HOSPICE PROFESSIONALS REPORT ABOUT END-OF-LIFE CARE FOR
PERSONS WITH SCHIZOPHRENIA

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Approval of the Dissertation

HOSPICE PROFESSIONALS REPORT ABOUT END-OF-LIFE CARE FOR PERSONS WITH SCHIZOPHRENIA

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Abstract

HOSPICE PROFESSIONALS REPORT ABOUT END-OF-LIFE CARE FOR PERSONS WITH SCHIZOPHRENIA

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In the last decade, awareness increased regarding provision of quality care to the terminally ill, and there has been increased end-of-life care research. Despite new research and knowledge, some groups remain underserved and understudied, including persons with schizophrenia and other serious mental health conditions. People with serious mental health issues have long been stigmatized and have had poor access to medical care. In particular, people with schizophrenia are often marginalized, misdiagnosed, and many times receive suboptimal medical care.

Ten providers were selected from end-of-life service agencies in Southern California. The research design included a semistructured questionnaire for in-person interviews with end-of-life service providers.

End-of-life service providers reported willingness to provide end-of-life care to referred terminal patients with schizophrenia. The agencies had no statistical data on how many terminal patients with schizophrenia have received services. Participants reported significant challenges in end-of-life care for terminal patients with schizophrenia compared to those without schizophrenia or other psychiatric conditions. Although staff are trained about depression, anxiety, and dementia-related diseases, the agencies offer no formal education on schizophrenia or other complex psychiatric conditions. Most
directors indicated they did not feel qualified or know the distinction between schizophrenic hallucinations/delusions and visioning or near-death awareness hallucinations/delusions. None of the agencies had psychiatrists or psychiatric nurse practitioners on staff. The social workers employed at the agencies had limited knowledge of end-of-life issues and none on more complex psychiatric conditions (e.g., schizophrenia, bipolar disorder). Interviewees stated that educating physicians about the benefits of referring a terminally ill person for end-of-life care was the greatest improvement needed to add to the quality of care and of the dying experience.

This research has implications for increasing awareness in the end-of-life care system to improve service delivery to improve living and dying for people with a terminal illness and a secondary diagnosis of schizophrenia. In addition, the study points to a need for a pilot program in which mental health care providers are part of the comprehensive end-of-life care team.
Dedication

This dissertation is dedicated to people who experience schizophrenia and thousands who have died alone and in pain. My hope is that from this moment forward, truly all people will be comforted at the end of their life. To my husband Richard and my two sons, Rick and Steve, for their unconditional love, motivation, support, and enormous sacrifice that was required for this dissertation to be completed. Most of all, for embracing my passion for people who experience schizophrenia.
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CHAPTER 1
INTRODUCTION

Purpose of the Study

This study expanded on my practicum research (Madrigal, 2007) and explored the availability and quality of end-of-life care for people with schizophrenia. This study differed in that it included a larger sampling of end-of-life service providers. In the practicum study, I interviewed only three hospice managers face-to-face. The present research extended the sample to include 10 face-to-face interviews with end-of-life service providers to gain a greater perspective on agencies that provide end-of-life care.

The research design used a semistructured questionnaire of questions related to the topic. The objectives of the research were (1) to explore what end-of-life care agencies are providing end-of-life services to persons with schizophrenia, (2) to gain an in-depth understanding from end-of-life service providers on what services are being providing to persons with schizophrenia, and (3) to increase the awareness in the end-of-life care system by conducting educational presentations and trainings in the end-of-life care system.

Background

Every day, healthcare professionals (physicians, nurses, clergy, social workers, psychologists, in-home supportive service workers, physical therapists, nurses aides, and many others) provide caring and compassionate care to people who have terminal illnesses. The professional, “though he or she cares about the patient, may resist getting close enough to recognize, understand, and share in the patient’s suffering” (Arbore, Katz, & Johnson, 2006, p. 13). This phenomenon is called parallel suffering, which
occurs when professionals try to keep their suffering separate from the patient’s suffering.

Arbore et al. (2006) stated,

Unfortunately, by distancing from the patient’s suffering, the clinician loses opportunities not only to strengthen the patient’s ability to fight for hope (for example, hope that the patient will be able to endure physical, emotional, or spiritual pain), but also to help the patient make meaning of his or her struggle. When this happens, sick and dying people are left isolated and alone in their pain and suffering. (p. 13)

I conducted an informal online survey (Madrigal, 2006) with mental health professionals who treat people with schizophrenia and representatives of organizations that specialize in end-of-life care. The study showed that hospice care is generally unavailable to people with schizophrenia. When hospice care providers were asked about services for people with schizophrenia, most indicated that such services were unavailable, or at best, those people were offered referrals to a mental health agency. The study revealed a large discrepancy between what end-of-life care providers aspire to do and the services that they actually provide.

I conducted an informal survey on Survey Monkey (Madrigal, 2007) with representatives who participated on an end-of-life list-serv. Twenty end-of-life service professionals responded to the survey. The study showed that 50% of the professionals did not know whether end-of-life care was being provided to people with a terminal illness and schizophrenia. Also, 18 of the 20 professionals felt that they were not qualified or properly trained to provide care to people with a terminal illness and schizophrenia, and finally, many felt reluctant to provide end-of-life care to people with schizophrenia.

I conducted a pilot study (Madrigal, 2007) that included three structured interviews with three end-of-life service managers who worked at local hospice
organizations. When I asked hospice care providers about providing services for people with a terminal illness and a secondary diagnosis of schizophrenia, all three indicated that such services were available but only one reported providing any services to this population. Furthermore, hospice providers did not report that they recognized that people in this category might have special needs. Overall, the study revealed a discrepancy between what end-of-life care providers aspire to do and the services that they actually provide. The study showed that people with a terminal illness and a secondary diagnosis of schizophrenia may be underserved in terms of hospice care and that end-of-life service providers are unaware that some of their patients may have a secondary diagnosis of schizophrenia.

Statement of the Problem

The past 10 years have seen an increase of awareness regarding provision of quality of care to the terminally ill and a greater emphasis on end-of-life care research. Despite the increase in new research and knowledge, some groups continue to be underserved and understudied, such as persons with serious mental health issues (Baker, 2005; Foti, 2003; McGrath & Jarrett, 2007). In addition, people with serious mental health issues have “long been a disenfranchised minority who access to general medical care has been limited” (Felker, Yazel, & Short, 1996, p. 1356) and consistently neglected (Baker, 2005). In particular, people with schizophrenia are often misdiagnosed and many times receive suboptimal medical care (Brown, Inskip, & Barraclough, 2000; Carney, Jones, & Woolson, 2006; Felker et al., 1996). Some of the contributing factors involved in the suboptimal care and lack of discussion about end-of-life care with people who experience schizophrenia is a fear that the person will have an escalation in psychiatric symptoms, that the person is impaired and cannot comprehend the subject matter, and
that the healthcare staff is not educated or trained in facilitating discussions about end-of-life care and advance care planning (Foti et al., 2005).

Compared to that of the general public, mortality of people with schizophrenia is remarkably high, with life expectancy reduced by 8.8 to 10 or more years (Brown et al., 2000; Carney et al., 2006; Dembling, Chen, & Vachon, 1999; Harris & Barraclough, 1998; McGrath & Jarrett, 2007; Mortensen & Juel, 1993). Many homeless persons also experience schizophrenia. “Homeless persons have high rates of mortality with a mean age at death being reported to be 34-47 years and 2.3-4 times higher than the general public” (Podymow, Turnbull, & Coyle, 2006, p. 81).

In general, natural deaths among people with serious mental health issues are related to medical diseases that many times are in the late stages before diagnosis of a terminal illness. Many times the care that is provided for comorbidity is suboptimal or worse to persons with serious mental health issues. Unnatural deaths are generally related to suicide, homicide, and accidents (Allebeck, 1989; Brown et al., 2000; Carney et al., 2006; Cohen, Dembling, & Schorling, 2002; Dembling et al., 1999; Dickey, Normand, Weiss, Drake, & Azeni, 2002; Felker et al., 1996; Harris & Barraclough, 1998; Mortensen & Juel, 1993; Simpson & Tsuang, 1996). Along with suboptimal care, the financial cost of schizophrenia is extremely high.

Medical and Financial Costs of Schizophrenia

The cost of medical care for people with schizophrenia is extremely high. Wu et al. (2005) conducted a study that evaluated the excess annual costs associated with people with schizophrenia in the United States. The study concluded that the overall, the U.S. cost of schizophrenia in 2002 was approximately $62.7 billion, with $22.7 billion excess direct health care costs ($7.0 billion outpatient, $5.0 billion drugs, $2.8 billion inpatient,
$8.0 billion long-term care). In addition, the direct non-health care excess costs, including living costs, were estimated at $7.6 billion. The indirect costs were estimated to be $32.4 billion. Also, an estimated 10-15% of people with schizophrenia are able to work full-time, whereas the remainder receive federal disability payments (Wu et al., 2005).

As stated above, despite the increase in new research and knowledge, some groups continue to be underserved and understudied; therefore, more research is needed to help to explore what agencies are providing end-of-life care for persons with schizophrenia.

This study has provided the necessary data to fill the existing gap between the end-of-life care system and the mental health care system in meeting the needs of terminal ill patients with schizophrenia.

