isolate...friends said "we don't want to play with you."

> It felt like, ah, it didn't feel, it wasn't a good feeling but you know I lost a lot of friends when I hallucinate. They look at my face and say what it is; we don't want to play with you no more and stuff like that. And then as I got older it had stopped. And then it just came back to me when I was in school you know, I can do my work but when it comes to answering all those questions that's something I couldn't do...

Hallucinations interrupted her learning...She recalls it as a "disturbance of the mind." The hallucinations interrupted her day-day activities. There is an ebbing and

flowing component to these hallucinations...sometimes they are present, sometimes they are barely there...she uses the word scary when describing the hallucinations. She doesn't always know who or what they are... is it a man or women...are they talking to each other?

> A he, and sometimes it might sound like a woman, yes. But she used to talk to me at first. It was kind of strange, but it's not like I'm one of those loonies, but I'm just telling you what I hear and what my problem is. She would talk at first about the other man, that voices that I hear, saying "You're not going to do anything to her," but after a while I was going in and out to the clinic and everything and then when that changed she was gone. But I couldn't see her either it was just a picture or an image of the wall, staring at the wall saying somebody's there and you can't see nobody, but I can hear.

Paxy lives a confusing life, and she would agree that she feels her mind is disorganized.

> Well it's, ah it's not going that great because I got to come here everyday. I want to do my task, work on the telephones and do, you know, and just have a conversation with somebody or look at a magazine and I'm being interrupted with the voices. I mean it's like this in and out of my mind at the same time while I'm trying to do whatever I want to do.

Paxy plans on making changes. She would like a "private life." "Private" does not mean alone, but rather a life without voices. "I plan on making changes when I get older. I'm planning on like ah (pause) just to keep it confidential and private; to have a private life. I know it's awfully boring, but I think I need a more prerogative or private life."

Paxy tells us "I feel good about myself." She uses external kudos (certificates) to feel good about herself. "I get a lot of certificates, so I should feel good." Paxy also communicates that hallucinating "doesn't make me feel any different," perhaps because

external evidence (certificates) tell her she's doing well. "…the reason I have so much self-esteem is that at the end of the year, once a year, Opportunity House gives you a certificate on the work that you do." Paxy also relates her self-validating strategy. Paxy's method is to remain alone. "When I'm alone, I have at least an hour to myself. I have my own confirmation of myself."

Paxy uses the certificates and "alone time" to validate her sense of self, and further makes choices to separate herself from the voices. She chooses to ignore the voices. "I try to ignore them, though. I won't say it out loud. I don't want to repeat it. I'm not going to say it out loud. " Ultimately, Paxy finds a positive in this experience…the experience of hallucinations gave her courage, "…courage to come out; a little bit more courage."

Participant # 11-PFC

PFC is a young man is his early thirties…who is probably a miracle story. He was jailed when he was 18 years old and subsequently spent the bulk of his adult years at Eastern State Hospital…until the advent of Clozaril. Clozaril allowed him to leave the confines of the state mental hospital and live in the community. He is nervous. Wringing his hands, he responds slowly and deliberately. His eyes are often downcast…but throughout the interview he looks up, as if seeking a confirming response from the interviewer.

Initially PFC appears wary and cautious. He wants to talk about his medications. "I have a chemical problem" and "I'm on a medication called Clozaril." He speaks of the hallucinations invading his body. "I once put a $5.00 bill into a vending machine; where

you get the tray, and the coin falls down the toilet-something attacked me...I was either pushed or magnetically pulled into the machine." PFC also relates medications as a "mixed blessing" i.e., "Prolixin...I became allergic to that." "Clozaril-blood pressure was a little high. 325 grams in the morning, 325 grams in the evening-Honestly, I can speak good, but sometimes I start to slobbering-and you know –lose some memory-and stuff like that." Sometimes PFC believes "the meds make me hear voices." "The medications got something to do with that, I was trying to tell my doctor that." "In my medication, some of it's making me hear voices, you know I don't know which one it is, but it's making me hear voices." PFC describes the details of a childhood memory of hallucinations, when he was nine years old. Later he corrects himself, and says it was when he was four and one-half or five when he piloted a plane. PFC minimizes the hallucinations, they appear to be a nuisance, they are in the way; it is really the medications that are the problem. In fact, the medications are the cause of a host of his problems:

> The way it affects me is I have seizures, spasms, mind loss, there are physical problems, speech problems, psychopathic problems, psychiatric problems, mental health problems... problems. I'm feeling better about myself now that I can get my ah... I feel better now that I've been able to get into a program like this like the, because it's helped me.

Yet, later he admits to the "dangerousness," of hallucinations. "Don't have them very often because they can be dangerous." The hallucinations got him into trouble, he went to jail, and the voices compelled him to limit his food intake. "Kind of gets you not to eat food and stuff, whatever reason, I can't really say. I went to a correctional unit, and I wouldn't go in the kitchen and eat food for three and one-half or three years, and

then, I left there." The hallucinations are persuasive. "The voices are telling me to be,

emotional, like move the wrong way."

Often, PFC seems to be saying that reality can be negotiated. Upon the

investigator's query, "do you see things?" he replies, "yes, the sky, the moon, earth." He

hedges while acknowledging hallucinations…" "I might see visions that people might not

see,' cause we all don't see alike." The hallucinations appear to be more of an irritant for

PFC-slightly in the way of day-to-day activities-but not responsible for acute distress.

PFC talked about his hallucinations.

> For instance you can't do any work. I can't – shaving and keeping your
> face clean and your pants clean. Going into businesses and shops and
> stuff like that without going out to shop so much pick up something that
> you're not supposed to be picking up. Pick up little wrong things on the
> clothes amount and it's a whole bunch of things like noise while you're
> buying them. So you can't just walk in any store and you know take what
> you want you got to stay in there and pay for it. See I had a problem --- in
> the canteen. I once put a $5 bill into a vending machine thing where you
> got the tray in and the coin falls down in the [toilet].

PFC acknowledges that if he no longer experienced hallucinations he would "be

happy," "but you know I might miss those hallucinations." "I might miss seeing myself

on TV." Facets of PFC's experience present a "mixed blessing." Hallucinations are at

once problematic, dangerous, and compelling. Yet PFC minimizes the impact of this

experience. PFC attempts to negotiate a different reality for himself…a reality that allows

him to live with the hallucinations. After all, if the hallucinations totally disappeared, he

might "miss them." Perhaps, that is the reason he believes the medications present a host

of problems… the medications themselves present a "mixed blessing." Conceivably it's

not in PFC's best interest to have our reality (to have the medications really work)…

because the hallucinatory reality is the only reality that is constant and certain. PFCs'

reality is that his hallucination is a friend. "Hallucination is a friend within a friend." and he can live with that.

Participant # 12-Tutti

Tutti is dressed in black …she walks at a tilt, and talks as she walks in. Her dress however, belies her demeanor, which is excited, ebullient and anxious to begin. Her cup of coffee is grasped precariously and room is made to find her a seat. As we talk, Tutti listens attentively. The office is stifling, and she fans the air dramatically.

Tutti relates a long history of psychiatric inpatient stays over a period of fourteen years. She struggles with schizophrenia/schizoaffective disorder. Her chaotic life has been composed of successive hospitalizations, suicide attempts, decompensation to the point of "running around naked," and lighting the stove with her head inside-only to be saved from a fiery death by her husband. "Then I went in the kitchen, I turned on the gas stove; a woman was talking to me in my head, I was hearing voices real bad…"

She hears voices, she sees worms coming through her pores, at other times she feels someone rubbing against her; often she is paranoid. Tutti has had verbal altercations and physical fights—one with a nurse (hitting her and breaking her jaw). In her own words, she is labeled NGRI (Not guilty by Reason of Insanity), and she is sent to Eastern State. For Tutti, the turnaround began when she attended church on a regular basis, and she credits this habitual churchgoing with her ability to remain out of the hospital. She recalls a stay at Central State before–when she had been "off meds" and was placed in solitary confinement. That memory evokes shadowy pictures of frequent injections, multiple shock treatments, and a period of catatonia, even coma. The voices called her

"whore, bitch...them bad things, and tell me to do bad things." This experience affected

how she perceives herself. "They made me hate myself; I didn't like myself." However,

Tutti concludes, "I'm lucky I'm living." She attributes her survival to the "grace of God."

Tutti also feels the medications have made a positive difference in her life, and, armed

with this knowledge, Tutti bargains with her doctor to release her earlier.

> I feel better about myself because I take my medicine and I know that I need it.
> Like I told my doctor, I say Doctor _____ if you discharge me from Eastern
> State Hospital in Williamsburg, Virginia, if you discharge me and let me go back
> to the community, I will take my medication for the rest of my life cause I know
> that I need it

More than that, as demeaning and destructive as these experiences were,

hallucinations were a motivator for Tutti: "it gave me something to strive for, to better

myself-not to go back-but to go forward." Looking back she can understand, she can

differentiate the hallucination from reality-she tells a story of seeing her family across the

street in another house and she asks herself-"how could this be?" She recognizes now

that this was when she began to doubt herself-to recognize that this was her mind playing

tricks. "But your mind can play tricks on you. And a mind ain't nothing to play with."

She's pretty resilient, with or without the hallucinations; she is still the same

person. She would still be who she is, but she wouldn't miss the hallucinations. "They

were scary."

Themes

Theme 1: Are they who they are?

"Are they who they are?" concerns the loss of realistic appraisal. This internal

dialoguing questions not just the "who," of "Are they who they are," but also the very

structure of the phenomenon. Initially, participants are so certain that this is an "out there" phenomenon, that they resist looking inward. Connecting the voices or visions with mental illness does not occur until they are confronted with the reality and consequences of their behaviors. What happens instead is the movement of the hallucinatory phenomenon into their present reality. "Merging with reality," participants voice struggling to find meaning and significance in this experience. "Are they who they are?" is a theme that relates the experience of hallucinations with the sub themes of "conscious of a negative," "merging with reality" and "lending meaningfulness to the experience."

Conscious of a negative

Participants described the initial experience of hallucinations as a first awareness of a negative, a recognition that "I am not all right." "I thought when I first heard the voices, that …this is the beginning of the end." Mary recalled, "Umm, I be seeing things that's not there and some people say they don't see it and sometime I see it. And sometime it be there and some time it don't." It is as if one's self-appraisal was all wrong. One now belongs to a different club. The trouble is one doesn't know the rules, one doesn't know what's going on or what is expected. There begins a series of internal questionings: what is real, who are they, who am I and who am I in relation to them? Participants described an inner struggle, using all their senses to determine the reality of the experience. Jimmy remembered, "It was as if I was losing my mind; the voices told me to hurt myself. "It was horrible; I felt like I was losing my mind, it was horrible." As he looks back on this experience he says, "I think that's crazy, you know, that's crazy."

"The messages go negative," is how Akim remembered his first awareness of hallucinations. Several participants used the word "scary" to describe the emotion-laden experience. Harley's fear broke like a torpid rain cloud. "The first time, it was kinda scary. It kinda had a bad effect on me. It was very strong. I couldn't organize my thoughts, scary thoughts, scary feelings." Mary reiterated, "I didn't know when it started, but it was pretty weird." When asked what she meant by "weird", Mary responded "Because they were voices telling me to kill myself."

Moreover, hallucinations possessed both disturbing and fascinating characteristics. Paxy remembered this aspect of her hallucinations. "But I still get this hallucinating feeling, and you know it's a disturbance of the mind. Like when I'm talking to somebody it interferes with the conversation I'm having with somebody, and when I'm talking I just cut off and I'm just saying, well I'm listening, okay I hear you..." Katrina recalled, "Yeah, it was not exciting, but wow, you know. Just to be seeing things and it ain't there you know..."Conscious of a negative," participants attempted to find meaning in the voice, shape or person. Individuals talked about a perpetual sense of foreboding and preoccupation with the content. Courtesy tells us, "it told me to hurt others, but I was, I mean I was always worried, I'm prone to worriness and sometimes I always, but I am truly less worry because I pray a lot, I pray a lot and make the best decisions I can." Louise states, "I can't express myself too much, but it bothers me to hear voices, it bothers me ...they wanted me to stop talking...say I talk too much." So compelling are the hallucinations that even today Akim will choose not to watch TV, the source of his original visual hallucinations.

ummm-I was watching –it was like someone was watching television-someone was forecasting and it was like someone was talking to me…on the television- that kind of thing-I'm still uncomfortable watching TV-not just because of that experience-but I just don't watch TV and become addicted-and I was watching Oprah and she is giving some kind of challenge and one of the challenges is not watching TV ,but she said "not watching TV you can get more things done…and I tried and I thought yeah and umm…I've been doing that ever since.

Participants would also mention struggling to hear the content, what is the meaning for me? Louise questioned the gender of the voices. Was it a man or a woman, are they talking to each other, are they talking about me?

A he, and sometimes it might sound like a woman, yes. But she used to talk to me at first. It was kind of strange, but it's not like I'm one of those loonies, but I'm just telling you what I hear and what my problem is. She would talk at first about the other man, that voices that I hear, saying "You're not going to do anything to her," but after a while I was going in and out to the clinic and everything and then when that it changed she was gone. But I couldn't see her either it was just a picture or a image of the wall, staring at the wall saying somebody's there and you can't see nobody but I can hear.

Merging with reality

For many participants hallucinations merged with reality. The voices, shapes, persons, appeared so real they at once became part of the person's reality, or resembled a waking nightmare. For Mack, hallucinations were undifferentiated from his nightmares: "I probably fell asleep and I wake up and I swear I see a figure in a cloud or something and I see a gun pointed at me. And it said go back where you belong…something I don't understand, the hallucinations are there when all the lights are out…"Katrina vividly remembers when she was in a hospital room, and then this dream, the hallucination comes true: "Seeing myself in the hospital and in a room and running up and down in the room you know. And they put me in seclusion, you know, so I always, you know, be going there." It is all one reality…which is the hospital stay. For Katrina it is not

hallucinations or mental illness that results in a hospital stay, but rather, the hallucinations presage or predict the outcome, then, hallucinations become one with the outcome. It is all one reality...which is the hospital stay. As Katrina became immersed in the experience, she also used hallucinations to inform her. "I thought I saw myself in a gym suit, outside a door running next door to get a glass of water, and then I remembered not exercising, and I exercise now, and saw the striped gym suits." She uses the hallucinations to tell herself that she is not exercising and taking care of herself-"I started to eat the right foods and stuff."

Merging with reality may mean that reality is hard to discover. For some participants there is a dissociative quality about the hallucinations...as if they are looking at themselves and outside themselves. Individuals describe a disembodied experience in which their bodies are separate from them...as if their bodies are doing something without their permission or knowledge. PFC remembers, "Sometimes I might go down my tonsils and all...they get bigger-kind of bigger-sometimes they go down but I can't say what kind of disease it is."

As the voices became more absorbing, they become a part of their daily lives. Participants related responding to them with increasing frequency. Thus began a pattern of ever-increasing isolation. Often families became concerned and initiated the first of many hospital stays. Participants found themselves thrust in a maze of differing psychiatrists, multiple medication changes, diagnoses, referrals, hospital stays, periods of self-imposed seclusion, thoughts of suicide, stigma, and estrangement from family and friends. "... my family had a hard time dealing with it...my dad put me in the hospital a

few times and I was acting crazy at my Dad's house." Struggling to survive this experience often meant attempting to find significance or meaning in this experience.

Lending meaningfulness

For many participants, as scary, depressing, defeating, disturbing, irritating and sometimes funny and helpful as these hallucinations might be, the hallucinations provided some kind of meaning for them. Harley describes hallucinations as an energizer as - "Well it perks me up…you know kinda like a cup of coffee or something." Louise recalled that the hallucinations helped her raise her children. "Sometimes they told me how to raise my children and to ask for help too…to raise them." Participants described a world of voices and visions that appeared to express their duality. Mack remembered, "The hallucinations control my bad side." Mary also described this duality" "… but I didn't know if it was a conscience voice or demons-you know what you call demons?" As time wore on some participants found it difficult to view the hallucinations as meaningful and wondered if something was wrong with them. Catherine struggled with the very idea of hallucinations. "I didn't know why I was born this way and why I was living this way." Lending a different meaning to hallucinations came at a later time, when participants were more accustomed to the phenomenon, and more able to cope.

<div align="center">Summary</div>

In this section, hallucinations are viewed as a foreign land, one in which the language and customs are unknown. In this new land, participants became conscious of a negative. They experienced feelings of fear and foreboding. Struggling to become part of this new landscape, they lost familiarity with the old landscape, and as a result existed

in neither world. In effect, there was a merging of reality. Participants began to view this new country as one that had special meaning for them. A way of surviving in this new land was to readjust their expectations and their thinking.

Theme 2: A not so certain life

Jimmy's experience of multiple hospitalizations and difficulties with family underscored a reality of "life as different" and unpredictable. With the first awareness that hallucinations were a part of the participant's reality, another realization occurred soon afterwards. That is, that life would never be the same again. Instead, ambiguity about treatment and the compellingness of hallucinations became sub themes in a increasingly difficult effort to keep hope alive.

Ambiguity about treatment

Akim remembered depression and visual hallucinations that affected the way he thought about himself. "The hallucinations-broadcasting on TV and everything-the messages go negative-what's the word I'm trying to think of it's like a put down-but umm-it affected my self-esteem-I would stay to myself a lot-hygiene would go down." Akim related regret about areas of his life for which memory is sparse or nonexistent. "I had ECT (electroconvulsive therapy) and there are whole pieces where I have no idea what happened. I have a year when I don't know what happened." Akim did not rely on the standard forms of treatment and thus sought his own treatment in substances, mainly alcohol. The same memory losses (blackouts) that he experienced with alcohol, paralleled the memory loss he experienced with ECT. Ambiguity about treatment is communicated in participants' distrust of medication and frustration with the lack of

response. Mack communicated this concern. "I wish there were some medications that would take away these hallucinations...but I know that's not going to happen in my lifetime. Maybe in my niece's or nephew's lifetime, but, not my lifetime." Mack continues, "I discuss this with my therapist...my therapist and I are not always on the same wavelength...when I was on Depakote I had hallucinations, when I took Klonopin I heard voices." Mary considered her medication history before her current, more effective, medication management, "well, yeah...when I got on medication –they tried everything on me-medications and what I was taking, wasn't really working." PFC spoke of side effects. "...I can't really say what kind of disease it is I have, but I think that another medication could be brought up, but I'd be allergic to it...325 mg in the morning and 325 at night. Honestly I can speak good and all that, but sometimes I start to slobbering, and you know lose memory and all that." PFC speaks of specific side effects: "And I kind of leaning over like this when I'm walking and things like this, you know that's why I can't work at Hardees no more because I always end up wobbling around the lobby of the store and medically I'm fine...." Other participants shared feelings of gratefulness and felt immeasurably improved by medications, particularly Jimmy.

> But I just want you to know that ever since I took Clozaril they have gotten a lot better-I don't feel like I used to feel-I've felt like I've left my body a few times-but I take my medicine-sometimes I do hallucinate-but it's not severe enough-sometimes I hear someone say "Jimmy" "Jimmy" but I don't see nobody.

Tutti concurred, and stated, "I know I need it honey. I know I need my medicine. I do. I know I need my medicine because I, what do they call me? They used to say I was paranoid schizophrenia and now they told me I'm (schizo-affective)." Both Mary and Harley agreed but related ambivalence regarding the cessation of hallucinations,. Mary

likened medications to imprisonment, desiring "freedom from medications." Harley

reminisced, "I might miss them (hallucinations) though."

Compellingness of hallucinations

Participants described a world of voices and visions that were also compelling.

Participants often identified a coercive feature of hallucinations that was as puzzling to

them as it was to the onlooker. Not only did the voices urge them to listen, but also to

obey and to act on the directions (of the voices). The consequences of acting on

commands from the voices were considerable. Participants illustrated potential and real

outcomes such as homelessness, incarceration and suicide attempts. Mary talked about

voices telling her to walk out in the street; "I hear voices –they tell me what to do. What

not to do-tell me to hate myself when I'm really down They gave me sorrow. I used to sit

and watch cars go by. They'd tell me to go out and walk in the street and get hit by a

car." Voices tried to coerce Mary to act against her own survival instincts. "I was in an

apartment-and I turned the gas on-and I stopped the air in the doors-if it hadn't been for

my roommate I would probably have been dead..." The need to obey, or at the very least

listen, to the hallucinations, describes the compelling quality of hallucinations. Courtesy,

in effect, stated "I know better…And I knowed everything I was doing. I couldn't walk

straight and all I wanted to do was sit out in the rain and all of that. And I know

everything I was doing but I just couldn't help it. I knowed everything I was doing but I

just couldn't help it." Courtesy continued, "They would tell me to sit out in the rain and I

couldn't hold my head up out of the plate. And I know everything I was doing, but I just

couldn't help it."

This compellingness to listen does not rest with commands or instructions, but often includes demeaning comments that attack the personhood of the individual. Akim discussed the insulting features of his hallucinations; so insulting to him that they must be believed. The voices specifically assailed his identity, "as far as my lifestyle-my sexual preference-if someone made fun of me or put it out there-I'd go to pieces-I was a mess."

A feature of this compellingness is feeling powerless...feeling powerless to fight. Jimmy defines this sense of powerlessness when he tells us that he would like to be "master of my own fate." Mack reveals a sense of powerlessness in the "not knowing." It appears that hallucinations cannot be regulated or influenced. Mack noted,

> Something I don't understand, the hallucinations are there when all the lights are out...then the lights are on there's nothing...I don't understand that ...then I go back to sleep and they're gone...It usually happens about three in the morning... and you get so scared you can't tell anybody...Scary, because there is no one that can help you.

This loss of power is akin to feeling personally vulnerable. Mack would look down and close his eyes when he revealed feeling "at risk" "in danger." He remembered, "That's because they were scary situations...I was really scared."

Summary

Continuing the metaphor of strangers in a new country, participants found it hard to find help. When they sought medical help, they found that the responses they received were either not helpful or confusing. Perhaps the directions were confusing. "Ambiguity of treatment" became a theme for them. They were foreigners. Perhaps they really ought to try and listen-adapt to the customs of their new country. They felt compelled to blend and follow the traditions of this new land...to acculturate

Theme 3: Finding strength in the broken places

Participants experienced intense pain and sadness. The unremitting nature of hallucinations, the unexpected return of hallucinations, and the consequent fall-out from this experience, resulted in their finding ways to make life worthwhile amidst the "broken places." "Broken places" such as depression and loss, refer to those places in the experience of the individual that are the disabling aspects of the hallucinatory experience. "Finding strength" concerns overcoming and living life in a different way. Sub themes identified include: broken places, living with loss, regaining balance and finding strength.

Broken places

Living with sadness entailed living without joy. Initially, participants described listening to voices whose messages were scary and whose very compelling ness provoked fear. For many participants an ongoing depression materialized. Akim was one of many participants who related long term depression:

> When it gets to the point of hallucinations I become very depressed. Well…that would be…at least two…when it got to the point when I got depressed this has happened at least twice-and I say I think, because I had ECT and there are whole pieces where I have no idea what happened—I have a year when I don't know what happened. There's some gaps-I don't know what's going on. I remember one time-I quit my job-drinking-I hated my job-my friend and I were not going on too well-I remember being very paranoid it's like I can remember depression.

While depression was a predominant memory for Akim, depression was so encompassing for Harley, that it's as if he cannot remember life without depression. Noteworthy is the depth of sadness that both Mary and Harley verbalize. Mary used the word "sorrow"…"I feel sorrow"…a word that stands out. To deconstruct this word invites a perspective of sorrow as grief, loss. It is more than just sadness. Harley

describes depression as a norm. He can barely differentiate depression from day-to-day living. Harley's sadness encompasses lost opportunities, and not making plans. "I don't think I'm completely wasting my time. I guess there would be a better way to use my time." Additionally, it appears Harley cannot differentiate depression from daily living. In fact, Harley seems so used to this feeling that depression is akin to relaxing, "I mean you can have this depression and relax about yourself." Mary's sadness is isolating, not socializing, and feeling "un-free." When challenged to imagine life without hallucinations, she felt at a loss for words, "Great, I'd be free. I'd like where I don't have to take medication."

Participants discovered a depression so crippling that suicide becomes a way out. Jimmy self-mutilates as a response to the commanding voices and a way to die. He overdosed on aspirin. "Well a long time ago, ummm, I bought a bottle of aspirin, and there were 100 pills in it-and I took the whole 100. I was feeling like I couldn't deal with it no more." Jimmy continues, "I took 100 Tylenol pills-I almost died from that-I was lucky." Catherine remembered:

> Umm, like I want to commit suicide and don't want to live, don't want to be this way, I want to be like somebody else, I want to be different. Ah, I, sometimes I sleeps at night and I toss and turn, then I wake up dreaming and ah, wake up scared, somebody is scaring me, over me, trying to do something to me. And I wakes up being scared, and like a lot and I end up crying in the middle of the night when I'm sleep.

Living with loss

Depression was further heightened by the losses experienced by almost all participants. Most poignant, as previously mentioned, is the loss of power, as Jimmy illustrated when he described wanting to be "...master of my fate." "I wouldn't be here,

I'd be my own boss-you know master of my fate-because ever since I hallucinated it's made my life pretty bad-you know-real bad." Additionally, almost all participants described a succession of "missed opportunities." "Missed opportunities" involved: not having a real job, never getting married, not having a family or being without friends. Harley recalled that a kind of paralysis set in, "Well the truth of the matter is, when it came time to make plans, I didn't set plans." Mack remembered, "I have a grandmother who's still living, and she's 93, and she's sad because I didn't accomplish as much as I wanted to." In other words, the normal developmental markers did not happen for them-and as a result, there is the sense of being "left out." The clarion call of this experience of hallucinations, and in effect, mental illness appears to be "I haven't done anything with my life." Additionally, those traits that culturally define success are missing for the majority of participants. Instead the "job" is part-time or disability, family and friends translate into clubhouses, and home becomes the group home.

Indeed, almost all participants had deferred marriage, lived in group homes, and were jobless or had part- time jobs. The very definition of group home underscores the belief that the individual is "unable to make it on his or her own." This theme comes across as a palpable loss for participants at the very time that voices are belittling or discouraging. Loss is then manifested as "I am less than." Hallucinations often reinforced negative facets or even nonexistent facets of the participant's personality. The participant came to accept as true the beliefs expressed by the voices about him or herself. Additionally, the participant did not listen to feedback that supported a view contrary to the hallucination. Interspersed with these internal conflicts, is the sense of

being labeled or stigmatized, which, again supports the sense of being "less than." Mack

spoke for all participants when he reflected, "I have been judged all my life."

Loss occurs in a larger sense as the individual's role in their community subsides.

Participants isolate, and in response to their hallucinations appear disheveled,

disorganized and behaved oddly or inappropriately. Hence, avoidance behavior on the

part of others served to deepen a societal disconnect.-and the participant appeared fully

aware of this. Akim regretted behaving badly…and in retrospect he was able to recognize

that his illness, and not him, made this happen. Akim recalled, "But other times -thoughts

were-my behavior was inappropriate-nothing really, really bad-but out of place." Akim

remembered that he didn't feel good about it. In acknowledging awareness, participants

expressed shame, but were unable to disregard or resist the hallucinations. A difficult

time in Tutti's experience included inappropriate behavior that initiated hospitalization.

"Every time I get sick I don't want to keep clothes on. One time when I was in the

Eastern State Hospital in Williamsburg, Virginia I stayed in a ward for a night and a day

naked. Every time I get sick it seems like my clothes irritate me and I take them off."

A final loss was the loss of family. Participants mentioned a deepening divide

and eventual loss of family connections as their illness worsened. Jimmy remembered,

"Yeah he was taking care of me …my dad decided to live somewhere else. I was about 19

and my dad went and lived somewhere else-I've been in adult foster care-this was early

the 1990's-I was with Ms.__ I've been living in adult homes after this." Katrina

remembered,

> Well, they all said you just like ma. You just like ma. You're just like her, and I
> go yeah and they say when you leaving the house? And they moved out of the

house last year you know, and I go, I'm leaving, I'm leaving. And they said, I'm waiting for an excuse she'll still be in there. They said she's been taking care of you for 25 years and they said and she is wondering when you going to leave your house. Yeah, and I go yes and they're when you going to leave? And I left so she's alright you know.

Mack also struggled with family disruption related to his illness.

My father's the same way...he's upset that I'm suffering through this...he's upset that I'm mentally ill, he's upset that I'm born bipolar (schizoaffective), he's upset that I have to fight so hard to get anything that I want. I think my aunt is embarrassed by me...I'm not allowed to see my cousins or anybody.

Finally Catherine threads the numerous elements of loss, when she stated:

Ummm, not wanted, needed, not being in love, not being loved, umm family. I feel that my family don't want to be around me and stuff. And now I guess I wants to be around my family to get, you know more know them and stuff because I don't like being by myself and I stay by myself and I don't like being by myself.

Regaining balance

Finding strength in dealing with hallucinations, and regaining mental health metaphorically resembled a tightrope walk. Regaining balance after the initial experience of hallucinations was one aspect of finding strength. Despite persistent disappointment and continuing effort, participants eventually discovered internal and external resources and opportunities for growth. Many participants verbalized losing years of their lives to an unknown entity that engulfed almost every waking, and sometimes sleeping aspect of their lives. Some participants regarded hallucinations as an opportunity to be energized or motivated. Accepting the reality of the hallucinations, whatever that reality was, became a slow process of living with hallucinations.

While not understood, some participants accepted the phenomenon on somewhat uneasy terms. PFC discussed negotiating a different reality. "We don't all see alike on

most things. Together me and you might be talking and come up with an idea and I don't think that's good, what I believe in. It's kind of like a negotiable thing where you learn to speak through others if you want to speak to yourself." Other participants dreaded the return of hallucinations and described always being "on guard." Hallucinations evoked similar apprehension for Louise. "Well…it causes me to suspect things…it makes me suspect different things that are going on in my life. I try to do better…but when the voices talk it makes me think that something is going wrong."

As a way of regaining balance, participants discovered different ways of coping with hallucinations. Some participants described using strategies such as ignoring or sleeping through the voices. Other participants actively engaged and sought out the voices. Four participants revealed using voices as companionship or to assist them. Many participants struggled with treatment, and in particular, medications. During this period of medication management participants would often decompensate (reappearance of symptoms) and find themselves hospitalized again. Participants most often verbalized a fear of further hospitalization as the greatest impetus for remaining on medication. Additionally, recognition of their losses and missed opportunities reinforced the goal of remaining mentally healthy. Jimmy believed, "I feel like I'm doing much better-I think the medicine has really helped me. I feel like the medicine I'm taking has really helped me-I'm just glad to be on some medicine-If I didn't take my medicine I'd be back at Eastern State or Maryview."

In the same way that hallucinations were a source of missed opportunities, hallucinations also provided opportunities for growth and change. Some participants

came to believe that they grew stronger by surviving amidst the depression, isolation and loss. Participants often discovered characteristics of the hallucinatory experience that gave them a unique perspective. Some participants expressed gratitude; others recognized that suffering effected a heightened sensibility to the suffering of others. Akim advised, "Try to be there with support, because for the person hallucinating it can be very scary...extremely scary." Some participants clearly saw their own suffering as an opportunity to help others. Mary stated, "Makes you more giving." Still others had recognized that they had developed working strategies that helped them overcome. Almost all participants verbalized that the experience, good or bad, made them more human.