Case Study of a Woman with a Terminal Diagnosis and Schizophrenia

This report would not be complete without sharing the human experience of one such person named Judy. She represents the hundreds, perhaps thousands of people with a history of schizophrenia who were diagnosed with a terminal illness and yet never received end-of-life care, compassion, respect, dignity, spiritual guidance, and emotional support, but instead died alone and in pain (Madrigal, 2006).

I first met Judy through a colleague who was Judy’s favorite cousin. When Judy was diagnosed with stage four, small-cell lung cancer, a local branch of the American Cancer Society was contacted in an effort to draw upon community resources that could offer Judy end-of-life resources and support. In a telephone conversation with a volunteer at the American Cancer Society, I asked whether there were any volunteers who could visit Judy in the skilled nursing facility to offer her support and advocacy. The American
Cancer Society volunteer stated, “No, we do not have any volunteers that are familiar with schizophrenia” (American Cancer Society, personal communication, July 5, 2005).

A Terminal Diagnosis

Lattanzi-Licht, Mahony, and Miller (1998), in their book, The Hospice Choice: In Pursuit of a Peaceful Death, reminded us that “the dying process pushes us to the edges of our understandings and leaves us standing there feeling alone and lost” (p. 9). A terminal diagnosis brings an array of emotions, ranging from shock and disbelief to terror and panic. Judy felt shell-shocked and overwhelmed with so many feelings on the day that she received the news about her biopsy and pathology results. The pathology report read: Stage four, small-cell lung carcinoma.

Judy recalled sitting in the cold, sterile hospital meeting room, with several healthcare professionals and her cousin Dorothy. She stared vacantly at the floor, with her legs pulled up to her chest. She grasped her legs and rocked back and forth. All of a sudden, she began to pace around the room, her eyes shifting back and forth in sheer panic.

She so desperately wanted to flee and get away, and yet there was no running away from the news that she had just been told. Judy had just been told that her prognosis would be negative with or without treatment. It was just a matter of time.

The medical team asked Judy whether she would participate in a study for a new drug from Japan for small cell lung cancer; either way, Judy’s outcome was terminal. Judy had so many decisions to make. She was overwhelmed with so much information all at once. Receiving the news that “there is nothing we can do” is overwhelming, frightening, shocking, and surreal for any person; but it was especially difficult for Judy, who had a 40-year history of schizophrenia.
Elisabeth Kubler-Ross, M.D., renowned psychiatrist and authority on the end-of-life process, stated in *Death: The Final Stage of Growth*, that there five stages of dying that a person will typically experience. These include: denial, anger, bargaining, depression, and acceptance. Upon hearing of her diagnosis, Judy exhibited disbelief and shock, characteristic of the first of Kubler-Ross’s stages. Kubler-Ross asserted that most people value their lives (Kubler-Ross, 1975, p. 10).

*Comprehending End-of-Life*

Some mental health providers and family members avoid discussing end-of-life care with persons with schizophrenia for fear of provoking a negative reaction or possible decompensation (Foti, Bartels, Van Citters, Merriman, & Fletcher, 2005). Some people believe that people with schizophrenia cannot comprehend the dying process or manage the decisions that need to be made when they are diagnosed with a terminal illness. Judy’s cousin stated, “I’m not sure Judy understands what is happening. She is so scared and doesn’t know what to do” (Anonymous representative, personal communication, July 5, 2005).

In an unpublished essay, a respected psychologist recalled that when he was 11 or 12 years old, he had a conversation with a friend in the presence of his “autistic/retarded” brother. While he and his friend were talking, the psychologist wondered aloud whether his brother could comprehend their conversation. To the psychologist’s surprise, his brother said, “You know I do understand,” then he slipped back into his autistic-regressed state (Anonymous, personal communication, January 10, 2006).

Many of the end-of-life publications mention the importance of support, companionship, and no person dying alone. I began to wonder who supports, holds the
hand of, and comforts people with schizophrenia. All that Judy wanted was not to be alone to suffer and have someone support her.

Despite her schizophrenia, Judy clearly knew what she was facing. She stated, “I don’t want to die.” She stated that she did not want to suffer or be unable to enjoy life any longer. She vacillated about whether to have any medical treatment. She asked repeatedly, “Should I have chemotherapy or not? What if the cancer comes back? What other choices do I have? I can’t breathe, I don’t want to be in pain, I don’t want to suffer.” Judy had very good insight into her situation. Even though Judy had stage four lung cancer was staying in a skilled nursing facility, end-of-life care services were never offered. Why was end-of-life care never offered to Judy or her family? As noted above, this may be due to the widespread belief that people with schizophrenia cannot comprehend the dying process or make decisions about end-of-life care. Because of those beliefs, many healthcare professionals do not address end-of-life care for people with schizophrenia.

I had the privilege of spending her last few weeks with Judy before she passed away. Elisabeth Kubler-Ross (1975) noted, “The dying person’s willingness to converse in depth about his or her present awareness of memories, dreams, and hopes” (p. 160) was validated when Judy began to share her memories, dreams, and hopes about her life in a series of conversations with this writer.

The Sacred Meeting

As a girl, Judy loved her long, blond hair that was now long, gray, and worn in a French braid. She had no teeth or dentures; she had lost her eyeglasses and commented, “My vision is blurry.” Judy’s long fingernails were stained orange/yellow from years of smoking. She wore a beautiful candy-apple velvet sweater that illuminated her blue eyes.
Judy routinely laid in a fetal position when I arrived for a visit. Her facial expression conveyed the familiar look of shock, fear, confusion, and the gazed stare into space that accompanies a terminal diagnosis. Judy and I spent many hours talking about life, love, spirituality, and dying. There were also many moments we sat quietly, no words needing to be spoken.

**Judy’s Fond Memories**

Judy had good times and challenging times in her life. She had times of homelessness, hospitalization for psychiatric symptoms, and times of separation from her family for years at a time. She also enjoyed an eight-year committed relationship, lived in Hawaii, worked in her father’s store, worked as a secretary, and enjoyed her life: “I’ve lived my life the way I wanted to; I don’t want to be in pain or die.”

Judy reported that she had a 40-year history of schizophrenia, paranoid type. She was born in 1946. As a young girl she played the piano magnificently and developed her singing voice. She loved to perform for others. Her mother would invite family and friends over for an evening of extravagant solo piano performances by Judy. She would wait until all the guests were seated and then make her grand entrance into the room. Her mother would dress her in beautiful frilly little dresses, black shiny shoes, and curl her long blond hair.

Judy’s favorite playmate was her cousin Dorothy, who loved to listen to Judy play for the family and friends. Many compared the two as twins. Dorothy said that she felt that Judy was more favored in their youth.

Judy was an only child until she was 12 years old, when her brother was born. Life changed for her at this point. She told this writer that when she was 16 years old, she
had some allergy testing done that caused her to have a severe allergic reaction that sent
her into a catatonic state.

Her mother was frightened and had her admitted to a hospital that tried to snap
her out of her catatonic state by giving her shock treatments. Because the hospital could
not find a reason why Judy was in such a state, she was admitted to a psychiatric hospital
in the 1960s. She remained in the psychiatric hospital for more than one month. Upon
discharge, she was told that she had been diagnosed with schizophrenia. She told this
writer that she never felt the same after the shock treatments or being in the hospital for
over a month. She was very clear that she lived her life the way as she had desired.

Judy held several jobs. She enjoyed working in her father’s jewelry store as a
saleslady: “He gave me this watch.” The watch that she showed me no longer worked
but had sentimental value to Judy. She had also worked as a secretary and at a local ice
cream store.

Judy demonstrated that she could form close relationships. She talked about the
men who loved her and whom she loved. She married Roy in 1983, but they divorced
within a year. After the divorce, she enjoyed the companionship of Mike and then Chuck.
She mentioned that Chuck and she lived together for five years in an apartment. They
wanted to have children, but they were never able to conceive. Later she found out that
she had been sterilized as a young woman during surgery for an ovarian cyst. Judy talked
extensively about her relationship with Chuck and how she wished they could be together
again during her last days. “We loved each other so much; he always took really good
care of me.” Nothing made Judy smile more though than when she mentioned the name
of her childhood sweetheart, Johnny. Her eyes glistened and sparkled while she
reminisced about her youth. She said he was the cutest young man she had even laid eyes on.

One day Judy mentioned to her cousin that she had a new friend: “Mary is my friend.” We shared memories and food together, played blackjack, and talked for hours about life. When it was time for me to leave, Judy would always say, “Do you have to leave?” She would look at me and say, “I love . . . when you come and visit me.” Then she would start talking about her life again. She wanted to be close to people.

*Judy’s Hospital Experience*

Several times, Judy told this writer, “The hospital staff will not listen to me.” Hans O. Mauksch, Ph.D., observed that patients have been groomed to be “grateful to physicians and nurses,” and if a patient, especially a person who has schizophrenia, tries to express anger, cry for help, or express a personal need, this “violates the culture, the rules, the expectations of the institution and thereby threatens the system” (as cited in Kubler-Ross, 1975, p. 11).