In the beginning participants described a period of just surviving, making it through the day. Jimmy recalled, "Yeahhh, I'm just glad I'm through it. I was scared- sometimes I feel scared-but it's not as bad as it used to be." Louise simply tried to cope. "I'm just trying to cope with the voices...just like I said, I have to be quiet...just like I am today...sometimes people say you don't feel good, no it's not that...I kinda talk to them and tell them I'm alright...but that's myself today..." One way survive was to reestablish priorities in one's life. Catherine stated, "I feel pretty good. I just found out that I'm working, so I got two jobs, but I got to figure out which one I need." Katrina recalled, "Well I don't know. I never really know. I don't know, I was really low but ummm...Well its more interests in myself and ah it involves more interests in helping myself like being more independent and responsible for myself." Courtesy summed it up for many participants, "I'm doing great now...I'm making it."

Another way to regain balance was to rethink or to lend a different meaning to the hallucination. On making plans Catherine stated "Ummm, learn how to read and go to school, finish school and get a car, and a job and do all the things I want to in my life." Louise provided a different meaning to her hallucinations. "There is not too much that is negative about them. I'm just trying to cope with the voices. Harley now saw that hallucinations may be helpful. "Well it kinda helps me in doing what I want to do. Like…you…see the stuff I get now is stuff I've heard…."

In the midst of regaining balance and surviving, participants developed strategies that made the hallucinations less powerful and more livable. Paxy ignored the voices. "Well, yes, I try to ignore them though. I won't say it out loud. I don't want to repeat it. I'm not going to say it out loud." Louise used a similar strategy. "Well in a way I did…I kind of avoid them if I can…if I couldn't, I'd take a nap…they come once in a while…" Louise remembered Well…trying to get along with people…try to get along -I'm just trying to cope with the voices.

Regaining balance also meant seeking and getting help. Catherine sought help. "Sometimes I let someone know how I feel. Sometimes I will sleep and tell myself not to worry about it." Catherine continued, "I'd think I'm doing good and I feel good and I do to things for myself and I wouldn't need nobody to help me do nothing because I know I can do it for myself and by myself. And if I do need a little help than I just try to get somebody to help me."

Moving outside themselves participants connected with others and became more giving and helping. With distance and time participants revealed that hallucinations had

given them something. Catherine learned to, "... talk to them and get to know them, and talk about, they talks about their illness and I tell them something about mines and you know how I feel. And that tells them they need to talk to their doctor about it, because doctors are the only ones that will listen to them and do what they say...and listen to what they say and they will get them the medication that he feels that they need and that you know that will make them feel better and they to take it the way it's supposed to be taken." Jimmy facilitated clients' understanding of mental illness, "Well I do talk to people around here about mental illness all the time...at the clubhouse...and they tell me about their experience –that kind of affects me too." Louise tries to "be with" and reassure other clients, "Well I try to comfort people and cooperate with people."

Finding strength

Some participants discovered that the experience of suffering provided momentum for change and growth. Living with a different reality did not mean that participants were unable to live a fulfilled and complete life. For many participants hallucinations then became a tool, a means of renewal and change. Mack used his hallucinations to strengthen his resolve. "In some ways I think it made me stronger...you do have to fight for things ...for me, this is hard to put it into words...I'm angry with myself." Mary concurred stating, "Made me strong-it really did..."and hallucinations made her go outside herself. Paxy acknowledged this perspective, stating that hallucinations also gave her courage, "Courage to come out; a little bit more courage." "Finding strength" also meant visualizing a future. Jimmy stated, "It tells me if I can overcome this, anybody can do it. If I can do it anybody can do it."

Summary

Participants missed their homeland. They missed their families, their friends, and ways of doing things. In this new land opportunities were not always available and they found that lacking citizenship status kept them back. When they sought medical help, they found that the responses they received were either unhelpful or confusing. However, participants discovered that in maneuvering the "ins and outs" of living in a new land, they tapped skills and strengths they hadn't known they possessed.

Theme 4: I am still me

Living with hallucinations was an experience that infiltrated participants' sense of who they were and became part of their world. It's as if the hallucinations diminish who you are, muzzle your voice to be replaced by another voice that is not you, yet speaks for you. Participants discovered that despite numerous attacks on self-esteem they would remain in touch with the remembered me.

Damaged self-esteem

Not being who you are, not loving self is expressed in Harley's words, "I really don't love my self-esteem. I don't really think much about self-esteem anymore. It's just a matter of doing what I have to do and doing what I don't want to do." Mary revealed a similar sentiment, "I have no self-esteem … so it makes me feel down in the dumps-I isolate."

That is, who you are is articulated in your hallucinations. Eight participants revealed that their first awareness of hallucinations were negative images or voices that attacked their personhood, often calling them names or relegating immoral or unkind

practices to them. Mack felt hurt and scared. "They were telling me you deserve this...you're a hardened criminal...you committed murder. You're in love with Charles Manson...that scared me." Akim recalled feelings of shame. "Ummm-being a screw-up-I know those words are inadequate-feeling scorned-but as far as my lifestyle-my sexual preference-if someone made fun of me or put it out there-I'd go to pieces-I was a mess."

Participants revealed that not only were the words spiteful, but the voices had a mean, cutting, characteristic that surprised them. Tutti recalled, "They would cuss me, call me bitches, whores, them bad things and tell me to do bad things." Courtesy and Jimmy remembered feeling "bad." Courtesy asserted, "I didn't feel good about myself." Louise remembered, "I felt talked down to." Voices evoked feelings of self-loathing. Tutti affirmed, "They made me hate myself; I didn't like myself." Jimmy remembered, "It made me feel bad about myself." However, while this appeared to be true for the majority of participants, three participants felt that hallucinations actually increased self esteem. Katrina felt hallucinations seemed to help. "They say anyone could have mental problems, physical problems, well the hallucinations seemed to improve it." Katrina recalled a time when hallucinations helped her.

> Well the hallucinations, it seemed to improve it because when I had the low self-esteem I would watch television and the television would just take over my whole world and then I started having hallucinations and it made me notice myself; then I start looking in the mirror and I said Lord, God, let me do something with myself you know (smiling). And then that helps. I guess it helps. It helps.

Tutti and Harley also agreed that hallucinations seemed to improve not only their self-esteem but also their outlook. Tutti revisited what hallucinations gave her. "It gave me something to strive for, to better myself not to go backwards but to go forward."

Getting in touch with me

As damaging as the hallucinations were to the psyche there still was the core, the being, of the remembered person. Paxy remembered herself, "I believe about myself-I'm a good person and not a person who likes to fuss." While hallucinations affected the whole person, it is not as if the real person disappeared. Participants revealed "I am still me." Underneath the behavior, underneath the chaos, "I am still me." Louise emphatically stated, "I am still me." Harley, agreed, "It's the real me all right."

The perception may be that mental illness and the symptoms of mental illness, hallucinations, destroy personhood. There are two aspects of this experience that may be responsible for this perception: (1) that the individual feels diminished by the substance of the voices and (2) diminished by how they are perceived by others. However, "who they are" does not suddenly disappear. Additionally, many participants refuted the idea that they were part and parcel of their hallucinations. Rather, participants revealed that their hallucinations were a phenomenon that was part of their illness, but it was not "who they were." Almost all participants acknowledged hallucinations made them appear differently, caused them to act out, to isolate, and, to lose touch with family members. However, the appearance of acting differently and appearing differently did not represent the real person. In the end one asks, what other illness cause you to act this way? What other illness asks you to question your reality and your sense of being? What other illness represents a different you from the real you. What other illness questions whether you are inherently evil or flawed?

Participants also verbalized that underneath all of this "I am still me." Katrina responded "I guess I'm just an old fashioned person, I am." Paxy knows what she likes to do. "Well...I try to comfort people and cooperate with people...I just love to do things to better myself." Louise confirms this same belief in herself, and further, her desire to help. "I'd be a good person...a very good person...I'd like to tell people what's going on their lives and how they can better themselves and everything."

Summary

Blending in with the customs and traditions of their new country became difficult for the participants. They felt ostracized. Participants were treated like foreigners. Repeatedly they were ridiculed, and because they looked and dressed a little differently, targeted as irresponsible, stupid, and even criminal. Whether this was true or not, the end result was that they **felt** diminished, their sense of self-esteem was damaged. Participants began to doubt themselves. Nonetheless, participants remembered one thing-"I am still me." The bleak realities of living in this new land might define them as a foreigner, but they remembered that they were essentially, good, caring, giving, possessed innumerable skills, and could weave their way through this new land.

Pattern: A life disrupted: Still lived

Paradigm case: Akim

In Heideggerian hermeneutics, themes are threaded by a pattern that constitutes the meaning of the whole. The pattern that most clearly represents the whole, and was present in every narrative in this study is "A Life disrupted: Still lived." This pattern is illustrated in the paradigm case-Akim's story.

The essence of living a life with hallucinations is recounted in Akim's story as a phenomenon that threatens the core of his existence, his sanity. His life is disrupted inalterably. Akim is forced to realize that the voices are coming from within, when they appear to intrude from the outside. In an unguarded moment the hallucinations arise from his television set. Who or what are they? Akim is so fearful that he vows never to watch television, and Oprah Winfrey has provided him with the rationale. "You'll have more time to do things." Akim has time-time to wonder about the demeaning aspects of the voices? Is this the inconsequential self doubt that rests in every person, or does the voice know something he doesn't know? The voice appears to be an object, but it is the subject of Akim's own feelings of self-worth

What proceeds is an almost existential meltdown. What is the central truth here? How do I arrive at truth? Akim arrives at the ontological question-"who am I really?" The basis for asking this question rests on accumulated self-doubt. Doubt incurred by voices calling him names. Voices tell Akim he's a *"screw-up."* Akim even uses a phrase to describe this series of "put downs" that epitomizes his experience as an outcast, *"feeling scorned."*

Additionally, more doubt was acquired by his past inappropriate behavior. It's almost a relief when Akim discovers he has a mental illness.

> My diagnosis was given when I was in treatment…I thought, Oh, so this is what's happening to me, it means I can get better. I don't know if it has anything to do with mental health- I would say something or do something that was very unusual. My hallucinations were sometimes a blessing, but other times, thoughts were, my behavior was inappropriate-nothing really, really bad-but out of place.

When Akim is challenged by this researcher…"What kind of person would you be if you had never experienced hallucinations?" Akim succinctly replied, *"Boring."* Although some may interpret this comment as humorous or sarcastic, another possibility is that Akim's perspective has shifted. The person Akim has become is due to this experience. What ensues is a story of successfully navigating through life with an errant compass; a story of survivorship. Akim has shifted his perspective because hallucinations have provided him with *something*; he has given hallucinations a different meaning to make the experience more livable, and he is a more interesting person as a result. Akim is asked, "What would it be like to be free from hallucinations?" He paused, *"You know it would be a wonderful thing-but I'm gonna stick with what I have-for two reasons…if the level of hallucinations is the level it is, versus the level it was…then I'll take it."* Akim would rather have the knowable versus the unknowable experience. He knows he has survived -and he'd rather have the experience of hallucinations versus some other phenomenon that is unknown, and whose repercussions and outcomes are unknown. At some point the hallucinations become a manageable experience and Akim developed a certain capability in handling hallucinations. There is an expectation of what can happen-and a certain understanding of his ability to manage the hallucinations. .

Moreover, in experiencing the knowable, versus the unknowable, Akim is afforded a certain advantage. *"If something else happens then I'll guess I'll have to deal with it-but it would be probably harder than this hallucination piece."* In essence Akim is telling us, knowing that I've survived something that threatened me, has given me the strength to know that I can probably survive almost anything. That is, hallucinations may

be scary, irritating, and even devastating-but at least they are knowable. Over time

hallucinations come to be a known element that can be managed. Part of navigating

through obstacles and surviving is also the ability to reframe the experience. Akim

reiterated, *"It's part of my reality-and I know it can happen-but it doesn't stress me out."*

Akim redefined the event so that it becomes smaller, and less overwhelming. In the

process of reframing, Akim has been evaluating the phenomenon for what it really is,

minus the emotion, minus the clutter. Akim unequivocally stated, *"it is part of my*

reality-now that I know that-now that I know it can happen-it doesn't bother me as it used

to." Now Akim **sees** himself as surviving. What constitutes survival? For Akim,

surviving means getting back to school-and doing those things he never dreamed

possible. *"It's good-now I'm busy doing something I never thought I'd ever do-going*

back to _____University." Therefore, surviving a traumatic experience has a

transcendent quality. Transcendence is this movement beyond the initial struggle, to the

point that one can look back and say that Akim has learned something from this

experience. In Akim's words:

> …whatever I'm going through now-is nothing-it kinda helps you to measure your
> reality of your existence-so that I feel lucky and quite healthy-so even though you
> have to experience hallucinations-Gratitude, hope-like I said-hope is the
> expectation that something will get better

Akim also discovered that surviving means moving outside himself. From a more

global perspective, hallucinations had given Akim a better understanding of people in

general, and more specifically, of individuals suffering from mental illness. Akim

recalled, *"Umm…one of the ways …it helps me to talk and relate to people in*

that…ummm when I see people with mental health issues I'm not scared…" Akim also

reflected, is there not a real person there underneath it all-perhaps a concealed person?

Akim recalled, *"it helps me feel comfortable talking to anyone, and the other thing is,*

that once I'm not scared with someone with mental health issues going on, because one

of the things we have been talking about, if I'm scared of someone or something-I need to

face it –because pretty much it's a mirror image of me...it helps me to get along with

people to identify with them." Isn't it in the knowing and *being-with* that makes us more

human (Heidegger, 1927/1962)?

In the end Akim acknowledged that surviving does not simply mean just being-

there, but also being a part of the human experience. Being a part of the human

experience is synonymous with connecting and needing others. Akim reminded us that in

the process of connecting we become more aware of who we are..."it's pretty much a

mirror image of me." No only that, there is a feeling of completeness in connecting with

others. Akim advanced a different take on life: *"...one of the ways...it helps me to talk*

and relate to people in that...ummm...when I see people with mental health issues I'm not

*scared..."*Akim acquainted us with a picture of self and hallucinations:

(1) individuals are more than their illness and (2) hallucinations mask the person inside.

> Even when this person is going through this mental illness, I still see the person-
> even if they're combative or what have you-my grandmother is like that. I see the
> good in people. I'm not crazy or stupid or anything; I don't put myself in harm's
> way...try to get in there. I like to watch people-I like to connect.

> I don't know, I can't out it into words-it sounds strange, but I'm glad it happened.
> One of the lessons I get out of it. It helps me to not judge people, because seeing
> people in the hospital, I learned to have compassion for people...and I don't have
> any proof of this, but I believe that there are some cases or sometimes when
> people with mental health issues become themselves again...even if for a brief
> moment.

Akim provided insight into what survival looks like. Even when participants express regaining their life, at times they felt appropriated by their disease. Due to stigma, marginalization, and the recurrence of symtomotology the disease is always there. There were always reminders of their decompensation ...when they were admitted to a psychiatric hospital, when they attempted suicide, or when their behavior was inappropriate. The memories themselves were demoralizing experiences: *"I remember being scared, I can't remember specifics-I remember being very scared and paranoid."* *"Hallucinations led you to isolate and kinda stay to yourself."* Akim finds a way. Surviving began with giving. *"Gratitude, hope-like I said-hope is the expectation that something will get better."* Finding meaning in this experience and then doing something with that meaning is Akim's story of survival. In the midst of the interview Akim is taking on a new role-one of mentor and guide. Not specifically for clients, but for health care professionals. He recalls the fear...and tells us what to do.

> Don't be scared...try to be careful not to force your reality on that person-because in hindsight-in going thru hallucinations-what people fail to realize-that's reality for them-you can say whatever you want to -you're on the outside looking in-try not to impose –try not to impose how you feel on to that person-probably going to agitate the person.