On several occasions, Judy asked the hospital staff to cover her pikline intravenous therapy (IV) with a plastic sleeve that the oncologist had given her to protect her arm from becoming infected. The hospital staff ignored her request and instead wrapped her arm in a towel, which increased the likelihood of infection and resulted in the area getting wet. On another occasion, I observed Judy rushing down the long hospital corridor, desperately short of breath, only to be told by the nurses that it was not time for her breathing treatment. The nurses would not even look up from their paperwork to acknowledge her standing there, gasping so severely that her shoulders were raised up at her attempt to decrease the suffocating feelings caused by her stage four lung cancer.
At no time was end-of-life care, counseling, comprehensive care, interdisciplinary resources, bereavement counseling, pastoral care, or any other end-of-life care ever offered to Judy or her family by the team of physicians, oncology staff, skilled nursing staff, or the board and care staff that were responsible for her care. It was very clear that Judy needed an advocate to ensure that her requests and needs were met. It was not my original intention to become her advocate, but the need was very apparent. A strong voice was needed to ensure that ethical, compassion, respectful, and humane care was given to Judy.

Judy’s case illustrates this unfortunate situation. Many of her preferences were not respected in the skilled nursing facility that she called home. With enormous tumors in her lungs, stomach, liver, and brain, she was clearly in distress and pain. Her psychological state was very appropriate for someone who was facing the end of her life. There were times that she would ask for a cup of water, a tuna sandwich, or a battery for her room clock, but her request was ignored or dismissed by the staff.

_Neglectful Medical Care for People with Schizophrenia_

Judy’s misfortunes were certainly not an isolated case. Cara Mia DiMassa, a Los Angeles Times staff writer recently reported,

Authorities released a videotape of what they say is the dumping of a 63-year-old woman who is likely mentally challenged on the streets of skid row . . . a woman wearing a hospital gown and no shoes walks from the same direction, wandering in the street and on the sidewalk. . . . LAPD Capt. Andrew Smith said he believes the taxi took the woman, a 63-year-old Gardena resident, downtown against her will after she was discharged from a local emergency room. (Di Massa, 2006, para. 1)

A case manager reported to this writer that his friend had all of his teeth extracted due to stage four mouth cancer. After the dental surgery, he was released to walk home in the rain. Another said the man was driven to his closed down board and care home on a
five-mile dirt road in the desert by the hospital staff in the early morning. The hospital staff was aware that the board and care was closed, that no one was there, and that the man had no shoes. Even more inhumane was the day the coroner mistakenly stumbled onto Robert, who lay dead and forgotten in cold storage for two months.

Clearly Judy’s needs and requests were ignored, dismissed, and disregarded, and evidence suggests that this is an all too common scenario. She was accustomed to not being listened to due to her experiences with mental health practitioners. She may have been challenged with schizophrenia, but she was very insightful, educated, and talented in many areas of her life. In general, her medical concerns and requests were considered to be delusional attention seeking behavior, to be disregarded because she was a “mental case.” As Kubler-Ross (1969) asked, “What happens in a society that puts more emphasis on IQ and class-standing than on simple matters of tact, sensitivity, perceptiveness, and good taste in the management of suffering” (Kubler-Ross, 1969, p. 10).

Simple Pleasures in Judy’s Life

Judy was very simple and practical and at times had primitive mannerisms. One of my fondest memories of her was when I brought her a frosted chocolate brownie with sprinkles on it. I could see the excitement in her eyes at the sight of this chocolate brownie. I left the room for a couple of minutes, just long enough to ask the nurse for a cup of ice for her Dr. Pepper™. Upon returning to her room, she had stuffed the entire brownie into her mouth. She had chocolate all around her mouth, on the rims of her lips and the tip of her nose. That was Judy. We just laughed together. She had a great sense of humor.
Judy’s favorite drink was Dr. Pepper™ and her favorite food was mashed potatoes. As mentioned above, her eating habits were very primitive. She gulped her drink and shoved her food in her mouth, most of the time barely chewing, and swallowing her food in large chucks.

*Red Roses*

It was apparent that Judy was declining rapidly. I decided to buy her some fresh flowers. Her favorite flower was, “anything red.” One morning, I decided to buy some red roses for her. The morning of July 25, 2005, I took the red roses into Judy’s hospital room. She did not spring up that morning, as she usually did. As I touched her forehead, she was profusely sweating, stating that she was too weak to get up and that she did not want to eat anything. She noticed the beautiful red roses. I read her a special message that was written on the card and placed the flowers at a level where she could see them while lying down. As her advocate, I instructed the staff to allow her to sleep. We said good-bye. Later that afternoon, Judy went into cardiac arrest. She had a medical advanced directive, but the hospital staff did not send it with her to the emergency room, thus she was put on life support.

*The Final Good-Bye*

I was deeply moved by Judy and the moments we shared in the last few weeks of her life. As she progressed toward death, our encounters were profound and sacred experiences. At last, I went to the critical care unit at the local hospital where Judy lay dying. We shared one last tender moment together. To honor both her and her death, this writer held Judy’s lifeless cold hand, touched her forehead, and said good-bye to the sacred journey we had shared.
Later that afternoon, Judy’s cousin came to visit. The charge nurse mentioned to her that she had “just missed Judy’s friend.” The cousin replied, “Judy doesn’t have any friends,” but then, she remembered what Judy had said earlier: “I have a friend, her name is Mary.”

Judy was taken off life support on July 26, 2005. She was flown home to be buried in the family plot. In a follow-up conversation with Judy’s cousin six months later, the cousin told me that Judy did not receive a burial ceremony and no headstone had been ordered to mark her grave.

Research Questions

This study will contribute to answering the following research questions:

1. What end-of-life agencies are providing palliative and end-of-life care to persons with schizophrenia?

2. What services are being provided to dying persons with schizophrenia?

3. What measures do workers in the mental health care and end-of-life service industry believe can help increase the awareness of and amelioration of this situation?

I hope that this study will provide data that will help fill the existing gap between the end-of-life care system and the mental health care system that will ultimately improve the our ability to meet the needs of terminally ill patients with schizophrenia.
CHAPTER 2

REVIEW OF THE LITERATURE

This review of the literature examines the current state of our knowledge about end-of-life service providers who may be underserving people with a terminal illness and schizophrenia. This chapter provides a definition of terms and a brief overview of the medical model positing genetic and biological causes of schizophrenia. This chapter considers alternative views of schizophrenia, therapeutic communities, the benefits of the psychosocial model, natural and unnatural causes of mortality for people with schizophrenia, the comorbidity that may contribute to excess mortality, and the financial costs of schizophrenia.

Several studies are reviewed to determine the natural and unnatural causes of death in the target population. I show that part of the issue has to do with how people with schizophrenia are treated in this society. I briefly explore the issue of stigma along with contributing factors that may interfere with quality medical care. The differences between schizophrenic hallucinations and near-death awareness hallucinations experienced by others at end-of-life are examined. In addition, this chapter reviews three programs that contribute to quality of life of people with schizophrenia by interacting with them with dignity and viewing them as human beings capable of taking active roles in their own lives.

Finally, as a mental health professional with extensive experience working in both biomedical model and psychosocial model settings, I discuss several firsthand experiences of individuals who received suboptimal medical care.
Definition of Terms: What is End-of-Life Care?

The section offers definitions of the term *end-of-life care* and identifies who provides end-of-life care for dying people with schizophrenia. According to the National Hospice and Palliative Care Organization, “Since 1983, the Medicare Hospice Benefit has enabled millions of Americans and their families to receive quality end-of-life care that provides comfort, compassion, and dignity” (National Hospice Foundation, 2002). In their *Medicare and End-of-Life Care Report*, Marilyn Moon and Cristina Boccuti of the Urban Institute stated,

> We refer to palliative care as a particular type of end-of-life care that terminally ill people may receive . . . specifically, palliative care is noncurative care that focuses on controlling symptoms such as pain, maximizing personal functional activities, and addressing the emotional, spiritual, and social concerns associated with death and dying. (Moon & Boccuti, 2002, p. 4)

The five goals relevant to palliative care are as follows:

(1) Respecting patient preferences.

(2) Providing comprehensive care.

(3) Maximizing interdisciplinary resources.

(4) Acknowledging caregiver concerns.

(5) Creating health care systems flexible enough to support these goals (Moon & Boccuti, 2000, pp. 4-5).

The National Hospice Foundation (2002) stated that hospice services are available to patients of any age, religion, race, or illness “and the hospice team consists of the patient, and family/caregiver; the patient’s personal physician; Hospice physician (or medical director); nurses; home health aides; social workers; clergy or other counselors; trained volunteers; and speech, physical, and occupational therapists, if needed” (p. 3). People who have “life-threatening illnesses who can no longer benefit from curative
treatment and usually have life expectancies of six months or less, as determined by a physician” (p. 5) can receive hospice services. The services include:

- Physician services for the medical direction of the patient’s care;
- Regular home care visits by registered nurses and licensed practical nurses;
- Home health aide, health aides, and homemaker services attending to the patient’s personal needs;
- Chaplain services for the patient and loved ones;
- Social work and counseling services;
- Bereavement counseling;
- Medical equipment;
- Medical supplies;
- Drugs for symptoms control and pain relief;
- Volunteer support to assist loved ones;
- Physical, speech, and occupational therapy; and
- Dietary counseling.

Definition of Schizophrenia

In 1898, Emil Kraepelin (1855-1926) coined the term *dementia praecox* and listed three classifications: “catatonia, or stupors, ‘hebephrenia,’ or silly and stilted behavior, and ‘vesania typica,’ or hallucinations and delusions” (Szasz, 1976, pp. 10-11). In 1911, Eugen Bleuler (1857-1939) identified and recorded the term *schizophrenia*.