How many nursing books still advise introducing reality or clarifying reality for the hallucinating or delusional client? Akim tells us...it's not worth it...and further, this may agitate the client. And Akim learns a lesson from his own story of survival...that of connecting, *"Try to be there with support, because for the person hallucinating it can be very scary...extremely scary. If that person will permit, hug them, hold their hand and something, reassure them-whatever is reasonable.*

For Akim hallucinations required his living in a world not of his making. He did not choose this experience; rather he was thrust into a world that caused him to question

his sanity. As a result, Akim encountered a different world, a world of numerous loses, hospitalization and frequent bouts of depression. It was actually the language of mental illness that served to jumpstart this story of survivorship. What was once a disrupted life was given a name-a label-Schizoaffective Disorder. This provided hope and a sense of purpose.

"Still lived" represented the future as possibilities. Akim redefined and reframed his experience of hallucinations. Hallucinations had given him something-he is interesting-not boring. In fact, he finds hallucinations are a phenomenon that he can live with-because they are knowable.

Finally, the art of being present to another human being, caring, is ironically not represented in the guise of the nurse. Instead, Akim viewed this as his own responsibility, part of his own plan for survival.

CHAPTER 5

Conclusions, Discussion, Implications, and Limitations

Introduction

The purpose of this chapter is to (1) present and discuss the conclusions of the study; (2) outline the implications of the study; (3) present limitations of the study and (4) delineate areas for future research. This study was undertaken within a Heideggerian-hermeneutic framework with emphasis on the perception of being as outlined by Heidegger (1962, 1968, 1969, 1971, 1972). The study utilized a method developed by Diekelmann, Allen & Tanner (1989) termed Heideggerian hermeneutic inquiry that arose within that paradigm. Therefore, the conclusions reached are part of an overarching pattern that links the themes voiced by the participants.

Just as we acknowledge the research gains made during this the "decade of the brain" we are still confronted with clients who are overwhelmed with the experience of hallucinations and health professionals who are confused by this phenomenon. Clients talk about this phenomenon as "making me feel different" "I feel separated." Many clients knew their lives would never be the same again. Some clients talked about feeling powerless "feeling resigned to my fate." Some clients actively sought help, and this included a state of watchfulness, vigilance "I always have to be on the lookout."

Hallucinations are a phenomenon. Understanding the ordinary experiences (narratives) of living with hallucinations raises the questions of "How do I feel about myself" What does mental illness mean to me? How do I keep hope alive? How do I go on? Illness narratives allow us as health care professionals to see what is behind the

obvious. For example, behind the current treatment strategies of medication management and cognitive–behavioral strategies, what of stigma and self-esteem-and does one reinforce the other? We would believe that with the cessation of hallucinations there is the cessation of illness. What of clients who cherish their hallucinations, who view hallucinations as "old friends"?

Does this mean that health care professionals should disregard current strategies in an effort to "preserve" hallucinations? No. However, understanding hallucinations from the perspective of the client provides us with a thoughtful beginning.

Worldwide, schizophrenia affects approximately one percent of the population (Mariani, 2004). While medical outcomes are measured by the cessation or diminishment of hallucinations, and other parameters of mental illness, these "outcomes" may have different meanings for clients.

Conclusions and Discussion

Conclusions of this study reflect the focus of this study: the unifying themes of a group of persons experiencing hallucinations in relation to their sense of being, sense of self. The conclusions emanated from the shared/common manifestations of experiences outlined in Chapter four. Each of these conclusions is intricately linked, derived from a common experience. Conclusions are listed below and will then be discussed separately, in relation to each theme.

1. With two exceptions participants described a litany of negative consequences, both episodic and long-term from this experience.

2. All but one participant was able to recall or currently describe hallucinations as giving them something positive amidst the chaos. (Courage makes me giving, motivating or strength-providing).

3. Living a life of loss, losing connections with family and links with the community was an unexpected result of this experience

4. Most participants related lending a different kind of meaning to this experience of hallucinations as integral to surviving mental illness.

5. All participants recognized a sense of overcoming and eventually surviving, in their own way, and defined on their terms.

6. Almost all participants agreed that hallucinations were not expressive of who they were. Rather, who they were; their "being" was separate from hallucinations. Additionally a *persistent sense of self* defines a sense of self that remains consistent throughout.

The Constitutive pattern of "Life disrupted: Still lived "became a backdrop for the four emergent themes of: *Are they who they are? A not so certain life, Finding strength in the broken places* and *I am still me.*

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Theme 1-Are they who they are?

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Conscious of a negative-introducing chaos

Just like anyone who navigates new territory, for the person who experiences hallucinations the phenomenon is uncharted territory. Rather than "who are they?" the initial question becomes "are they who they are?" "Are they who they are?" more accurately describes a cognitive search...not just who, but what, and why. It is a question

of structure that surrounds this phenomenon. This initial appraisal, this kind of questioning is not unlike the questioning Heidegger describes the inquirer might ask of him or herself. Heidegger tells us that we are each entities free to ask the question "what is Being?" (Being and Time, 1927/1962)." While to the outsider this appears to be an ontological search, *"who am I?"* to the participant it is one of structure *"what is it?"* Throughout the interviews, as participants described their hallucinations, there was an initial questioning; did the voices or perceptual disturbances emanate from an external source? The recognition that voices or other perceptual disturbances are derived from an inner source, the participant's own mind, invited a sweeping reappraisal of their sanity. Hence a second layer of questioning occurred, attempting to define the phenomenon.

For most participants *are they who they are* described this kind of searching. The language ("scary", "It was scary," "It kinda had a bad effect on me," "It was very strong") used to describe the phenomenon, was comparable to Chadwick and Birchwood's (1994) study in which clients used similar language. This searching was an attempt to make sense out of the unknowable and undecipherable. Chaos theory (Butz 1997; Capra, 1996; Gleick, 1987) described this effort of making sense out of chaos, thereby discovering an underlying pattern. The underlying tenet of chaos theory is that systems are self-organizing. Only when systems are out of balance can order or pattern emerge (Capra, 1996). According to Capra (1996), self-organizing systems should meet three criteria: (1) They should have the capacity to create new systems of organization through "process of development, learning and evolution;" (2) The emergence of ordered patterns from self-organizing systems-be they new behavioral styles or new structures-

become apparent only when those systems are far from a state of balance as implied by terms such as "equilibrium" or "homeostasis;" (3) There must exist a "nonlinear interconnectedness of the system's components (p. 85).

First, humans are nonlinear, dynamic beings whose ways of thinking and doing may appear chaotic. The experience of hallucinations by its lack of predictability and lack of understandability fit the proposition of a random phenomenon. Secondly, the emergence of ordered patterns occurs only when the system is far from an ordered state. In attempting to achieve a sense of order participants in this study attempted to make this new reality fit the existing reality. PFC verbalized "my reality is not your reality...maybe it's negotiable." Participants struggled with the label of mental illness; others found this a way to develop direction (at least I know what I have and can do something about it). Third, this process occurs as an evolving state of thinking, feeling and acting (Shulman & Mosak, 1988, p.1). Order emerged out of chaos. Voices held meaning for the participants. Participants remembered the voices were there to hurt them or help them. The voices told them what to do. The voices stimulated activity, perked you up, or helped raise your kids. Participants developed strategies and new ways of coping. Hallucinations provided a different kind of meaning. In the end, unwittingly perhaps, for the participants, the voices became instruments of change.

Merging with reality-applicability of chaos theory

Merging with reality is this slow evolution of chaos becoming order. Capra (1996) indicated that the more chaotic the system the more likely order will emerge. The experience of hallucinations was so chaotic, so bizarre, so disorderly...that it seems only

order could emerge. Certainly Katrina found some kind of order in her hallucinations that inform her, that tell her she needs to exercise and comb her hair. Order emerges as Paxy tells us that only through the hallucinations could she raise her children. Tutti at once recognizes reality as she views her hallucinations. Her family couldn't possibly be on the balcony across from her…therefore, she tells herself "this must be a hallucination." Again, the more disorderly the phenomenon the more orderly it becomes.

Lending meaningfulness and meaning-making

Another way to make order out of disorder was to lend meaning to this experience. An aspect of the compellingness of hallucinations was also the belief that hallucinations were personally significant to the participant. This made it necessary to respond to hallucinations. Participants related that part of their watchful, anticipatory attitude was in waiting to hear what the voice would say. Beck and Rector (2003) posited that voices were personally applicable because they expressed unacceptable wishes. Romme and Escher (1993) indicated that for some participants in their study, hallucinations represented a spiritual guide. In this respect communicating with spirits was viewed as a gift and revealed openness to spirituality. In this study, several participants described a spiritual component to their hallucinations. They spoke of God speaking to them or sending someone to help them. For a few participants, the opposite was also true. Participants described a different dimension of evil and demons. For still other participants, who had not been spiritually inclined previously, addressing their spirituality assisted them in coming to terms with their hallucinations. In this respect, it

was not that the hallucinations had a spiritual characteristic, but that addressing their spirituality became a coping tool.

The initial appraisal of this experience of hallucinations created a questioning of the structure of their experience...not just who but what? The ordering of this phenomenon was similar to the mechanism of chaos theory, in which nonlinear organisms create order out of chaotic phenomenon. A first glance, order does not emerge out of the disorganized phenomenon. However, there is a merging of reality that occurs in which the hallucination may merge into the real world, or the real world merges into the fantasy world. Either way, participants attempted to make some sense out of this by lending meaning or personal significance to the phenomenon, and order is created that has meaning to the participant, while, perhaps, not apparent to the onlooker.

Theme Two-A not so certain life

Like any traveler venturing into the unknown, the perspective of having an illness, particularly a chronic illness, causes one to look at his or her life differently. The art of living has changed; life is not so certain. Furthermore, mental illness presents a different picture of chronicity. For individuals who struggle with mental illness, illness is defined in socio/behavioral, moral, or even existential terms. Social in terms of estrangement from family, neighbors, and friends; moral in terms of "acting out," legal ramifications, or even incarceration; and existential, being a person defined by delusions or hallucinations. What other disease process has this kind of multi-faceted sequelae-on numerous levels? In this study, participants related a sense of ambiguity about treatment that was similar to the uncertain course of any chronic illness.

Ambiguity about treatment-living with a chronic illness

Chronic illness The uncertainty of hallucinations, their waxing and waning is reminiscent of the good and bad days with cancer, the highs and lows of diabetes, and, the manageable and unmanageable congestive heart failure. Additionally, there is a sense of powerlessness amid difficulties accessing care and medication management. The same treatment issues regarding care still arise.

Like any chronic illness schizophrenia is characterized by relapse, and there is extensive literature focusing on strategies to prevent relapse and deal with recidivism. Many programs utilize a cognitive-behavioral approach coupled with social skills interventions (O'Connor, 1994; Miller, O'Conner, Di Pasquale, 1993; Buccheri, Trygstad, Kanas, & Dowling, 1997; Sayer, Ritter, Gounay, 2000). While these therapies may be utilized in specific inpatient and outpatient programs few address the perspective of recidivism from the client's perspective. Davidson, Steyner, Lambert, Smith and Stedge (1997) used a phenomenological-participatory action approach to study the circumstances and experiences of re-hospitalization. They discovered that clients found the hospital setting attractive in that people cared for them and they felt listened to. Additionally, clients felt the pull of the hospital as they described an impoverished community life, lacking the elements the hospital provided that is, people to talk to, decent food, and sanctuary. Additionally, clients felt disconnected to community mental health services and often felt powerless and fatalistic.

In this study, for a majority of the participants, hospitalization was described as a low point in their life. Reliving memories of inappropriate behavior triggered feelings of

fear, sadness and confusion. As opposed to the findings of Davidson, Steyner, Lambert, Smith and Stedges' (1997) participants did not look forward to hospitalization. The contrasting findings between the two studies may be explained in the living situations of the study participants. None of the participants interviewed in this study was homeless and that might account for the decreased attractiveness of hospitalization. Findings that remained consistent with Davidson et al. (1997) were in participants' lack of understanding regarding prevention. While some participants acknowledged a link between medications and relapse, others were either unaware or viewed prevention as unimportant. Participants also related a sense of powerlessness; but missing was the fatalism that Davidson et al. (1997) attributed to the participants in their study. While powerlessness was ascribed to the compellingness of hallucinations and to their mental illness, almost all participants envisioned a better future and saw themselves as surviving.

The chronic illness literature is replete with vocabulary that includes phrases such as proactivity, self-efficacy, self-sufficiency and empowerment. While such vocabulary may be empowering for the majority of clients who suffer from chronic illness, participants in this study often described feeling overwhelmed with the business of getting better. Mack describes his father "fighting for him." Jimmy's father left because he could no longer fight for him. Hardly feeling empowered, participants related their fatigue in accessing care. The perception that health is dependent on individual prowess serves to overpower the limited means of the individual with schizophrenia. Clients often felt lethargic because of their medication, thoughts may be disrupted due to hallucinations and delusions, and amotivation is one symptom of schizophrenia.

However, self-sufficiency in small things makes life less uncertain. In this study, one participant related his joy at succeeding in taking the number one bus to the zoo. Another participant barely contained her excitement discovering she had two part-time jobs. Katrina enjoyed cooking for others, and Jimmy was a self-described mentor. In terms of being a consumer, participants expressed difficulty navigating the health care system. Gaining a sense of power or control over their hallucinations, or other symptomotology of their illness, was not voiced as a priority outcome by the participants in this study. Rather participants related joy in daily gains made; gains such as working at a part time job, going to school, experiencing low level hallucinations that day, or taking a bus ride. There is certain autonomy here, but is it sufficient to manage the vigilance needed to remain out of the hospital? Is it any wonder then that clients relapse and care is uncertain? Davidson, Steyner, Lambert, Smith and Stedge (1997) noted that clients felt a lack of control in their personal lives, becoming more apathetic and less connected. Additionally, clients who had experienced multiple relapses, found the assistance offered by the mental health services appeared to be of little or no help. In fact, clients did not appear to see any connection between strategies learned in outpatient treatment and increased risk for re-hospitalization (p. 777).

One of the uncertainties of a chronic illness is the waxing and waning of the illness (Davidson et al., 1997). In this study, participants described a continuous stance of vigilance. The inequity of mental illness, and indeed any illness, is that one is thrust into this illness. After the initial experience, participants described a state of readiness. Memories of hospitalization served to reinforce preoccupation, "worriness," and was

most often the one factor contributing to medication adherence. However, medication, and all that medications implied, incorporated a host of concerns.

Carder, Vuckovic and Greene (2003) conducted a study using grounded theory techniques investigating how adults with mental illness perceive their need to take medications during the illness. The findings related that an individual initially negotiates with him or herself, in terms of adapting to the illness, taking medication, and self-identity. Individuals appear to fight the symptoms and question whether they are ill. Secondly, the authors note an ongoing exchange between resistance and acceptance. Resistance may follow the experience of side effects, the number of medications or the disruptive aspect of medications. The authors describe this as internal negotiating. The authors also relate another type of negotiation that is ongoing. This struggle is referred to as external negotiation, and that is "both battling and working with physicians over medication (p. 414)." For some participants this took the form of developing a partnership, for others this was seen as continuing battles with their physician, and still for others as their need to go outside of traditional medicine.

In this study, findings suggest a similar response. While medications did not consistently surface in every interview, several participants suggested medication-taking as a topic. Negotiating with self was a very real phenomenon in this study. Not always explicitly stated were participants' concerns regarding the essence of the personality. The thought of taking a mediation that "made you think more clearly" was akin to changing your personality. The internal negotiation rested in the struggle between changing who I am "makes me different" and eliminating hallucinations. Similarly,

participants resisted the idea of even being ill. Over a period of numerous relapses and

hospitalizations some participants viewed medication as necessary. "I know I need it

honey." "Thank God for Clozaril." Other participants verbalized negotiating with their

physician in the same way that Carder, Vuckovic and Greene (2003) indicated. A

compromise takes place that is not unlike the negotiating achieved by clients with their

physicians and nurses in other chronic illnesses. This external negotiation took the form

of a collegial battle, and at other times could result in enforced medication adherence, in

the form of a court order or hospitalization preceded by a court order. None of the

participants in this study investigated nontraditional medication.

Compellingness of hallucinations and aspects of powerlessness

The power of hallucinations is in their very ability to make participants listen. So

compelling are the hallucinations that participants modified their behavior in respond to

them. Participants verbalized suicide attempts, acting out resulting in hospitalization, and

behaving inappropriately in social settings. Many participants were willing to behave

as directed by voices. This included responding and following through with dangerous,

bizarre and immoral commands, because the voices appeared so real. Beck and Rector

(2003) suggest emotional reasoning validates the voice for the client. In other words, the

emotion attached to the voice i.e., fear or joy verifies the voice as real. "I wouldn't feel

this way if the voices weren't real." "The vividness of the voice or vision makes it more

real "(Beck & Rector, 2003, p. 37).

Beliefs about voices and the attribution of omnipotence appeared to create a fear-

based need to comply (Chadwick & Birchwood, 1994). Chadwick et al. believe that the

beliefs about the voices' omnipotence and the penalties of disobedience shaped compliance. This conclusion is borne out in this study. Participants felt compelled to listen and compelled to obey-even when they knew better. Voices were so compelling that participants related feeling scared and pulled to act in ways that might feel stupid to them or even immoral. Additionally, because participants viewed themselves as powerless against the voices, they also *felt* powerless.

"A not so certain life" resembled the trajectory of a chronic illness. Participants were thrust into a life not of their own making. Participants related ambiguity about treatment, specifically treatment couched in language that was often overwhelming. Additionally, medication-taking revolved around both internal and external negotiations. One way mental illness is so different from other chronic illnesses is in the phenomenon itself. The compellingness of hallucinations is unlike other chronic illnesses in which one's own sanity is called into question, and thinking and behaving become features of the illness.

Theme three-Finding strength in the broken places

Living with loss and disenfranchised loss

Several participants mentioned suffering from depression and three participants verbalized attempting suicide at least once. All talked of emotional suffering as they grappled with negative feelings about themselves and their relationships with others. These facts are consistent with statistical and/or anecdotal information from numerous sources (Walters, Badcock, Maybery & Mitchie, 2002; Beck & Rector, 2003). Depression and loss appear to be part of the picture of living with schizophrenia. Losses

occur in the form of missed opportunities, fractured relationships, diminished self-esteem, and a lost way of life. In fact, there is consensus in the literature that any time people experience loss; they will experience grief (Kubler-Ross, 1975; Worden, 1991).

Doka (1989) conceptualized disenfranchised grief as grief the individual experiences from loss that is not granted acknowledgement, support or the opportunity to mourn. Disenfranchised grief research encompasses circumstances when the loss has no social legitimacy, when the loss is not recognized or when the griever is not recognized. Loss that has no social legitimacy is illuminated in Doka's (1989) seminal work *Disenfranchised grief: Recognizing hidden sorrow.* An example of this is the loss friends and relative experience when their loved ones have died of AIDS. The stigma attributable to the disease serves to minimize the loss (no social legitimacy) or make it *unrecognized.* Nichols (1989) discussed *unrecognized loss* resulting from prenatal death. Parents are attached to the infant, yet the societal response is one of minimizing the loss, since the lost person is an unborn infant. Additionally, the griever can be *unrecognized* when he or she possesses certain characteristics that minimizes or disenfranchises their own grief. Swihart, Silliman and McNeil (1992) used the example of children who are seen as resilient, and, hence the loss is minimized. Furthermore, the authors related the societal belief that children are unable to realize or take in the loss, and are therefore excluded from rituals in the guise of protection.

Disenfranchised loss also has application for the mentally ill. While no current literature specifically addresses disenfranchised loss in the mentally ill, participants in this study verbalized numerous losses in their life and related the freeing aspects of our

discussions. It was as if they had no right to grieve since the participants' disease was responsible for the loss. The sadness accompanying multiple losses, and particularly losing a way of life, a life free from hallucinations, had not been acknowledged. Loss is disenfranchised due to stigma and a societal belief system that individuals who are mentally ill desire homelessness, are violent or create havoc, and thereby deserve what they get (Schulze & Angermeyer, 2003). A comprehensive body of knowledge indicates that persons suffering from mental illness are viewed by society as different and unwanted (Goffman, 1961). While stigma has recently been viewed as declining (Substance Abuse and Mental Health Services Administration, 2004) other stigma studies classified the mentally ill as no better than criminals (Corrigan & Penn, 1999; Link, Phelan, Breshnahan Steuve & Pescosolido, 1999). One recent study (Monahan & Applebaum, 2000) indicated that individuals with schizophrenia represent the lowest risk of violent behavior among the affective disorders, disorders associated with substance abuse, or personality disorders, yet the general public continues to view persons with schizophrenia as "very violent" or "most likely to be violent" (Pescosolido, Monahan, Link, Steuve, & Kikuzawa, 1999). Even among stakeholders, persons with schizophrenia remain stigmatized. Van Dorn, Swanson, Elbogen and Swartz (2005) conducted a comparison study of stigmatizing attitudes toward persons with schizophrenia using four stakeholder groups. The stakeholder groups included: individuals with schizophrenia, family members of individuals with schizophrenia, mental health clinicians and members of the general public. The researchers specifically focused on key attitudes toward individuals with schizophrenia such as: likelihood of

violent behavior, desire for social distance and probable causes of the illness. Essentially

the findings of Van Dorn, Elbogen and Swartz (2005) revealed that "persons with

schizophrenia, clinicians and their family members were no different in their attitudes

from members of the general public in expectation of violence or desire for social

distance (p. 160)." Therefore, if those closest to individuals with mental illness,

including those individuals who suffer from mental illness, hold these attitudes, how

likely is it that depictions of loss and the visible expressions of mourning are easily

heard? The need for an opportunity to grieve became apparent as participants in this

study mourned their losses. While many participants' verbalized understanding the

distancing by family and the numerous losses, this was still a loss made more palpable in

feeling personally responsible, yet also feeling out of their control. In this study,

participants' grief was disenfranchised because mourning became a complicated process

due to stigma attached to the disease and a personal sense of responsibility.

Regaining balance

Regaining balance was akin to surviving. Most participants related lending a

different kind of meaning to this experience of hallucinations as integral to surviving

mental illness. Findings of this study are somewhat consistent with the perspective of

"positive withdrawal" as a means of lending meaning to their experience (Corin &

Lauzon, 1992). Corin and Lauzon analyzed open-ended interview questions in a

quantitative/qualitative study. Results indicated that "positive withdrawal" (Corin,1990),

a means of maintaining distance from social roles and social relationships was a way of

lending meaning and maintaining links with the environment. Investigating recidivism,

the authors discovered that, in the non re hospitalized client, a stance of social distancing, essentially a withdrawn position was one of choice. The client presented a kind of neutrality; a social interaction existed, but on the clients own terms. Essentially, rather than appearing physically marginalized, clients marginalized themselves from people as both a way of distancing and interacting. Additionally, this neutral stance was often extended to family members. Other conclusions the authors derived from this study were that most of the interactions were with the non-psychiatric world, that neighbors and acquaintances dominated this world, and that a different spatiotemporal frame exists, in which activities are routinized, such as walks in the park, or visiting restaurants. The routine is varied somewhat, but the routine has an aura of ritual. Included here is the routine of a daily ritual contact with someone who provides a sense of belonging, without over involvement. Finally, the authors suggest that what can appear as an inactive and unreceptive representation of schizophrenia is in reality, an important part of the restructuring process.

The authors note the dichotomy here. Clients who desire to connect, yet, at the same time withdraw. Again, Corin and Lauzon (1992) suggest that in the process of withdrawing clients are constructing an inner space that is a significant step toward connecting with others. In a case study, the authors reframe the marginality: "Withdrawal is a way of protecting himself against the demands of society, in order to have access to that which gives meaning to life, and is a source of strength and courage p. (274)."

The participants in the current study shared commonalities with several components of positive withdrawal. However, clients at the clubhouse setting may present a different picture than the majority of non re-hospitalized clients. Certainly most of them had contact with the psychiatric world as opposed to the participants in Corin and Lauzon's (1992) study. However, the authors note that recently non re- hospitalized clients often spent large proportions of their time associated with the psychiatric world.

In this study, four participants actively engaged with others and made overt attempts to connect with others. Conversely, eight participants characterized the elements of positive withdrawal. It is unclear whether this occured as a response to perceived stigma and feeling rebuffed in previous attempts at connecting, or, is a different way of connecting, as Corin and Lauzon (1992) indicated. Nonetheless, the study participants often remained engaged on the outskirts of groups, not quite a part of the group, but certainly not completely removed. Additionally, participants expressed "taking care" in who they chose to speak to and be with, unrelated to their paranoia. Many of these same participants had daily activities that comprised set routines. The predictability and regularity of these routines appeared to provide comfort. These routines included meeting at Starbucks, taking the bus on certain rides that were enjoyable, going to the zoo, and frequenting the malls. Acquaintances (including other clients) and neighbors seemed to encompass the majority of social contacts. Additionally, several participants had daily contact with special individuals--for some a mother or sister, for others another participant or friend. These activities seemed to cement the idea

that the "day had gone well." When these things did not happen, participants verbalized feeling alone.

The neutral stance extended to family members that Corin and Lauzon (1992) spoke to was not confirmed in this study. Three participants related missing family contact, and expressed a strong desire to reconnect with family members. Instead these same participants experienced only rejection. Four other participants retained strong family relationships and cherished the support of those same family members (mother, parents, children and sibling).

In essence, participants supported some aspects of positive withdrawal. Finding special places and routines had special meaning. Participants in this study reframed this as a need for alone time and "to be by myself." Taking care whom they chose to be with was an aspect of positive withdrawal, but could also indicate both a history of rejection and a strategy of protection. Additionally, the findings of this study indicated participants' desirous to connecting with families, and of cherishing those times, and some participants were willing to go outside themselves and make links with their environment.

Finding strength

Some participants discovered that the experience of suffering provided momentum for change and growth. Living with a different reality and losing another, did not mean that participants were unable to live a fulfilled and complete life. Janoff-Bulman (1992) speaks to the loss of an assumptive world. The assumptive world is a set of assumptions or beliefs that buttress our world. Janoff-Bulman (1992) described an

assumptive world as "...the core of our internal world, we hold basic beliefs of ourselves and our external world that represent our orientation to the push and pull of the cosmos. Our assumptions ...are guides for our day-to-day thoughts and behaviors (Janoff-Bulman, 1992, p.4)." According to this perspective there are three core assumptions that create our worldview: (1) The world is benevolent, (2) The world is meaningful, and (3) The self is worthy (Janoff-Bulman, 1992, p.4)." When tragedy or trauma occurs it's as if one is navigating with an errant compass. Loss of what is believed to be good and true is tantamount to losing all directional signals. Part of adaptation is in reconstructing a new world view, a new set of assumptions. Corr (2002) suggests rebuilding a new world with parts of the old world, that is, an evolved world. In this study, for many participants, hallucinations became a tool, a means of renewal and change. Many participants spoke of this experience of hallucinations as strengthening their resolve. "In some ways I think it made me stronger...you do have to fight for things ...for me, this is hard to put it into words...I'm angry with myself." Participants spoke persuasively of courage, growth and "Finding strength," amidst the chaos.

"Living with loss" was complicated by stigmatization and disenfranchised grief. Finding meaning in the experience became one way of regaining balance. Corin and Lauzon (1992) suggest that in the process of withdrawing clients are constructing an inner space that is a significant step toward connecting with others.

While some aspects of their findings hold true in this study, other findings do not. As opposed to Corin et al. (1992) the findings of this study indicate "meaning-making" occurred as participants connected with families, with some participants even willing to

go outside themselves and make links with their environment. "Finding strength" also involved rebuilding a world educated by the experience of hallucinations, and with a different take on life.

<p style="text-align:center;">*Theme four-I am still me*</p>

Damaged self-esteem

Participants discovered their first awareness of hallucinations was negative images or voices that attacked their personhood, often calling them names or relegating immoral behaviors to them. Participants related "not liking my self-esteem." While Beck and Rector (2003) attributed damaged self-esteem to the client's own personal sense of inadequacy, the findings of this study are mixed. The findings in this study actually suggest that many participants somehow overcame this deficit, so that the sense of inadequacy may not be lasting. Moreover, the conclusions of this study more closely replicate the findings of Close and Garety (1998) who posit that the disapproving and pessimistic content of hallucinations generate a devaluation, which translates into low self-esteem. Many participants in this study discussed believing what the voices said, despite evidence to the contrary. In fact, reasoning with the participant only resulted in a cementing of beliefs regarding voice content. It appeared that time and treatment was the intervening factor that provided some distance and insight for the participant. Chadwick, Birchwood and Trower (1996) suggest that it is not the content of voices that has more personal significance, but rather the attribution. In other words, it is the belief clients attribute to voices that has more resonance than the actual voice content. Findings from this study support this perspective. Depending on the relationships participants had built

with their auditory hallucinations, a number of participants viewed advisory or critical

voices as "helpful" and intrusive voices as "friendly." However, accusatory,

commanding and scary voices were seen as just that. Participants related feeling scared

and developing tactics to avoid the voices. This is consistent with the research of

Chadwick et al. that indicated clients were more likely to engage with voices they

attributed as benevolent, and avoid malevolent voices. As damaging to their self-esteem

the voices were to them, however, participants verbalized almost always remembering

who they were.

I am still me-a persistent sense of self

I am still me-remembering who I am. Loss of self has been described as an

outcome of schizophrenia and schizophrenia spectrum disorders (Auerbach & Blatt,

1996; Jaynes, 1996; Eigen, 1986; Frosh, 1983). Saas (1992) describes connections to self

and others as so fragmented as to be indecipherable. Lysaker & Lysaker (2004. p. 106)

posit that the "loss of self in schizophrenia is compromised by the inability to maintain an

ongoing dialogue with self and others." The basis for this model of the dialogical self

states that, self-coherence is maintained by "ongoing conversations both within and

among individuals" (Lysaker & Lysaker, 2004, p. 107). The authors therefore suggest

that the loss of self in schizophrenia is the result of disrupted dialogue. Lysaker &

Lysaker (2004) further posit that dialogues would of themselves cease: "as self positions

were no longer ordered in such a way that enabled one to respond adequately to

experience" (p. 108). That is, aspects of the self (self as gourmet cook, self as mother)

disappear as the disease of schizophrenia progresses. Additionally, the authors

hypothesize that the voices may amplify the disruption of internal dialoguing. They give the example of authoritative commands or constant ongoing voices, which would seem to jeopardize internal dialoguing. However, the authors recognize that it is possible that voices may spur internal dialoguing, particularly when the voices speak to aspects of the person's self.

The idea that clients lose their sense of self, or who they are, is not borne out in this study. Rather, clients responded, "I am still me." The emergence of symptoma.tolgy does not automatically result in a "lost" self (here "self" will be used interchangeably as being, self-image, self concept). Living through this experience with its navigational twists and turns, represented in numerous losses and deficits, the participants still seemed to retain a picture of who they were. The self, as participants perceived themselves, remained consistent throughout this experience. Does this mean that all aspects of self remain unchanged? As participants uniformly related an ongoing assault on their self-esteem, it's possible their sense of self was damaged, diminished or suspended, yet underneath it all, participants felt they were still essentially the same person. This *persistent sense of self* was retained throughout the experience of hallucinations not as a fragmented self, or as a disintegrating self, but as essentially the same person. This *self* consisted of childhood memories, favorite hobbies and food, people participants enjoyed, things they liked to do and those things participants didn't enjoy. Sells, Staynor & Davidson (2004) describe a durable sense of self as distinct from the illness, and from stigma. Additionally, the authors suggest that an active and effective sense of self plays a crucial role in improvement for individuals with schizophrenia spectrum disorders. The

authors specify that this perception of self includes self-esteem, agency, identified shortcomings and perspective for the future. Davidson and Struass (1992) reported results from qualitative interviews of 66 clients who suffered from schizophrenia spectrum disorders. They concluded that aspects of "rediscovery and reconstruction of self" may provide a refuge from both illness and stigma.