According to the *Diagnostic and Statistical Manual* (DSM-IV-TR, American Psychiatric Association [APA], 2000), schizophrenia is a cluster of essential signs and symptoms (both positive and negative). To diagnose the condition, these symptoms must
be present for up to six months. The five subtypes of schizophrenia listed by the DSM are: paranoid, undifferentiated, disorganized, catatonic, and residual. Symptoms may be classified as positive or negative. Positive symptoms include: hallucinations, delusions, paranoia, disorganized speech, and grossly disorganized or catatonic behavior. The negative symptoms include affective flattening, alogia, anhedonia, and avolition (APA, 2000).

**The Biomedical Model**

According to the biomedical model of schizophrenia, the characteristic symptoms of the disorder are caused by a biochemical imbalance in the brain. Scientists do not know what causes schizophrenia. As Fauman (1994) noted, “The criteria defines the psychological concept of psychosis in the DSM-IV, but imply nothing about the etiology of the disorder” (p. 140). In fact, according to *Mental Health: A Report of the Surgeon General—Executive Summary*, the etiology of “schizophrenia has not yet been determined” (U.S. Department of Health and Human Services, 1999, p. 276).

Furthermore, Mary Boyle (1990) asserted that the historic development of schizophrenia has never been validated and that Kraepelin and Bleuler were merely “postulating the existence of a peculiar pattern of symptoms that they then attempted to un成功fully validate” (cited in Romme, 2007, p. 2). John Read (Read, Mosher, & Bentall, 2004) also stated that “Kraepelin and Bleuler admitted they could not find any evidence of a biological cause” (p. 60).

The following section examines the literature on alternative views and the psychosocial effect of schizophrenia. This is a limited review of this subtopic.
Alternative Views of Schizophrenia

Loren Mosher (1933-2004), a Harvard-trained physician and psychiatrist, believed that schizophrenia could be a “reaction as someone’s altered states of consciousness in response to a crisis” (Mosher & Hendrix, 2004, p. 11). According to Ken Wilber (2004, as cited in Reynolds, 2004), “altered states are nonordinary or non-normal states of consciousness that are always temporary . . . and can range from drug-induced states to near-death experiences to meditative states” (p. 318). If a person were experiencing a psychotic episode, it would affect the person’s entire reality, relationships, and community. Mosher stated that the affected person’s state usually “involves personality fragmentation with the loss of a sense of self” (p. 11) that greatly influences the person’s sense of terror and disintegration. “Mystical experiences are common in the state beyond reason” (p. 11). Mosher taught his staff at his residential program to “regard mystical qualities as metaphorically valid and comprehensible” (p. 12).

Based on his theory and philosophy, Mosher and Hendrix (2004) created a residential, community-based treatment program called Soteria House as an alternative to traditional psychiatric wards in the San Francisco Bay Area (Mosher & Hendrix, 2004). Soteria provided a sanctuary for young, newly diagnosed people with schizophrenia in a fairly unstructured environment with other residents who experience schizophrenia. The staff consisted of nonmedical and nonpsychiatric workers. Soteria’s goal was to assist the people in working through the psychosis in a mostly drug-free environment to regain independence and integrate into the community without being demeaned, disregarded, or reduced to a psychiatric label.

In fact, Soteria’s philosophy was to treat everyone as a respected, whole human being who had altered states of consciousness and not a broken, diseased brain. Soteria
was successful in assisting many of the residents to regain independence and integrate into the community as productive citizens. After two years, the clients of the original Soteria house were working at significantly higher occupation levels, living more independently or with peers, and experiencing fewer hospitalizations (Mosher & Hendrix, 2004).

David Lukoff noted in his article, “The Diagnosis of Mystical Experiences with Psychotic Features” (1985), that “psychotic and religious experiences have been associated since the earliest recorded history” (p. 155) and that the “Bible describes persons who wandered around talked to themselves” (p. 157). Likewise, when people appear to experience schizophrenia or psychosis, they may be having a mystical or spiritual experience. It is not uncommon for some people to report hearing God’s voice or seeing angels. “In contemporary Western society, the widely accepted cultural model for explaining such unusual phenomena is mental illness” (Lukoff, 1985, p. 160).

Stanislav Grof, a professor of psychology at the California Institute of Integral Studies and the Pacifica Graduate Institute and pioneer in consciousness studies, extensively studied nonordinary states of consciousness and described them in his book, *When the Impossible Happens: Adventures in Non-Ordinary Realities* (2006), which disputes the popular viewpoint that hearing voices is a sign of severe “mental illness”. Instead this symptom may indicate a mystical experience that results from a variety of pathogenic factors including intense stress, severe interpersonal conflicts, and lack of sleep, but also from inspiration. Grof (2006) also stated, “The current model of the psyche offers only a limited range of therapeutic mechanisms such as remembering forgotten and repressed traumatic events” (p. 278). These measures do not resolve the
underlining root of trauma. Thus, the person continues to suffer and experience distressing symptoms.

Hearing Voices Network (HVN) is an organization that understands and supports hearing “voices.” According to their Web site, HVN is an international network of enlightened peer support groups, for people who experience a variety of sensate experiences, visions etc. Groups ideally integrate both “patient” and “non patient” voice hearers. Some people experience voice hearing as traumatic and seek psychiatric services (patients), some people have these experiences in a way that is helpful or non-traumatic (non-patients). It is important to point out that all people who hear or see things are not necessarily mentally ill or receiving mental health services. The field of psychiatry has long neglected this fact. The goal of these groups is to de-stigmatize the experience of hearing voices and work toward a society in which voice hearing will be no more considered indicative of illness or something to be cured, than left-handedness. (Intervoice, 2007, para. 1)

Another alternative viewpoint has been offered by the International Society for the Psychological Treatment of Schizophrenias and Other Psychosis (ISPS-US). Some experts believe that schizophrenia is a defense mechanism utilized in response to severe trauma or terror. Bertram P. Karon, a member of ISPS-US and professor of psychology at Michigan State University, believes that schizophrenia is a “manifestation of chronic terror or defenses against the terror. The chronic terror tends to hide other feelings” that the person has that are severely overwhelming (Karon, 1981, p. 27).

Patricia Deegan stated in her (1996) essay, “Recovery and the Conspiracy of Hope,” that the person with schizophrenia is in psychological anguish and that there is a split in the I-Thou relationship. Deegan believes that recovery from schizophrenia is possible. Rather than a biological or genetic defect, she sees schizophrenia as “a way of life; an attitude and a way of approaching the day’s challenges” (Deegan, 1996, pp. 6, 13).
Courtenay M. Harding, a professor of psychiatry at the University of Colorado, noted in *Monitor on Psychology* (2000) that “given half a chance, people can significantly improve or even recover” from schizophrenia. As reported in Carl Cohen’s (2003) poignant book, *Schizophrenia into Later Life*, Harding examined 10 scientific studies from 7 countries. All of the studies indicated “a wide heterogeneity of course and social and work functioning, significant weakening of traditional predictors” (p. 38). In contrast to the traditional assumptions, “The most remarkable finding of these long-term studies is the confluence of results showing that at least 50-60% of each intact cohort studied across 2 to 3 decades significantly reclaimed their lives” (Harding, 2003, p. 38).

One person who reclaimed her life is Joanne Greenberg, who wrote the moving book, *I Never Promised You a Rose Garden* (1964). Greenberg stated, “Schizophrenia is made up of metaphors that the person can no longer contain within the person . . . delusions, hallucinations, and paranoia are metaphors for the deeper pain that the person is masking” (J. Greenberg, personal communication, October 20, 2005).

The observations of Mosher, Lukoff, Grof, Karon, Deegan, Harding, Greenberg, and many others strongly suggest that people with schizophrenia can significantly improve their lives, and even recover completely and have productive, long, and meaningful lives.

In summary, this section attempted to demonstrate that there are different theories about the etiology of schizophrenia, and it is likely that significant differences of opinion will continue. Whether a person has a biological, genetic, psychosocial, mystical, or nonordinary state of consciousness, the person with a terminal illness and a secondary diagnosis of schizophrenia is human and has the same human needs as everyone else when dying.
Knowing how to be with and respond to the “suffering of others, especially when it is out of usual and familiar practice” (Abore et al., 2006, p. 17) is essential in providing quality of care to the dying person no matter what symptoms are experienced.

The next section discusses the natural and unnatural causes of death for people with schizophrenia.

Natural and Unnatural Mortality of Schizophrenia

The literature on the mortality of schizophrenia exhibits several similarities among studies: there is an excess of mortality from natural and unnatural deaths. In general, natural deaths are related to medical diseases that many times are in the late stages by the time a person is diagnosed with a terminal illness. Many times the care that is provided for comorbidity is suboptimal or worse for persons who experience severe mental conditions. Unnatural deaths are generally related to suicide, homicide, and accidents (Allebeck, 1989; Brown et al., 2000; Carney et al., 2006; Cohen et al., 2002; Dembling et al., 1999; Dickey et al., 2002; Felker et al., 1996; Harris & Barraclough, 1998; Mortensen & Juel, 1993; Simpson & Tsuang, 1996).