Corin and Lauzon (1992) describe how sense of self can be nurtured in recovery. One of the three outcomes in recovery, they identify "larger life frames," is a means of upholding a sense of self. One component of "larger life frames" includes relating one's history positively with the present time frame. Jimmy remembered that he was glad he finished High School before he became ill. He now has a basis for further education and he hasn't lost important educational years. Most participants talked about viewing the future as a link to the past. Another component of "larger life frames" includes finding "psychological space" i.e., going to school and having a job outside the usual setting. In this study, almost all participants gained a sense of self-worth and importance through their part-time jobs. Additionally, others felt important in their self-directed jobs as mentors and advice-givers. Participants had newly defined themselves in this way. Still others used the research study to feel invested in a worthwhile endeavor "that would help other people like me." A final component includes "elaboration of a personal history." As an example, the authors describe an individual, Mr. C., who elaborates or fabricates a personal history of a close and intact family (he is disowned by his own family), then developed other relationships on his own, in the community. In this study, almost all participants forged new relationships in their group homes, in the clubhouses, and in their

schools and places of worship. Katrina defined herself in a remembered favorable light, "I'm just an old-fashioned girl." She likened that to someone who is sweet and approachable. Tutti, who had been violent in the past, and has been hospitalized for NGRI (Not guilty by reason of insanity) attended church and defined herself as a church-going member of her community.

A persistent sense of self appears to be supported from a neurobiological perspective as well. Zimmer (2004) explains there is not simply one spot on the brain that defines *self*, rather all the perceptions and memories combine to create a sense of self that is a unitary expression of who we are. Therefore, who we are may not change substantially.

Summary

A life disrupted, still lived. In speaking with these participants, there is the thread that life is not over--life is **still** lived. Disrupted invites the comparison of a stop along this long trek, a stop that is life changing, perhaps brutal, and life will never be the same again--and yet, life is not over; it is just that the art of living has changed. The participants in this current study both demonstrated and related during their interviews that they had become more willing to share this experience. Several said that sharing of self through storytelling was a difficult process and one that still carried the fear that they might be ill again. However, all participants were willing to share of themselves as part of this research, thereby lending new understanding to this phenomenon.

Summary of key findings

Findings from this study revealed hallucinations as an experience both frightening and confusing. The mechanisms of order emerging from chaos bore a close resemblance to the basic tenets of chaos theory. The aforementioned studies validated the findings of this study in that participants felt powerless and ambiguous about treatment. The perspective of living with hallucinations, living with schizophrenia is also a picture of chronic illness. There is the same waxing and waning of the disease, there is the lifelong picture of living with the disease and there is the same ambiguous perspective of treatment. Much of the chronic illness vocabulary included terminology that supported self-sufficiency, yet participants sometimes felt unequal to the task. Gains were made in small ways that is not always recognized by nursing. This study supported the hypothesis that a different spatiotemporal frame exists, which is meaningful for participants, and includes routine activities such as walks in the park, meeting friends in coffee shops, and visiting restaurants. Therefore, acknowledging the ways people with schizophrenia live their daily lives supports an individualized approach to treatment.

Living with hallucinations was analogous to living with loss. Participants often felt a deep sense of loss, but were never given the opportunity to grieve. An aspect of this is that participants, by virtue of who they were and their perceived stigma were not given the same opportunity to mourn the loss of family, a remembered life, and their sanity. This denial of an opportunity to grieve is identified as disenfranchised grief.

Nonetheless, participants were able to recall (or currently describe) hallucinations which gave them something positive amidst the chaos. Most participants related the

ability to lend a different kind of meaning to this experience of hallucinations was integral to their surviving mental illness. The literature reported results that support meaning–making by developing an evolved world view, as an aspect of survival.

Despite literature that conceptualizes a "lost self" within the experience of hallucinations for individuals suffering from schizophrenia spectrum disorders, almost all participants agreed that hallucinations were not expressive of who they were, rather, who they were, their "being" remained separate from their hallucinations. Additionally, a *persistent sense of self* defined a sense of being that remained consistent throughout. This experience validates the findings that there is a perspective of self that is always there.

This study departed from the current literature in several other ways. Some aspects of positive withdrawal, that is a stance of social distancing, did occur to some extent with the participants in this study. However, this stance was not extended to friends and to family members. Additionally, while neighbors and acquaintances seemed to dominate this world, there was a significant proportion of participants' whose interactions included the psychiatric world. While participants described a sense of powerlessness, missing from their interviews was the same fatalism described in other research. Instead, for the participants in this study, what emerged was an impression of overcoming and eventually surviving, in their own way, and defined on their terms.

Implications for Future Research, Practice and Future Policy

Implications for Research

While there is increasing impetus focused on qualitative schizophrenia research, the majority of the research on hallucinations focuses on causality and prevention of

reoccurrence. An imbalance between the numbers of quantitative and qualitative research studies remains, with continued focus on quantitative studies. More specifically, literature regarding relapse and re-hospitalization remains primarily quantitative. However, sociology and medical anthropology has re-energized the movement toward increasing qualitative work, and is making strides in this direction. Nursing can follow this lead investigating disenfranchised grief, preservation of self in the hallucinatory process, and meaning and issues of re-hospitalization,

The findings of this study suggest that participants underwent both a cognitive and emotional search as they attempted to explain the experience of hallucinations. The experience appears chaotic and disorderly yet the resolution appears to mimic chaos theory in that disorder becomes a more understandable order. Research investigating this experience, this process of coming to terms with hallucinations would enlighten us as to how clients can understand this experience in light of cognitive deficits and the disinhibitory qualities of hallucinations.

In this study findings included the sense of powerlessness participants expressed particularly in light of the compellingess of hallucinations. Additionally, powerlessness broadened to a larger picture of an experience that resembled a chronic illness. Yet the trajectory and the sequelae of mental illness are unlike any other chronic illness. For this reason, the language typically used by nurses in chronic illness is essentially overwhelming and may not fit this population. Research addressing treatment options that emphasize an individualized approach both in language and expectations would be one way of understanding the chronicity of mental illness.

One final arena for research is the clients' perception of hospitalization. When the alternative is so scary...is it any wonder that clients still choose hospitalization? Qualitative research that looks at this experience from the client's perspective "sees what the client sees," can help us make the kind of decisions that can really meet the needs of the mentally ill. Finally, we must ask ourselves, how is community not caring, if hospitalization is so attractive?

Implications for Practice

Caring has been identified as the heart of nursing (Benner, 1989). Smythe (2002) describes Heidegger's two opposing notions of caring. One conception of caring is "leaping in" – the aspect of caring that sweeps in. A notion of caring that absolutely takes care of things. A notion of caring that alleviates. And there is the other notion of caring; caring as "leaping ahead," "an aspect of caring, or concern that doesn't merely take care away, but gives it back to them (p.174)." This study highlights a perspective of caring that is both "leaping in" and "leaping ahead." When individuals struggle with the experience of hallucinations and the sequelae of schizophrenia spectrum disorders they are often exposed to an environment that is unreceptive to their kind of being. Simply making choices, navigating the health care system and living life become mountainous obstacles. While self-sufficiency and autonomy are ideals well worth seeking, one must consider the enormous movement it takes for the individual to reach those ideals. There must be a balance between taking care, "leaping in" and giving back care "leaping ahead." However, when the individual feels stronger, and when their need for care is not

so immediate, then "leaping ahead," that is, providing opportunities for autonomy, and using self-sufficiency are ways to maintain health.

Implications for education and practice based on this study suggest that one cannot ignore the need for a dual approach to care. Comprehensive care may at once be "leaping in" and "leaping ahead." Providing care in different ways may mean addressing the needs of the individual when they are feeling their most vulnerable, as a very different provision of care when they are feeling safe and stronger. As previously suggested, changing the focus from reducing recidivism to seeing what the client needs can meet both needs. The nurses' goal of keeping the client out of the hospital does not necessarily mean that that is the goal of the client. "Leaping in" and "leaping ahead" are ways of balancing care that both supports the physical being, that is meeting the person's needs and a notion of caring that respects their individuality and need for self-sufficiency. The balance is a fine one. In "leaping in" one may disregard the person's desire for autonomy and in "leaping ahead" one may stretch a client in ways he or she may not be capable of.

Leaping ahead consists of employment of an individualized framework in a practice arena that expands the possibilities for interaction and care on the part of providers. Use of such an approach also broadens possibilities of choice for change on the part of both provider and client. Education of psychiatric nurses in this area may help to insure the incorporation of its use in the practice arena.

Educational research compels one to examine how we educate our nurses. Teaching nurses alternative ways of approaching the client i.e., learning and understanding aspects of positive withdrawal (Corin, 1990), use of less overwhelming

language in facilitating health care access, and supporting the *persistent sense of self-* through individualized treatment programs. One such program is *Hearing Voices Network,* developed by Romme and Escher (1993), which provides support and strategies in dealing with auditory hallucinations. In providing support to the individual, Romme and Escher (1993, p.126) suggest that professionals should attempt:

- To accept the patient's experience of the voices;

- To try to understand the different language patients use to describe their frame of reference as well as the different language the voices use for communications;

- To consider helping the individual communicate with the voices;

- To stimulate the patient to meet with other people and to read about hearing voices in order to diminish taboo and isolation.

Finally, in recognizing that the individual is at the core of this disease, no matter how bizarre the symptomatology, the need for individualized care always remains paramount.

Implications for Public Policy

Advocacy in the name of mental illness has been slow and unpopular. As images of individuals who may act and appear bizarre invade the publics consciousness, efforts to help the mentally ill remain in the background. Additionally issues of marginalization and stigmatization are very much a part of this discussion. Stigma appears to be on the decline, yet is still of paramount concern in mental illness (Substance Abuse and Mental Health Services Administration, 2004) Ongoing efforts to deal with homelessness reveal a significant percentage of the population as homeless. Nearly half of the homeless

population is mentally ill (Varcorolis, Carson & Shoemaker, 2005). The issues of recidivism may center around the starkness of community living. The attractiveness of hospitalization may be more attributable to homelessness, victimization and inability to access mental health care. Additionally, recognizing that this population will always have basic needs such as food, housing, and medical care, by providing for some of those needs, the need for hospitalization may not be as acute. Finally, it is certainly within the sphere of legislation to examine issues of equality, parity, availability, access, funding and reimbursement.

<div align="center">Limitations of the Study</div>

This study was restricted to two circumscribed locales (Portsmouth and Richmond) and reflects the mentally ill in these regions only. While commonalities were found and utilized to construct a group profile, replicating this study in other geographic areas may produce very different outcomes or emphases. Additionally, a large number of participants were from the clubhouse setting, and therefore cogent issues such as homelessness were not an expressed concern.

Gender issues were not addressed in this study. The study participants were evenly distributed with six women and six men participating in the study. However, the study focus was the experience of mental illness as it relates to being, so gender issues were not part of the consideration. A research study developed exclusively around women or men could potentially produce a very different picture. That issue would have to be addressed in future studies.

Similarly, there were no Hispanic/Latinos, Asian Americans or American Indians represented in this study. Once again, since the target for this research was a group profile, issues of ethnicity were not considered. Future studies could include only specific populations.

Yet another limitation of the study was the distance of members of the Heideggerian team. Group work was limited by emails, phone calls and some face-to-face. In retrospect, I would enjoy and value the face-to face interaction with all members of the team, just as I did with three members of the group who lived nearby.

Conclusion

This chapter has presented and discussed conclusions and themes of the study, outlined the implications of the study, presented study limitations and delineated areas for future research. Areas for future investigation were outlined for research, education and practice, and public policy. Limitations of the study were also presented. The overall study itself has provided a glimpse of what it is like to live with and recover from the experience of hallucinations within the context of mental illness, to discover a new and better way of living through hallucinations, and to preserve an orientation of self in the process. Additionally, a review of pertinent literature reflecting recent thought and research on hallucinations /mental illness has been provided. Moreover, the voices of those contributors who courageously shared of themselves episodes which illustrated pain, despair, loss, commitment and hope, and who spoke of small victories over a period of time were heard. This study was framed within the Heideggerian/hermeneutic philosophy (1962, 1968, 1969, 1971, 1972) using the hermeneutic circle and employing

Tanner & Diekelmanns' steps (1989). It was humbling to this author that the participants

in this research spoke of their experience of hallucinations using words and terms such as

"I feel sorrow," "gives me courage," "I'm full of gratitudes," and "makes me giving."

They spoke with valor and honesty; they exemplified humanity in the face of illness,

recovery and living a life still to be lived. The stories each individual related were

emotive reminders of the power of the narrative to enlighten, relate feelings, and

universalize the experience. The experience of these individuals exemplified the

harshness of a rough voyage-a turbulent onset-with the hope of calm seas. Almost all

these individuals voiced the prospect of hope.

References

Allen, D. (1994). Hermeneutics: Philosophical traditions and nursing practice research. *Nursing Science Quarterly,* 8(4), 174-18.

Allport, A. (1985). *The historical background of social psychology.* In G. Lindzey & Aronson (Eds). *Handbook of social psychology* (Vol.1, 3rd ed., pp. 1-46). New York: Random House.

American Heritage Dictionary, (1985). Boston: Houghton-Mifflin.

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders. (4th ed.).* Washington DC: Author.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: Text revision (4th ed.).* Washington DC: Author.

Auerbach, J. & Blatt, S. (1996). Self-representation in severe psychopathology: The role of reflexive self-awareness. *Psychoanalytic Psychology*, 13, 297-341.

Baumeister, R., Bratlavsky, E., Muraven, M. & Tice, D. (1998). Ego depletion: Is the active self a limited resource? *Journal of Personality and Social Psychology*, 74 (5), 1252-1265.

Beck, A.T., Emery, G., Rush, J. & Shaw, B. (1987). *Cognitive therapy of depression.* New York: Guilford Publications.

Beck, A.T. & Rector, N. (2003). A cognitive model of hallucinations. *Cognitive therapy and research*, 27, 1, 19-52.

Behrendt, R.P. (1998). Underconstrained perception: A theoretical approach to the nature and function of verbal hallucinations. *Comprehensive Psychiatry*, 39, (4), 236-248.

Bem, D. (1972). Self-Perception Theory. In L. Berkowitz, (Ed*.). Advances in experimental social psychology*, (Vol. 6) New York: Academic Press.

Benner, P. (1994). *Interpretive phenomenology.* Thousand Oaks, CA.: Sage.

Benner, P. (1985). Quality of life: A phenomenological perspective on explanation, prediction, and understanding in nursing science. A Heidggerian approach. *Advances in Nursing Science, 8 (1), 1-14.*

Benner, P., & Wrubel, J. (1989*). The Primacy of caring.* Menlo Park, CA: Addison-Wesley.

Bentall, R.P. Haddock, G., & Slade, P.D. (1994). Cognitive-behavior therapy for persistent auditory hallucinations: From theory to therapy. *Behavior Therapy, 25*, 51-66.

Birchwood, M., Meaden, A., Trower, P., Gilbert, P., & Planestow, J. (2000). The power and omnipotence of voices: Subordination and entrapment by voices and significant others. *Psychological Medicine,* 30, 337-344.

Bouchard, S., Vallieres, A., Roy, M.A., & Maziad, M. (1996). Cognitive restructuring in the treatment of psychotic symptoms in schizophrenia. *Behavior Therapy Review*, 27, 257-277.