Medical Comorbidity

Clinical antipsychotic trials of intervention effectiveness (CATIE) found that schizophrenia affects 3.2 million Americans (Berg, 2006). Medical comorbidity is common among people with schizophrenia, which puts them at high risk for neoplasms (cancer), endocrine diseases (hormone, lymph, thyroid, and diabetes), nervous diseases (brain or nervous system), circulatory diseases (stroke, heart, and lungs), respiratory diseases, digestive diseases (Brown et al, 2000) due to a variety of risk factors including unrecognized or minimized medical issues, unhealthy lifestyle choices (e.g., smoking, poor diets, impaired hygiene), inability to access good health care practices, and side
effects of psychotropic medications, along with years of stigma. As people with schizophrenia age, they require higher levels of skilled medical care, which can be very costly (Foti et al., 2005; Harris & Barraclough, 1998; Joukamaa et al., 2006).

Carney et al. (2006) examined the comorbidity of 569 women and 505 men diagnosed with schizophrenia from an Iowa Blue Cross/Blue Shield database. The researchers concluded that persons with schizophrenia had three times or more medical diseases or conditions than others without schizophrenia. In addition, persons with schizophrenia had elevated odds of diabetes, hypothyroidism, liver disease, hepatitis C, polysubstance abuse, renal disease, fluid and electrolyte disorders, heart disease, and cancer. Carney et al. also noted that the participants had greater access to medical care due to having insurance; however, they still experienced a delay in receiving adequate care. The study noted that the reasons include misdiagnosis, patient difficulty following through with doctor appointments, and inappropriate assessment of the person’s needs.

Cohen et al. (2002) reviewed the National Mortality Followback Survey (NMFS) records of 130 men and women diagnosed with schizophrenia compared to 18,603 people without schizophrenia to determine whether cancer was more common in persons with schizophrenia. The authors concluded that on average, people with schizophrenia die 10 years younger than those in the general population and that the diagnosis of cancer is less than to equivalent to that of the general population. There is a substantial discrepancy in the number of participants who are registered with NMFS who are diagnosed with schizophrenia compared to the number of participants without schizophrenia.

According to Brown et al. (2000), there is significant excess in the mortality of people with schizophrenia. The researchers conducted a 13-year follow up study of 370 participants (213 men and 157 women) who were identified as having schizophrenia. The
age range for men was 19-64 and women 16-66. The average age for men was 39 years and for women, 43 years. In the 13 years of the study, there were 79 deaths, with 58 people dying from natural causes including neoplasms (cancer), endocrine diseases (hormone, lymph, thyroid, and diabetes), nervous diseases (brain or nervous system), circulatory diseases (stroke, heart, and lungs), respiratory diseases, and digestive diseases compared to 19 from unnatural causes including suicide and accidents. Brown et al. asserted that the greatest unnatural cause of death for people with schizophrenia is suicide, followed by unrecognized medical disease, unhealthy lifestyle choices, poor medical compliance, refusal of medical treatment, and a small but significant mortality associated with antipsychotic medications. The remaining people died from unknown causes.

Harris and Barraclough (1998) reviewed 152 reports from a Medline search from 1966-1995 that explored 27 different mental conditions and treatment methods. Only 20 reports were exclusive to the study of schizophrenia; that is fairly limited, considering the date range of the search. Two studies by Mortensen and Juel (1990, 1993) were reviewed. Combining the studies, the participants included 36,000 men and women from nine countries. The study revealed significant excess in the mortality of people with schizophrenia from natural causes including infectious diseases, endocrine, mental, circulatory, respiratory, digestive, and genitor-urinary systems disease. There was significant mortality in women from neoplasms (cancer); however, the researchers noted a lower incidence of cancer in men due to the men being limited to 20 cigarettes per week in the hospitals during the 1950s.

Unnatural deaths were 4.3 times higher, with suicide being higher than expected. The average age for unnatural deaths was under 45 years. Mortensen and Juel (1990)
asserted that unnatural causes include accidents including falls, homicide, and “aspirations of food [that] may have been caused by psychotropic drugs” (as cited in Harris & Barraclough, 1998, p. 23).

In a cross-sectional study, Dickey et al. (2002) examined 26,332 Medicaid beneficiaries who ranged in age from 18-64 years to determine whether certain medical disorders were more prevalent among people who experience severe and chronic mental conditions and the effects of substance use on the mortality of people with severe and chronic mental conditions. The study concluded that there is a higher level of medical disease associated with individuals with schizophrenia and other mental disorders. Dickey et al. found that there was also a significantly higher prevalence the occurrence of two or more medical disorders that included heart disease, respiratory disease, gastrointestinal disorders, and infectious disease.

Dickey et al. (2002) highlighted several factors as contributing to the increase in medical disease, including the use of psychotropic medications with side effects of weight gain, diabetes, and hypertension. Other factors include poor attention to hygiene and grooming, which increases the risk of infectious disease, and excessive smoking, which contributes to stroke, heart disease, respiratory disease, and cancer. Along with Dickey et al. and Harris and Barraclough (1998), Joukamaa et al. (2006) questioned how much the use of neuroleptics and psychotropic medications contribute to the ill health of people with schizophrenia. Joukamaa et al. conducted a study with 99 people diagnosed with schizophrenia. In the 17-year follow-up study, 39 of the 99 participants had died. The researchers also found that the males had an excessive rate of cardiovascular disease and that the females had extremely high rates of respiratory and cerebrovascular disease. The unnatural cause of mortality was suicide. Joukamaa et al. also noted that lifestyle
choices of poor diet, smoking, hypertension, and body mass index greatly influence mortality in people with schizophrenia. In addition, it is well documented that “QT interval of the electrocardiogram is associated with fatal arhythmias” (p. 126) and that some antipsychotics can have side effects of sudden cardiac death and other respiratory diseases that result in death. Joukamaa et al. recommended more studies to determine the effects of antipsychotic medications on the mortality of schizophrenia.

Felker et al. (1996) gathered data from MEDLINE to demonstrate the existence of a lack of service to people with “mental illness” and to increase the awareness that better health care services are needed for these people. The researchers found 66 papers published in English between 1934 and 1996, plus one German paper from 1912. In general, Felker et al. found that psychiatric patients have higher rates of comorbidity and repeatedly demonstrate excess mortality from both natural and unnatural causes. Several papers in the study concluded that people under 40 are at the greatest risk for suicide. Like Dickey et al. (2002), Felker et al. (1996) also found a strong correlation between substance use in the unnatural causes of mortality and similar medical diseases that contributed to the natural mortality of people with schizophrenia.

Felker et al. (1996) asserted that many people with psychiatric conditions are underdiagnosed due to many factors, including a lack of availability of medical services, poor attention to their own health, a long history of stigma, and being “a disenfranchised minority” (p. 1356). In addition, the study found that many people who experience severe and chronic mental conditions do not feel comfortable going to the doctor; when they did, they received suboptimal care or worse.

Simpson and Tsuang (1996) reported in a 40-year follow-up study that natural causes of death for people with schizophrenia were cancer, cardiovascular disease, and
infectious disease. Unnatural causes included rates of suicide, accidents, and homicides that were significantly higher than for the general public. Males died at a rate of 1.34 times earlier than females.

Dembling et al. (1999) reviewed the records of 43,274 adults served by the Massachusetts Department of Mental Health (MDMH) between 1989 and 1994. The state vital records indicated a significantly higher frequency of deaths from unnatural causes, including accidental and intentional injuries, particularly poisoning by psychotropic medications. Natural deaths from cancer, diabetes, and circulatory disorders were significantly less frequently reported. In addition, the study found that a person who received services from MDMH died 8.8 years earlier than people in the general population.

Mortensen and Juel (1993) studied 9,156 people (5,658 men and 3,498 women) diagnosed with schizophrenia and concluded that cancer and cerebrovascular disease were the most common natural causes of death. Suicide accounted for 50% of unnatural deaths for men and 35% for women. According to Mortensen and Juel, suicide was 20% higher than in the general public, with fatal accidents occurring four times more frequently among people with schizophrenia. Death by homicide was 10 times greater for men with schizophrenia than for the general public.

In a follow-up to a 10-year study of 1,190 patients with schizophrenia who were selected from a computerized patient database, Allebeck (1989) estimated that participants experienced twice the rate of the general population for cardiovascular disorders. Suicide and violent death were the most common unnatural causes of death among the study population.
According to Wellesley Institute (2007), many people who are homeless suffer from schizophrenia and face up to a 35% higher risk of violence and sexual assault than people who are not homeless. The Wellesley Institute promotes better health and welfare for the homeless. In addition, the study’s authors recognized an excess in mortality from natural causes or medical disease and unnatural causes including suicide, homicide, and accidents.

In addition to the Wellesley Institute, Broadman (2006) stated that people who experience severe and chronic mental conditions, homeless, unemployed, and others die at a much younger age and experience an excess of violence, lifestyle risk factors, tobacco and substance use, inadequate medical care. The use of psychotropic medications in this population may lead to infectious/medical disease and severe safety issues that greatly impact the health of people who experience severe and chronic mental conditions and the homeless. Broadman stated that individuals who experience severe and chronic mental conditions are among the disenfranchised and often are underserved, unserved, and face countless obstacles in accessing medical care. In addition, the services accessed are generally inferior and outdated.