Brebion, G., Amador, X., David, D., Malaspina, D., Sharif, Z., & Gorman, J. (2000). Positive symptomology and source-monitoring failure in schizophrenia-and analysis of symptom specific effects. *Psychiatry Research, 95,* 119-131.

Briera, A., Schreiber, J.L., Dyder, J. & Packard, D. (1991). NIMH longitudinal study of chronic schizophrenia: Predictors and prognosis of outcome. *Archives of General Psychiatry, 48,* 239-246.

Bucherri, R., Trygstad, L. N., & Dowling, G. (1997). Symptom management of auditory hallucinations in schizophrenia: Results of a one-year follow-up. *Journal of Psychosocial Nursing,* 309-317.

Bustillo, J., Lauriello, J., Horan, W., & Keith, S. (2001). The psychosocial treatment of schizophrenia: An update. *American Journal of Psychiatry,* 158, (2) 163-173.

Butz, M (1997). *Chaos and complexity: Implications for psychological theory and practice.* Washington D.C.: Taylor & Francis.

Capra, F. (1996). *The web of life, a new scientific understanding of living systems.* New York: Anchor.

Carder, P., Vuckovic, N., Green, C. (2003). Negotiating medications: Patient perceptions of long-term medication use. *Journal of Clinical Pharmacy and Therapeutics,* 28. 409-417.

Carper, B. (1978). Fundamental patterns of knowing in nursing. *Advances in Nursing Science,*

1, 13-24.

Casey, B., & Long, A. (2002). Reconciling voices. *Journal of Psychiatric and Mental Health Nursing.*9, 603-610.

Chadwick, P. & Birchwood, M. (1994). The omnipotence of voices: A cognitive approach to auditory hallucinations. *British Journal of Psychiatry,* 164, 190-201.

Chadwick, P. & Birchwood, M. (1995). The omnipotence of voices: The belief about voices questionnaire (BAVQ*). British Journal of Psychiatry,* 166, 773-776.

Chadwick, P. & Birchwood, M. (1996*). Cognitive therapy for voices.* In Haddock, G. & Slade, P. (Eds). *Cognitive behavioral interventions with psychotic disorders .* London: Routledge.

Chadwick, P. & Birchwood, M. (1997). Recovering from psychosis: Learning more from patients. *Journal of Mental Health,* 6(6), 577-588.

Chadwick, P., Birchwood, M. & Trower. P. (1996*). Cognitive therapy for delusions, voices and paranoia.* Oxford, England: Wiley.

Close, H. & Garety, P. (1998). Cognitive assessment of voices: Further developments in understanding the emotional impact of voices. *British Journal of Clinical Psychology,* 37, 173-188.

Corrigan, P.W. & Penn, D.L. (1999). Lessons from psychology in discrediting psychiatric stigma. *American Psychologist,* 54 (9), 765-776.

Corin, E. (1990). Facts and meaning in psychiatry. An anthropological approach to the lifeworld of schizophrenics. *Culture, Medicine and Psychology.* 14, 153-188.

Corin, E., Lauzon, G. (1992) Positive withdrawal and the quest for meaning: The reconstruction of experience among schizophrenics. *Psychiatry,* 14:153-158.

Corr, C. (2002). Rethinking the concept of disenfranchised grief. In K. Doka (Ed.),

Disenfranchised grief: New directions, challenges and strategies for practice (pp.

39-60). Champagne, Ill.: Research Press.

Davidson, L., Strauss, J.S. (1992). Sense of self in recovery from severe mental illness.

British Journal of Medical Psychology, 65:131-145, 1992.

Davidson, L., Stayner, D., Lambert, S, Smith, W. & Sledge, W. (1997).

Phenomenological and Participatory research on schizophrenia: Recovering the

person in theory and practice. *Journal of Social Issues*, 53, (4), 767-784.

Descartes, R. (1977). *The Essential writings*. (J. Blom, Trans.). New York: Harper &

Row.

Diekelmann, N., Allen, D. & Tanner, C. (1989). *The NLN criteria for appraisal of*

baccalaureate programs: A Critical hermeneutic analysis. New York: National

League for Nursing Press.

Diekelmann, N. & Ironside, P. (1998). Hermeneutics. In J. Fitzpatrick (Ed.),

Encyclopedia of Nursing Research (pp. 243-245). New York: Springer

Publications.

Dilthey,W. (1976). *Selected writings.* (Rickman, H.P., Trans.) Cambridge: Cambridge

Press. (Original work published in 1944).

Dreyfus, H. (1991). *Being in the world: A commentary on Heidegger's "Being and*

Time", Division I. Cambridge, MA: MIT Press.

Doka, K. (1989). *Disenfranchised grief: Recognizing hidden sorrow.* New York:
    Lexington Books.

Eigen, M. (1986). *The Psychotic core.* New York: Jason Aronson.

Ellenson, G.S. (1986). Disturbances in perception in adult survivors of incest. *Social*
    Casement, 66, 149-169.

Ensink, B. (1993). *Trauma: A Study of Childhood and Hallucinations.* In Romme, M. &
    Escher, S (Eds). *Accepting Voices.* London: MIND Publications.

Erikson, E. H. (1962). *Childhood and society.* (2nd ed) N.Y., N. Y.: Norton and CO.

Erikson, E. H. (1968). *Identity, youth and crisis.* N.Y., N,Y : Norton and CO.

Estroff, S.E. (1989). Self, identify, and subjective experiences of schizophrenia: In search
    of the subject. *Schizophrenia Bulletin,* 15: 189-196.

Farhall, J. & Gehrke, M. (1997). Coping with hallucinations: Exploring stress and coping
    framework. *British Journal of Clinical Psychology,* 259-261, 1997.

Feinberg, I. (1983). Schizophrenia: Caused by a fault in programmed synaptic
    elimination during adolescence. *Journal of Psychiatric Research,* 17, 319-334.

Fraser, N. (1989). *Unruly practices: Power and gender in contemporary social theory.*
    Minneapolis, University of Minneapolis.

Frederick, J. & Cotanch, P. (1985). Self-help techniques for auditory hallucinations in
    schizophrenia. *Issues in Mental Health Nursing,* 16 (3), 213-224.

Freud, S. (1924). *Neurosis and psychosis.* SE 1XX Republished 1961.London, Hogarth
    Press. 1961.

Frosh, (1983). The psychotic process. New York: Jason-Aronson.

Gaskin, J. (1988). *Hume's philosophy of religion.* (2nd ed). London: Macmillan.

Gergen, K.J. (1991). *The saturated self.* New York: Basic Books.

Gleick, J. (1987). *Chaos: Making a new science.* New York: Viking-Penguin.

Goode, E. (2002*). Deviance in everyday life: Personal accounts of unconventional lives.* Prospect Hills, Ill.: Waveland Press.

Goffman, E. (1961). *Asylum.* Garden City, N. J.: Doubleday.

Grodin, J. (1995). Sources *of hermeneutics.* New York: State University of New York Press.

Habermas, J (1984,1987*). The theory of communicative action.* (Vol I & II). (T. McCarthy, Trans). Boston: Beacon.

Haddock, G., Bentall, R. & Slade, P. (1993). Psychological treatment of chronic auditory hallucinations: Two case studies. *Behavioral Cognitive Psychotherapy*, 21, 335-346.

Hall, J. (1994). Marginalization: A guiding concept for valuing diversity in nursing knowledge development. *Advances in Nursing Science, 16, (4),* 23-41.

Hattie, J. (1992). *Self-Concept.* Hillsdale, New Jersey: Lawrence Erlbaum Associates, Publishers.

Hayne, Y. & Younge, O. (1997). The lifeworld of the chronically, mentally ill: Analysis of 40 written accounts. *Archives of Psychiatric Nursing 9,* (6), 314-334.

Heery, M. W. (1998). Inner voice experiences: An exploratory study of thirty cases. *Journal of Transpersonal Psychology.*21, (1), 73-82.

Heidegger, M. (1962). *Being and Time*. (J. Macquarrie, & E. Robinson, Trans.). New York: Harper & Row, Publishers, Inc. (Original work published in 1927).

Heidegger, M. (1968). *What is called thinking?* (J. Glenn Gray, Trans.). New York: Harper & Row, Publishers, Inc. (Original work published in 1954).

Heidegger, M. (1969). In W. H. Bossart. Three directions of phenomenology. In M. Greene (Ed). *The anatomy of knowledge*. Amherst: University of Massachusetts Press.

Heidegger, M. (1971*). Poetry, Language Thought*. (A. Hofstader, Trans.). New York: Harper & Row, Publishers, Inc.

Heidegger, M. (1972*). On Time and Being*. (J.Stambaugh, Trans.). New York: Harper & Row, Publishers, Inc. (Original work published in 1969).

Heinsen, R., Lieberman, R., & Kopolowicz, A. (2000). Psychosocial skills training for schizophrenia: Lessons form the laboratory. *Schizophrenia Bulletin*, 26, 21-46.

Hoffman, R.E. McGlashan, T.H. (1993). Parallel distributed processing and the emergence of schizophrenic symptoms. *Schizophrenia Bulletin*, 119-140.

Honig, A. Romme, M., Ensink, B. Escher, S., Pennings, M., & de Vries (1998). Auditory hallucinations: A comparison between patients and non-patients. *Journal of Nervous and Mental Disease*, 186(10), 646-651.

Hustig, H. & Hafner, R. (1990). Persistent hallucinations and their relationship to delusions and mood. *Journal of Mental and Nervous Disease*, 178, 264-267.

Huttenlocher, P.R. (1979). Synaptic density in the frontal cortex: Developmental changing and effects of aging. *Brain Research*, 163, 195-205.

Janoff-Bulman, R. (1992). Shattered assumptions. New York: Free Press.

Jaynes, J. (1996). *The origins of consciousness in the breakdown of the bicameral mind.*

Boston: Houghton-Mifflin & Co.

Johnstone, E.C., Owens, D.G., Frith, C.D., & Leavy, J. (1991). Clinical findings:

Abnormalities of mental state and their correlates. The Northwick Park follow-up

study. *British Journal of Psychiatry*, 159, 21-25.

Jones, S., Guy, A., & Omrod, J. (2003). A Q-methodological study of hearing voices; A

preliminary exploration of voice hearers' understanding of their experiences.

Psychology and Psychotherapy: Theory, Research and Practice. 76, 189-209.

Jones, W.T. (1975). *A History of western philosophy :Kant and the nineteenth century.*

Fort Worth: Harcourt Brace Jovanovich College Publishers.

Jung, C. (1969). *Memories, Dreams and Reflections.* New York: Pantheon Books.

Jung, C. G. (1939). On the psychogenesis of schizophrenia. In*: The psychogenesis of*

mental disease. Collected works 3. London: Routledge.

Kant, I. (1929). *Critique of Pure Reason.* (Norman Kemp Smith, Trans.). New York:

St Martin's Press.

Kleinman, A. (1988). *The illness narratives.* New York: Basic Books.

Koch, T. (1995). Interpretive Approaches in nursing research: The influence of Husserl

and Heidegger. *Journal of Advanced Nursing, 21* ,827-836.

Kubler-Ross,E. (1975). *Death: The Final Stage of Growth.* New Jersey: Prentice-Hall

Incorporated.

Laing, R.D. (1960). *The Divided self.* Baltimore: Penguine Press.

Lemay, E.C. & Pitts, J.A. (1994). *Heidegger for beginners*. New York: Writers and Readers Publishing.

Leonard, V.W. (1989). A Heideggerian phenomenological perspective on the concept of person. *Advances in Nursing Science,* 11(4) 40-45.

Leonard, V.W. (1994). A Heideggerian phenomenological perspective on the concept of person. In P. Benner (Ed.), Interpretive phenomenology: Embodiment, caring and ethics in healthcare and illness (pp. 43-63). Thousand Oaks, CA: Sage Publications.

Leudar, I., & Thomas, P. (2000). *Voices of reason, voices of insanity.* London: Routledge.

Levin, R. & Daly, R. (1998). Nightmares and psychotic decompensation: A Case Study. *Psychiatry, 61.*

Liaschenko, J.(1989). Changing paradigms within psychiatry: Implications for nursing research. *Archives of Psychiatric Nursing,* 3 (3), 153-158.

Lincoln, Y.S., Guba, E.G. (1985). *Naturalistic inquiry*, Beverly Hills, CA: Sage.

Link, B. (1987). Understanding labeling effects in the area of mental disorders: An assessment of the effects of expectations of rejection. *American Sociological Review*, 52 (1), 96-112.

Link, B., Phelan, J. C., Breshanahan, M., Seuve, A., & Pesosolido, B.A. (1999). Public conceptions of mental illness: Labels, causes, dangerousness and social distance. *American Journal of Public Health*, 89(9), 1328-1333.

Locke, J . (1954). *Essay concerning human understanding.* Section II, XXVII. In R.
Frondizi, *The Nature of Self* (p. 36). New Haven: Yale University Press (Original
work published in 1894).

Lysaker, P., & Lysaker, J. (2004). Schizophrenia as dialogue at the ends of its tether: The
relationship of disruptions in identity with positive and negative symptoms.
Journal of constructivist psychology, 17, 105-119.

Mann, D. W. (1986). Six months in the treatment of two young chronic schizophrenics.
Psychiatry, 49:231-240.

Mariani, S. (2004). Origin and neuropathology of schizophrenia, Medscape molecular
medicine, 6 (1). Retrieved Jan. 11, 2006, from http://wwwmedscape.com/view
article/465642.

Martin, P.J. (2000). Hearing voices and listening to voices that hear them. *Journal of
Psychiatric and Mental Health Nursing, 7,* 135-141.

MARTIN software (1995). Diekelmann, Lam & Schuster, University of Wisconsin.

McGuire, P. K., Shah, G.M. & Murray, R.M. (1993). Increased blood flow in Broca's
area during hallucinations in schizophrenia. *Lancet,* 342, 703-706.

Mead, G.H. (1934/1970).*Mind, self and society*. Chicago: University of Chicago Press.

Merleau-Ponty, M. (1964). *Signs*. Chicago: Northwestern University Press.

Miller, L. J., O'Conner, E., & Di Pasquale, T. (1993). Patients' attitudes toward
hallucinations. *American Journal of Psychology, 150:* 4, 584-588.

Monahan, J., & Applebaum, P. (2000). Reducing violence risk: Diagnostically based clues from the MacArthur Violence Risk Assesment Study. In S. Hudgins (Ed.), *Effective prevention of crime and violence among the mentally ill* (pp. 19-34). Dordrecht, The Netherlands: Kluwer Academic Publications.

Moran, D. (2000). *Introduction to phenomenology.* New York, N.Y.: Routledge.

Morse, J. M., & Johnson, J. L. (1991). *The illness experience: Dimensions of suffering.* Newbury Park, CA: Sage.

Naudin, J. & Azorin, J. (1997). The hallucinatory epoch. *Journal of Phenomenological Psychology, 2,*

Nichols, J. (1989). Perinatal death. In K. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow.* 117-126. Lexington, MA: Lexington Books.

NIMH, (1999). National Institute of Mental Health.

Nochi, M. (1998). Struggling with the labeled self: People with traumatic brain injuries in social settings. Qualitative Health Research, 8(5), 665-681.

O'Connor, F. (1994). A vulnerability-stress framework for evaluating clinical interventions in schizophrenia, *IMAGE Journal of Nursing Scholarship*, 26, 231-236.

Overall, J.E., & Goran, D.R. (1962). Brief Psychiatric Rating Scale. *Psychological Reports, 10,* 799-812.

Owens, J.A.(1998). Living with a Chronic Wound: A Heideggerian hermeneutical analysis *(Doctoral dissertation, 1998). Virginia Commonwealth University). Dissertation Abstracts International,* 51,417.