As a mental health professional, I am reminded of a time when I was employed as a case manager working with the homeless when an older adult who was homeless reported that he was given Benadryl™ for his diabetes by the community medical outreach team. Another time, a homeless older adult female reported that for her hypertension, she took aspirin that was dispensed by the community medical outreach team.

Broadman (2006, as cited in Wellesley Institute, 2006) and other mental health professionals conducted a performance-improvement project in which the authors
reviewed patient records from a behavioral health network and found medical underservice and excess mortality of people who experience severe and chronic mental disturbances. Broadman expanded the study to create a working model that integrated mental health services and medical care. Broadman recruited 76 participants from a survey sent to mental health facilities in Boston. The study concluded that people who experience severe and chronic mental health conditions have an excess of natural and unnatural deaths compared to the general public. In addition, people diagnosed with schizophrenia have higher lifestyle risk factors than people without schizophrenia. The risk factors include cardiovascular disease, tobacco smoking, and respiratory disease. Psychotropic medications, inadequate physical health care, poor assessments by medical professionals all contributed to the high excess of mortality.

Broadman (2006) highlighted several barriers encountered by the homeless and people who experience severe and chronic mental health conditions. One of the major barriers is access to appropriate and quality medical care. Very often, homeless people are underserved or misdiagnosed; have no medical insurance coverage; suffer stigmatization by healthcare professionals who may interpret the person’s symptoms as delusional, attention-seeking, or drug-seeking behavior; have financial hardships; do not have transportation; and because of their symptoms, have little to no motivation or energy to attend to their medical problems.

In summary, the studies reviewed in this section have primarily been from mental health facilities. All of the studies recognized excess mortality of people with schizophrenia and many factors that contributed to natural and unnatural deaths including lifestyle choices, misdiagnosis or inadequate medical care, ineffective assessments by medical and psychiatric staff, and psychotropic medications. The most common form of
natural death reported was from medical diseases, and the most common forms of unnatural death were from suicide, violent deaths, and accidents.

Stigma and Schizophrenia

This section examines the relationship between stigma and schizophrenia with particular focus on the issue of hallucinations. In general, people with schizophrenia are stigmatized. Cohen (2002, as cited in Whitaker, 2002) stated, “We still don’t understand [people who experience severe and chronic illness] and that lack of understanding makes us mean and arrogant, and makes us mislead ourselves, and so we hurt them” (p. 1). Farina, Gliha, Boudreau, Allen, and Sherman (1971) stated, “The mentally ill are disliked and degraded to a surprising degree” (p. 1). Along the same line, Peter Byrne (2001) defined stigma as a “mark of disgrace or discredit that sets a person aside from others” (p. 281). People who experience severe and chronic mental health conditions often report that their questions, concerns, and requests for medical attention or other needs are dismissed and disregarded, leaving the person with a sense of worthlessness and a diminished sense of self and identity (Bromley & Cunningham, 2004). Therefore, it is not surprising that many people with schizophrenia and other chronic mental conditions are diagnosed in the late stages of disease if at all (Brown et al., 2000; Byrne, 2001; McGrath & Jarrett, 2007).

According to James Hawkins, a geriatric psychiatrist who specializes in schizophrenia and palliative care,

If a person with a chronic mental illness such as schizophrenia reaches old age by not dying earlier from suicide, inattention to non-psychiatric medical illness, he or she usually faces death alone and is at least stigmatized in four separate ways; (1) they are dying and dying patients suffer from stigma; (2) they are elderly and in this society, there is a strong stigma against getting old and being elderly; (3) they have a mental illness; (4) commonly, elderly people with schizophrenia experience cognitive and/or memory impairments. (J. Hawkins, personal communication, March 20, 2008)
Hallucinations and Near-Death Awareness Hallucinations

In particular, I hypothesize that one reason people with schizophrenia may be stigmatized in hospice situations is for their hallucinations. Yet people who are dying commonly experience hallucinations.

The following section reviews the differences between hallucinations that are commonly associated with people who experience schizophrenia and hallucinations that are commonly experienced by people who do not have schizophrenia but report having nearing-death awareness (NDA), otherwise known as hallucinations at end of life.

As the dying process progresses in the final hours, days, and weeks, it is common for a terminally ill person to “make statements and gestures that seem to make no sense [and] to employ symbolic language” (Callahan & Kelley, 1992, p. 8). Dying people can also exhibit disorientation, hallucinations, confusion, disorganized thoughts, illogical verbiage, and delusions. These behaviors and symptoms are considered a normal part of the dying process, referred to as NDA (Callahan & Kelley, 1992). NDA is respected, honored, normalized, and considered sacred by end-of-life service providers. I have often observed that when a terminally ill patient who has a diagnosis of schizophrenia exhibits the same or similar behavior or symptoms, service providers generally consider them an escalation of psychiatric symptoms rather than a sacred, beautiful, and normal part of the dying process.

According to Callahan and Kelley (1992), the most commonly observed NDA behavior is the dying person’s hallucinating about a deceased person or unseen people when the dying person may or may not know. This dead person could be a spouse, friend, pastor, sibling, or parent. The dying person will sometimes talk or interact with unseen people, perform tasks or make gestures with nothing in their hands, or motion to an
unseen person or object. Another experience is when the dying person talks out loud about visiting a familiar place from the past and visiting with friends of that time who have since died. During my pilot study (Madrigal, 2007), an end-of-life service director stated that a caregiver reported to the staff at her agency that for more than an hour, she and her 85-year-old patient who was dying from cancer watched the dying woman’s favorite television show. The caregiver laughed when she told the staff how much she enjoyed the experience even though the television was not on.

Callahan and Kelley (1992) found that people with NDA generally do not experience any distress or fear about their hallucinations even if they do not recognize the deceased person. However, according to other research, some people have negative near-death experiences that involve extreme fear, isolation, loneliness, darkness, and demon-like visitors (Greyson & Bush, 1992; Moody, 1975).

One must ask, how do NDA hallucinations differ from the hallucinations experienced by people with schizophrenia? The similarities between the two types of hallucinations seem to include seeing things that others cannot see; interacting with people or entities that others cannot see or hear; hearing noises, tones, and voices; having tactile sensations or smelling or tasting objects without the presence of a source observable to others. Both groups can experience both positive and negative hallucinations.

Callahan and Kelley (1992) reported many stories of people experiencing hallucinations about interacting with unseen people or with a favorite deceased pet or relative; music playing; people on television talking to them; and watching their favorite television show when the television is not on. People with NDA can also experience negative hallucinations that are persecutory or that command them to perform acts that
The difference between the two kinds of hallucinations is that some people with schizophrenia report severe distress and functional impairments with their hallucinations. In addition, people with schizophrenia report that their hallucinations may command them to do something that has negative consequences and that the voices they hear are persecutory (APA, 2000). In general, people with schizophrenia tend to report that their hallucinations often continue for months or even years. This may result in the need for hospitalization if the individual becomes unstable due to the distress of the hallucinations. However, according to Intervoice Web site (2007), many people hear voices and tend to cope very well without psychiatric interventions. In addition, they find their voices inspiring and comforting. People who experience NDA tend to have hallucinations weeks or days before death that do not cause distress for most and tend not to be of a negative nature (Callahan & Kelley, 1992). However, Greyson and Bush (1992) reported that some people with NDA do experience distressing experiences that are unpleasant and even hellish.

I have personally observed a considerable discrepancy in how hallucinations are viewed among the two groups. I recall a female patient for whom a mental health agency provided case management services until she was diagnosed with a terminal brain tumor. She was admitted into a local skilled nursing facility. The patient complained of auditory and visual hallucinations and delusions that greatly troubled her. She coherently articulated the nature of her hallucinations and delusions. However, due to the progression of her medical disease and the severity of her hallucinations and delusions, the skilled nursing facility moved the patient, who was isolated and nonambulatory at this
point, into a room by herself so that she would not to disturb other residents. Baker (2005) explained that healthcare workers tend to “panic and seem unable to treat the patient with compassion because the mental illness gets in the way of caring for the dying person” (p. 299). The only human interaction received by the patient was from the nursing staff who fed, bathed, and changed her linens and from a mental health worker who visited occasionally. Sadly, the patient was estranged from her family with only her long-time companion (a stuffed animal) to keep her company at the end of her life. This patient’s end-of-life experience is not uncommon for people who experience schizophrenia or other mental conditions (Brown et al., 2000; Carney et al., 2006; Felker et al., 1996; Hawkins, 2002).

Medical staffs often are not trained or equipped to manage disturbing behavior. Some staff members feel that “there is no way he will come here and die here” (Felker et al., 1996; McGrath & Jarrett, 2007, p. 22). Often the medical staff has a difficult time understanding the complexity of how “mental illness” influences the behavior of a person. This lack of understanding can “lead to anger and frustration on the part of the healthcare providers” (Goldenberg et al., 2000, as cited in Baker, 2005, p. 300).

People with schizophrenia and people in late stages of dementia manifest many of the same symptoms, such as hallucinations, delusions, bizarre behavior, disorganized thoughts and speech, and paranoia (Sultzer, 2004; Wilson, Krueger, Kamenetsky, & Tang, 2005). Many times people with schizophrenia and people with dementia experience disregard and devaluation as a result of their symptoms or lack of medical staff understanding their nonordinary state of consciousness. Although these groups of people manifest similar symptoms, the medical staff interacts very differently with a
person who has a terminal illness and a secondary diagnosis of schizophrenia compared to a person with dementia.