Oxford English Dictionary (1989). (Vol. VI). London: Clarendon Press.

Palmer, R. E. (1969*). Hermeneutics: Interpretation theory in Schleiremacher, Dilthey,*

   Heidegger and Godamer. Evanston: Northwestern University Press.

Parse, R.R., Coyne, A.B., & Smith, M.J. (1985). *Nursing research: Qualitative methods.*

   Bowie, MD: Brady.

Parse, R.R.(1995). *The human becoming theory in practice and research.* National

   League for Nursing, New York.

Parse, R.R. (1998). *The human becoming school of thought.* Thousand Oaks: Sage.

Parse, R.R. (1998). The human becoming: Parse's theory of nursing. *Nursing Science*

   Quarterly 5, 35-42.

Perry, B.D., & Pate, J.E. (1994). Neurodevelopment and the psychobiological roots of

   post-traumatic stress disorders. Koziol, L.F., & Stout, C.E. (Ed.). *The*

   neuropsychology of mental illness: A Practical Guide. Springfield, IL: Thomas.

Pescosolido, B.A., Monahan, J., Link, B.G., Stuve, A., & Kikuzawa, S. (1999). The

   public's view of the competence, dangerousness and need for legal coercion of

   persons with mental health problems. *American Journal of Public Health*, 89(9),

   1339-135.

Polkinghorne, D. (1983). *Methodology for the human sciences.* Albany: State

   University of the New York Press.

Polkinghorne, D. (1988). *Narrative knowing and the Human Sciences.* Albany: State

   University of the New York Press.

Read, J., & Argyle, N. (1999). Hallucinations, delusions, and thought disorder among

psychiatric patients with a history of child abuse. *Psychiatric Services, 50,* (11),

1467-1772.

Ricoeur, P. (1991). *From text to action: Essays in hermeneutics II.* (K. Blarney & J.

Thompson, Trans.) Evanston, Illinois: Northwestern University Press.

Robson, C. (2002*). Real World Research: A Resource for social scientists and

practitioners: Researchers.* (2nd Ed.) Blackwell: Oxford.

Romme, M. & Escher, S. (1993). *Accepting voices.* London: Mind Publications.

Romme, M. & Escher, S. (1996). Empowering people who hear voices. In Haddock, G.

& Escher, S. (Eds.), *Cognitive behavioural interventions with psychotic disorders.*

London: Routledge.

Romme, M. (1998). Listening to the voice hearers. *Journal of Psychosocial Nursing,* 36

(9), 36-45.

Romme, M. & Escher, S. (1999). *Making sense of voices. London*: Mind Publications.

Ruocchio, P. (1989). First person account: Fighting the fight. The schizophrenic's

nightmare. *Schizophrenia Bulletin.* 17, 689-691.

SAMHSA , (2004). *Mental Health Weekly.* 14, 16 1-2.

Saas, L. (1992). Schizophrenia; Ontology. *Philosophical Psychology, 5 (2),* 109-124.

Sayer, J., S. Ritter, & Gounay, K. (2000). Beliefs about voices and their effects on coping

strategies.

Sayre, J. (1990). Psycho dynamics revisited: An objects-relations framework for

psychiatric nursing, *Perspectives in psychiatric care, 26 (1),* 7-12.

Schneck, J.M., S. Weir (1989). Mitchell's visual hallucinations as a grief reaction. *American Journal of Psychiatry, 146:409.*

Schleiermacher, F. (2002). *Lectures on Philosophical Ethics,* (Louden, R., Ed.). (Louise Adeyhuish, Trans.). University of Southern Maine: Cambridge University Press.

Schulze, B., & Angermeyer, M.C. (2003). Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives, and mental health professionals. *Social Science and medicine,* 56(2), 299-312.

Sells, D.J., Stayner, D.A., Davidson, L. (2004). Recovering the self in schizophrenia: An integrative review of qualitative studies. *Psychiatric Quarterly*, 75, 1, 87-97.

Shaw, K., McFarlane, F., & Bookless, C. (1997). The Phenomenology of traumatic reactions to psychotic illness. *The Journal of Nervous and Mental Disease, 185, 7,* 434-441.

Sheperd, G., Muijen, M, Dean, R., & Cooney, M. (1996). Residential care in hospital and in the community: Quality of care and quality of life. *The British Journal of Psychiatry,* 168,448-456.

Shulman, B. & Mosak, H. (1988). *Manual for lifestyle assessment.* Muncie, IN: Accelerated Development.

Skinner, B.F. (1971). *Beyond freedom and dignity.* New York: Knopf.

Slade, P.D. (1976). Towards a theory of auditory hallucinations: Outline of a hypothetical four-factor model. *British Journal of Social Clinical Psychology, 15,* 415-423.

Smythe, E. (2002). The violence of the everyday in healthcare. In N. Diekelmann (Ed.),

    First, do no harm (pp.164-203). Madison, Wisconsin, TheUniversity of

    Wisconsisn Press.

Strauss, J. (1989). Subjective experiences of schizophrenia: Toward a new dynamic

    psychiatry. *Schizophrenia Bulletin, 15,* 179-187.

Sullivan, H.S. (1962*). Schizophrenia as a Human Process.* New York: W.W. Norton &

    Company Inc.

Swihart, J., Silliman, B., & McNeil, J. (1992). Death of a student: Implications for

    secondary school counselors. *The School Counselor*, 40, 55-60.

Van Der Wal, J. (1989). The aftermath of suicide: A review of empirical evidence.

    Omega Journal of Death and Dying, 20(2), 149-171.

Van Dorn, R., Swanson, J., & Elbogen, E. (2005). A Comparison of stigmatizing

    attitudes toward persons with schizophrenia in four stakeholder groups: Perceived

    likelihood of violence and desire for social distance. *Psychiatry*, 68(2), 152-163.

Varcolis, E., Carson, V., & Shoemaker, N. (2005). *Foundations of Psychiatric Mental*

    Health Nursing. St. Louis, MI.: Saunders/Elsevier.

Vygotsky, L.S. (1978). *Mind in Society.* Cambridge, Mass: Harvard University Press.

Walters, F., Badcock, J.C., Maybery, M.T., & Mitchie, P.T. (2002). The role of affect in

    auditory hallucinations in schizophrenia. Unpublished manuscript.

Watson, J. (1988a*). Nursing: Human science and human care. A theory of nursing* N.Y.,

    N.Y., National League for Nursing.

Watson, J. (1988b). New dimensions of human caring theory. *Nursing Science Quarterly. 1(4),* 175-181.

Watson, J. (1985a). *Nursing: The philosophy and science of caring.* Boulder, CO: Colorado Associated University Press.

Watson, J. (1990). Caring knowledge and informed moral passions. *Advances in Nursing Science, 13 (*1), 15-24.

Watson, J. (1981). Nursing's scientific quest. *Nursing Outlook. 29* (7), 413-416.

Weber, S. (1986). The nature of interviewing. *Phenomenology and pedagogy, 4(2),* 65-72.

Weil, S. (1951).*Waiting on God.* (Emma Craufurd, Tran.), London: Routledge and Kegan Paul Ltd.

Weinsheimer, (1989). Hermeneutics. IN G.D. Adkins and L. Morrow (Eds.) *Contemporary Literary Theory.* University of Massachusetts Press: Amherst, MA. 117-136.

Worden, J. W. (1991). *Grief counseling and grief therapy: A handbook for the mental health practitioner.* New York: Springer

Zimmer, C. (2004). The Neurobiology of the self. *Scientific American*, 293, (5), 92-100.

Appendix A

Client Data Form

1.   Name_____

2.   Male_____   Female_____

3.   Ethnic background_____

4.   Education_____

5.   Age _____ and age of first hallucination experience (hallucinations include

     hearing voices, seeing things, tasting or smelling sensations, and feeling things

     that are not there)_____

6.   Most recent memory or experience of

     hallucinations_____

7.   Are you currently on medications?_____

8.   What kinds of medications are you taking?_____

9.   Would you like a copy of the summary report after this study is

     finished?_____

10. If your response is **yes**, what is your mailing address?

     Address_____

     _____

Appendix B

Site Consent Form (a)

We give our permission for Judith M. Jarosinski to seek volunteers from our site for the purpose of conducting a study on the experience of hallucinations. She has permission to:

1) **Affix flyers to bulletin boards in our common areas with her name and contact numbers.**

Signature_____

Signature_____

Site Consent Form (b)

We give our permission for Judith M. Jarosinski to seek volunteers from our site for the purpose of conducting a study on the experience of hallucinations. She has permission to:

2) Affix flyers to bulletin boards in our common areas with her name and contact numbers.
3) Conduct an information session which will include a short description of the study with copies of the flyers. Afterwards, Ms. Jarosinski will leave so that clients will not feel coerced to volunteer.
4) Use this facility for interviews

Signature_____

Signature_____

Site Consent Form (c)

We give our permission for Judith M. Jarosinski to seek volunteers from our

site for the purpose of conducting a study on the experience of hallucinations. She

has permission to:

1) Affix flyers to bulletin boards in our common areas with her name and
   contact numbers.
2) Use this facility for interviews

Signature_____

Signature_____

Appendix C

Referral Sources Guide

If you live in:

Porstmouth

If you are currently attending Opportunity House the counseling referral source phone number is: 757-393-8928.

Richmond

If you are obtaining services from Fan Free Clinic the counseling referral phone number for you is: 358-6343.

If you are responding to an ad in a Richmond paper your referral source is Richmond Behavioral Health Authority: Phone number is: 804-819-4100.

Norfolk

If you are responding to an ad in the Portfolio or Norfolk Community paper your referral source is Norfolk Community Service Board: The 24-hour counseling service is 757-664-7690

Virginia Beach

If you are responding to an ad in a local Virginia Beach paper your referral source is the 24- hour, in-person emergency services phone number: 757-427-8000. Enter code 100.

Appendix D

Open-ended interview guide

1. Obtain informed consent

2. The researcher will ask the subject to provide a pseudonym which will be used

   during the interview.

3. Remind the client of the confidential nature of the interview and the reason for using

   a pseudonym

4. Inform the client that the interview will be conducted for approximately 45 minutes

   and will be audio-taped. The initial questions will be:

   Tell me what is/was like for you when you hallucinate/ed?
   How does this experience influence the way you think about yourself?
   Does this experience make you feel differently about yourself?
   How do you see yourself?

   The use of probes and interrogatives such as: *"tell me more," "what is it like,"*

and "how is it" will be used. Nonverbal communication, the environment and the

researcher's impression will be noted and recorded in the journal and field notes

immediately after the interview.

   Subsequent interview questions will be unstructured, open-ended, broad–based

and designed to encourage self-reflection and the unfolding of the individual's personal

story.

Appendix E

Examples of theme development

and theme clusters

266	Accepting imperfection in a perfect world	"I feel a lot happier and um lets see-I'm more talking with people-you know –I'm not shying away from them because of the voices."
281	Living a life of confusion/ Merging with reality	"Well I was seeing things and I was seeing myself places, you know and seeing weird things and the devil and you know."
284	Compelling	"They would tell me to sit out in the rain and I couldn't hold my head up out of the plate. And I know everything I was doing, but I just couldn't help it."
305	Disturbing	"And my sister, I went to live with my sister, she was a registered nurse and she worked at _here in Portsmouth and she passed three years ago. And she took me to [MOPS], but I've never been hospitalized and they started to give me and that was in 1972. And then I took medication and I still had problems. I couldn't, a lot of times I couldn't make decisions on my own. I could not. When I wanted to go so I had..."
311	Awareness	"I don' really know when I first started, but it was pretty weird."
285	I'm still myself	"Now I can do, think, and make decisions on my own. And I highly enjoy... I try to enjoy life, I love

		people."
296	Merging with reality	"Well ah, one time I had a hallucination ah… Well okay, this is the hallucination. I thought I saw myself in a gym suit outside a door running next door to get a glass of water and then I remembered not exercising, and I exercise now and saw this striped gym suit. I remember this gym suit in school I used to wear. (laughter)"
273	Finding joy	"Now I can do, think, and make decisions on my own. And I highly enjoy… I try to enjoy life, I love people."
299	Damaged self-esteem	"Well, I used to have a low self-esteem and I ah, less self-respect you know, but then I didn't comb my hair and all that you know and then I just and I said, well I'm going to go tell somebody about this at least. They say well anybody could have a mental problem you know, physical problem, mental problems"
277	Merging with reality	"…seeing myself places, you know and seeing weird things and the devil and you know."
289	Awareness	"I don' really know when I first started, but it was pretty weird."
268	Persevering through the storm	"A lot like I am now…I think I've reached out"
274	Hope	

Theme Clusters

Are they who they are?
Fear , what is it?   What's going on?
Fear and dread
Dualistic thinking
Feeling scared
Feeling disorganized
Conflicting feelings
out of control
sense/intuition of doom

Life disrupted, still lived
Enduring in spite of the trouble
ebb and flow
life altering
Pushing thru the hard times
perseverance
A life interrupted, still lived
A life unlived, interrupted
Persevering through the storm
incorporating/adapting
coping

I'm still me
Health/connectedness vs illness/loneliness
Finding meaning
My life is still joyful
Accepting imperfection in imperfect world
I'm still me
I'm still the same person

Living with loss
Loneliness, isolation
loneliness
isolation
desire for socialization
loss
Fear and loneliness
Powerlessness
Damaged self-esteem.
lack of self-esteem
Distancing from others

Finding strength in the broken places ...
I'm still me
Making me strong in the broken places
finding purpose/meaning /regaining balance

Outliers
The Physical Price for Treatment/Ambiguity about Hallucinations/Dichotomy of Hallucinations

Vita

1. Personal information:

    Judith M. Jarosinski, RN, PhD
    Date and place of birth: March 27, 1953; Tokyo, Japan
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2. Education

2006	Virginia Commonwealth University, Richmond, Virginia: Ph.D. Nursing-Human Responses to Health and Illness Dissertation Title: *A life disrupted: Still lived*
1998	Master's Degree-VCU/Medical College of Virginia
1992	Bachelor's in Science Degree-University of Maryland
1973	Associate Degree in Nursing-Anne Arundel Community College

3. Professional Licensure

    Licensed Registered Nursing the Commonwealth of Virginia- #001054550- current

4. Awards and Professional Organizations

    Federal Traineeship Grant 1996, 1997, 1998
    Phi Kappa Phi
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5. Significant work experience

2000-present	Sentara School of Nursing-Faculty RN Program Coordinated Psychiatric Mental Health Nursing course (303) Coordinated Communications course (102) Chaired Admissions Committee
2002-2003	Tidewater Community College- Psychiatric Clinical

Nurse Instructor(Part time)

1999-2000	Sentara Norfolk General-PERS-Psychiatric Emergency Response System Nurse-Triaged and evaluated clients in the ED
1996-2005	Obici Hospital-Charge nurse in a collaborative team approach with acute and chronically mentally ill clients.
1995-May 1996	Maryview Hospital-Day Charge Maryview's Pain and Seizure Disorder Clinic.
1992-1995	Tidewater Psychiatric Center/Norfolk Psychiatric Center, Charge nurse/Evening supervisor
1989-1992	Lived overseas in England with family-completed Bachelor's of Science Degree.
1989-1986	University of Arizona for the Department of Defense/ US Navy. Site Coordinator for four sites for /NADSAAP, the Navy's Alcohol and Drug Safety Action Program
1984-1985	Department of Defense Dependent Schools, School Nurse Sullivan's Elementary School, Yokosuka, Japan.
1978-1984	Lived overseas in Italy with family.
1975-1977	Sentara Norfolk General-Charge Nurse – Adult Psychiatry. Implemented direct client care for acute and chronic psychiatric clients requiring medical management.

6.   Publication

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Maximizing learning outcomes: Nursing students' interaction with a standardized patient. *The Journal of Psychosocial and Mental Health Nursing, 8, 37-44.*