The attitude and response discrepancies give rise to questions such as, what is the difference between a person who is in the late stages of dementia who strikes out because they are trying to defend against a perceived threat, and a person who has schizophrenia and strikes out trying to defend against a perceived threat? Why do staff members respond differently to those with dementia than to those with schizophrenia? According to Link, Cullen, Frank, and Wozniak (1987, as cited in McGrath & Jarrett, 2007), it is not uncommon for someone in the late stages of dementia or other cognitive impairments to report to the staff that they are fearful that someone is poisoning their food. This comment is considered fairly normal for persons in the late stages of disease and care providers generally do not pathologize the person as delusional or psychiatrically decompensated. Despite the claim made by the DSM-IV-TR (APA, 2000), “It should be noted that most individuals with schizophrenia are not more dangerous to others than those in the general population” (p. 304). “They [staff members] respond very differently to the person who has a history of schizophrenia because of the perceived “fear of dangerousness that is associated with the negative stereotype of being mentally ill” (Link, Cullen, Frank, & Wozniak (1987, as cited in McGrath & Jarrett, 2007, p. 27).

Unfortunately, even when such a patient has a terminal illness, the stigma continues from mental health staff who are not familiar with end-of-life issues and from end-of-life service providers who are not familiar with schizophrenia (McGrath & Jarrett, 2007). Brown et al. (2000) stated that patients and caregivers do not recognize medical disease and that healthcare professionals can miss medical diagnoses. For example, two women who lived in a long-term psychiatric setting “died from lobar pneumonia, having
been examined by a doctor shortly before death. In neither case was pneumonia diagnosed or antibiotics prescribed” (p. 214). In addition, a 57-year-old man died of cardiac arrest. When the outpatient psychiatric notes were examined, it was noted that the man had an increase in confusion in the “two weeks before admission to the hospital, stuporous and hypothermic” (Brown et al., 2000, p. 214). As mentioned above, very often the concerns of people with schizophrenia or other severe and chronic mental health conditions are often discounted and disregarded.

McGrath and Jarrett (2007) conducted several interviews that focused on providing palliative care in a mental health setting. The participants were asked to describe their experiences in providing care for terminally ill patients who had a secondary diagnosis of a severe and chronic mental condition. The researchers concluded that the participants were frustrated by their lack of knowledge about palliative care, limited resources, legal restraints, and problems interfacing with palliative care services.

Foti et al. (2005) reported, “Despite advances in the use of psychiatric advance directives, often times the mental health system neglects to inform their consumers” (p. 585) of the benefits of having an advance directive. Some of the factors behind this type of neglect include: some mental health providers and family members avoid discussing end-of-life care with persons with schizophrenia for fear of provoking a negative reaction or decompensation. Some people believe that people with schizophrenia cannot comprehend the dying process or manage the decisions that need to be made when they are diagnosed with a terminal illness. Mental health staff and case managers are not informed and lack end-of-life care knowledge (Foti et al., 2005).
Areas of Growth

Though hospices may not provide sufficient care for persons diagnosed with schizophrenia, and health issues of such populations may not be sufficiently addressed, there are some signs that the mental health profession is beginning to improve in these areas. Broadman (2006) created a full-service pilot program as part of the study to determine whether persons who were homeless and had access to full-service medical and psychiatric care would attend to their medical and psychiatric issues more often. The program included a nurse practitioner who was available 24 hours a day to attend to patient needs and offer education on a variety of issues and topics.

The pilot program provided for patients to be seen by a primary care physician for further medical evaluation as needed. The results of the pilot study were very impressive in that the homeless and other participants began to attend to their health and psychiatric issues and utilize health-related resources more often. Emergency room visits decreased by 42%. Excess mortality continued, however, and the study acknowledged that more research was needed to develop better, more accessible resources for the homeless and people who suffer from severe and chronic mental health conditions.

One such resource in the community that is providing services to the homeless is called Ottawa Inner City Health Project (OICHP), created by Podymow et al. (2006) as a pilot study as part of a campaign to provide medical services to the homeless who were dying. Podymow et al. asserted that the mortality of the people living in shelters or homeless is high and that many homeless people are found dead in public places; others are found in home dwellings, or arrive dead at the local emergency room. The researchers recognized that many people who experience schizophrenia and other serious mental health conditions do not attend to their medical or physical health issues.
The aim of the study was to demonstrate that medical services could be provided in a shelter-like setting to people with a terminal illness and severe mental health conditions. The participants were 28 homeless, terminally ill patients who were admitted and died at the shelter-based medical facility. The age at death was reported as 34-47 years. Many of the participants had “co-existing substance abuse issues along with some that had AIDS and hepatic disease” (p. 81). The pilot program successfully demonstrated that effective medical care can be provided in a shelter for the homeless.

Foti (2003) created a program called “Do It Your Way”: End-of-Life Care for Persons with Serious Mental Illness. The program was implemented by the Massachusetts Department of Mental Health (MA-DMH). The participants consisted of 47,000 men and women from 58 cities and towns diagnosed with severe and persistent mental health conditions and severe functional impairments. The aim of the study was to build coalitions among healthcare providers, cross-train hospice and mental health workers, educate the community on the importance of advance care planning for people who experience severe and chronic mental health conditions, and more. The study reported an increase in awareness about mental health patient rights and advance care planning. With the success of this program came advancements in research and assessment tools for end-of-life care for people who experience severe and chronic mental health conditions that are paving the way for future programs. In a recent conversation with Foti, she stated that there is still great need to improve end-of-life care to people who experience severe and chronic mental health conditions (M. E. Foti, personal communication, April 17, 2008).

Broadman (2006), Foti (2003), and Podymow et al. (2006) describe three examples of programs that incorporate mental health services and end-of-life care for
people with serious mental health conditions. In addition, Angela Baker (2005) of the National Institutes of Health and National Institute of Neurological Disorders and Stroke recognized the great need for mental health professionals to be involved in the end-of-life care, treatment, and mental health process of terminally ill patients, especially the severe and persistent mentally challenged. Baker is an experienced psychiatric nurse practitioner who specialized in psychiatry. She proposed that to add to the quality of life of people who are terminally ill and have a history of schizophrenia, mental health professionals, including mental health nurses and nurse practitioners who specialize in psychiatry, must be part of the end-of-life care team to provide the quality of care received by others.

According to Baker (2005), death “knows no difference between those who suffer from mental illness and those who do not” (p. 302). Baker further asserted that by “providing understanding and compassion, knowledge and expertise, will and hope” (p. 302), the psychiatric team of professionals can greatly enhance the quality of life and death experience of people with schizophrenia and others with a chronic and persistent mental disturbance history.

Foti (2003) also demonstrated that “cross-training mental health staff with palliative care and end-of-life service providers with mental health would greatly enhance the quality of life for the terminally ill person, and would also add confidence and quality of work for the staff” (p. 667).

Naomi Feil, M.S., A.C.S.W., the developer of Validation (1992), created a technique for working with people who experience disoriented states and are “trapped in a world of fantasy” (p. 9). Feil also discovered that no matter how disoriented a person may be, “It is a deep human need: to die in peace” (p. 17). Feil developed an effective communication method called validation to assist disoriented people who were living in
skilled nursing facilities. She realized that “with no stimulation from the outside world, [disoriented people] become one of the living dead in our nursing homes” (p. 17).

Validation method is a developmental theory based on the basic belief that “to validate is to acknowledge the feelings of the person” (p. 10) without judgment. Acknowledgment of the person’s feelings decreases aggressive behavior, reduces stress, and increases the person’s dignity and happiness. Validation staff members are trained to listen, validate the disoriented person’s feelings, and use specific techniques for each of the four stages of disorientation: (1) malorientation; (2) time confusion; (3) repetitive motion; and (4) vegetation. For each stage, validation techniques can be used by trained staff to help the person find resolution.

Finally, on the cutting edge of integrating end-of-life care and mental health, the United Kingdom has created Alzheimer Cafés that emphasize valuing the person’s feelings, environment, perceptions, realities, and beliefs (Miessen & Jones, 2008). Miessen and Jones (2008) also recognized the importance of incorporating person-centered values of behaving with genuineness, being authentic, and relating to the person in the here-and-now. These approaches add greatly to the quality of the relationship between the staff and the person.

Summary of the Review of the Literature

This review of the literature examined the current state of our knowledge about end-of-life service providers who may be underserving people with a terminal illness and schizophrenia. This chapter provided a definition of terms, a brief overview of the possible genetic and biological causes of schizophrenia. This chapter considered alternative views of schizophrenia, therapeutic communities, the benefits of the psychosocial model, natural and unnatural causes of mortality for people with
schizophrenia, the comorbidity that may contribute to excess mortality, and the financial costs of schizophrenia.

Several studies were reviewed to determine the natural and unnatural causes of death among the target population. I demonstrated that part of the issue has to do with how people with schizophrenia are treated in this society. I briefly explored the issue of stigma along with contributing factors that may interfere with quality medical care. The differences between schizophrenic hallucinations and NDA hallucinations experienced by others at end-of-life were examined. In addition, this chapter reviewed three programs that contribute to quality of life of people with schizophrenia by interacting with them with dignity viewing them as human beings capable of taking active roles in their own lives.

Some organizations are greatly contributing to quality of life and creating new programs that can offer specialized services needed at end-of-life for people with schizophrenia. Certainly one solution is cross-training mental health and palliative staff to provide more comprehensive services that will add to the quality of dying a person can experience.

After examining the literature reviewed for this study, there is sufficient evidence that demonstrates the importance of conducting this research study to explore underservice to people with schizophrenia. This may facilitate a greater understanding of the availability and quality of end-of-life services, determine how to increase the awareness of end-of-life service providers and mental health professionals, and improve the quality of end-of-life care for this population.
CHAPTER 3

METHOD

In this study, I interviewed end-of-life service providers about the availability and quality of end-of-life care for persons with schizophrenia. The Interview method was selected because it allows the researcher to have a professional interchange or structured conversation on a common area of interest (Kvale, 1990). The Interview method allows the researcher to explore complex real-life events, situations, individuals, groups, organizations, cultures, and political phenomena (Creswell, 2003; Kvale, 1990; Yin, 2003). This approach allows the researcher to interpret the meaning of central themes or categories in the life world of the subject (Kvale, 1990). The Interview method provides a forum and the flexibility to capture the qualitative experience and knowledge of the interviewee without quantifying the data. A variety of data collection measures can supplement interviews, such as field notes, and observations (Creswell, 2003).

Research Design and Justification

The initial findings from my practicum study (Madrigal, 2007) suggested that these end-of-life service providers underserve people with schizophrenia and that the managers were unaware of ways to provide services to people with schizophrenia. No psychiatric history is taken upon admission or during the initial evaluation. No statistical information is kept on psychiatric diagnosis or histories. The managers asserted several times that they provide services to everyone and no one is treated differently. They showed relatively little knowledge about schizophrenia and felt that a special program could be created that would provide services for people who experience severe and chronic mental health conditions. The managers asserted that they provide good services with a team of highly trained physicians, social workers, nurses, caregivers, and
consultants. The managers also stated that they have ongoing weekly and monthly trainings and treatment team meetings in which they discuss each case and set up individualized care plans. However, the managers also stated that they have never had a workshop or training on schizophrenia or other serious mental health conditions. The managers also stated that they do community outreach, but not in shelters or board and cares for people with serious mental health conditions. In general, the managers were unaware of working with many people with a terminal illness and a secondary diagnosis of schizophrenia.

This study therefore expanded on the earlier study by including a larger selection of end-of-life service providers. In the practicum I interviewed only 3 hospice managers face-to-face. I extended the sample to include 10 end-of-life service managers. This larger sample demonstrated a greater perspective on end-of-life care being provided by agencies. I elected to interview managers instead of nurses, social workers, or caregivers because managers may have the most extensive and comprehensive knowledge about their organizations. I conducted semistructured interviews to gather the data. The interview included 17 questions (see Appendix A) that inquire about the services, training, and other related information that pertains to end-of-life service providers for terminally ill people who experience schizophrenia.

Participants

The 10 participants were recruited from end-of-life service agencies in Southern California. The first source of participant recruitment was the local chapter of a national organization that provides education and end-of-life services. I selected this association because they have a large membership of end-of-life service providers, and I am a member of the association. I requested permission from the organization’s chairperson to
post an invitation on the organization’s Web site for members to participate in the study.  
The second source was several hospice organizations that are listed on a hospice resource  
Web site that I retrieved from the Internet. I phoned and asked to speak with the  
organization’s administrator, manager, or director. If no one was available, I left a voice  
message stating that I was conducting a research project focused on the availability and  
quality of end-of-life care for persons with a terminal illness and schizophrenia. I left a  
contact number so that the director could contact me. Once 10 managers were recruited  
from these two sources, I did not pursue any other participants or interview appointments.  
I set up the interviews for the following weeks.  

Data Collection  
Data collection used a variety of sources, including interviews, observations, agency brochures, email discussions, other documents, and reviews of agency Web sites. Using multiple data collection sources allows for a more comprehensive exploration of the availability and quality of end-of-life care for persons who experience schizophrenia and expands the understanding of what agencies are providing services and related information. I met managers individually at their offices to conduct the interviews.  

Data Collection Instruments  
Semistructured face-to-face interviews were conducted at the participants’ offices  
using the interview tool (See Appendix A). I selected face-to-face over telephone or mail  
interviews because the in-person approach allows observation of relevant behaviors,  
activities, and environmental conditions that contributed to the richness of the data.  
To strengthen internal validity, I asked a variety of end-of-life service providers  
and mental health service providers to review the list of questions. The specialists  
included: 2 geriatric hospice psychiatrists, 3 psychologists, 1 director of a local hospice, 1
hospice social worker, and 1 grief counselor. They offered some feedback on end-of-life terms but overall felt that the questions were appropriate to gather the data to answer the research questions.

Procedures for the Interview

On the day of the interview, I met the participant at his or her office. The interviews ranged from 20 to 30 minutes depending on the responses to the questions.

I explained the interview process during the first few minutes of the interview and had the participant review the interview questions (see Appendix A) and review and sign the consent form (see Appendix B). I asked the participant for permission to tape record the session for accuracy. I read one question at a time and waited for the participant’s response. I took notes on any significant comments and observations. At the end of the interview, I asked whether the participant had any questions or needed clarification of anything (Kvale, 1996).

The data were transcribed into a report within 24 hours and archived in the case study database folder pending analysis. I assigned a code to the individual to ensure confidentiality. All data were secured in a password-protected computer. A follow-up email or card was sent to the participants’ personal email addresses that they provided during the interview process to thank them for their participation. In addition, I sent them a separate email with the transcribed summary of this report.

Other Data Sources and Procedures

Sources

Other data collection sources included agency brochures and Web sites. I obtained these sources by asking the directors of the agency for any information that would add
value to the research study in “collaborating and augmenting the evidence from other sources” (Yin, 2003, p. 87) such as the interviews, telephone calls, and emails.

**Service Provider Web Site and Brochure Review**

The purpose of the Web site and brochure review was to note the stark contrast between the services to which the general public has access compared to the possible underservice to which terminally ill people with schizophrenia have access.

The publications used by a variety of end-of-life service providers as informational material include depictions of a serene nature setting or some other environment that appears to be peaceful, calm, and caring. The Web site and brochures are illustrated with vibrant photographs of smiling patients, positioned very closely to caregivers or family members, who have their hands on the patient to demonstrate the caring, loving, supportive touch one deserves when dying. Most, if not all, of the publications mention compassion, dignity, and respect as the building blocks or foundation of the organization being represented. Most of the publications contain statements such as, “No one needs to die alone.”

According to this writer, the case studies presented in this dissertation, and the literature review, some terminally ill people with schizophrenia have not been touched or spoken to in a gentle, supportive, loving manner in decades. Many terminally ill people with schizophrenia also do not have any supportive family, friends, or caregivers. Many terminally ill people with schizophrenia go through the dying process being neglected, demeaned, and disregarded. Most of the publications do not mention mental health patients at all, and it is the opinion of this writer that if facilities accept these patients, they are segregated from others in the facility as stated in earlier chapters of this study.
Data Analysis

According to Kvale (1996), the “qualitative research interview has been depicted as the description and interpretation of themes in the subjects lived world” (p. 187). He also mentioned that there is no template to extract the meanings of the interview but that themes emerge from the analysis of the interview data (Kvale, 1996). Kvale recommended five general approaches: (1) meaning condensation, (2) meaning categorization, (3) narrative structuring, (4) meaning interpretation, and (5) ad hoc methods. Meaning condensation and meaning categorization convert the transcribed interview data into short statements and categories; narrative structuring and meaning interpretation use the transcript to gain “more extensive and deeper interpretations of meaning” (p. 201). I used a combination of these approaches, with a thematic or categorizing approach, for data analysis.

The first step of data analysis taken happened during the interview when I asked for clarification of the participants’ responses. The interviews were audiotaped, transcribed, and the transcriptions checked for accuracy against the original audiotapes.

Creswell (2003) also recommended a few procedural strategies in “making sense out of the text and image data” (p. 190). He recommended triangulation, peer debriefing, member-checking, and using an external auditor. Triangulation is using several different sources of information to build a justification for themes. Peer debriefing is important in ensuring the accuracy of the study by allowing someone other than the researcher to evaluate the qualitative study. I used member checking by having the participants review the transcribed version of the interview. The participants had the opportunity to ask questions and provide feedback on the content of the transcribed data. I used an outside
auditor to review the final research report. My dissertation committee was my outside auditors.

The data analysis for this study included following several suggestions by Kvale (1996), Creswell (2003), and my dissertation committee. In the first step, I retrieved the transcribed data from the interview study database and carefully reviewed it to familiarize myself with the content of each interview, then reduced the transcribed data to briefer statements while maintaining the content and meaning of the data by eliminating redundancy, repetitions, tangents, and nonessential material from the transcribed data. The second step involved creation of a matrix and listing each question that was asked during the interview session. In the third step, I entered the condensed transcribed data, observations, field notes, and other related material from each interview into the matrix. The fourth step analyzed the data systematically by examining the responses to each question, observations, and other findings. I analyzed the data to elucidate the most significant categories that emerged from the data. The categories are summarized in the findings section of this study. The structure of the questions and the responses from the directors allowed for most of the directors’ responses to be left in the original format. There are only a few questions that needed to be condensed due to the directors’ varied responses. I include a condensed narrative of the directors’ responses in Chapter 4.

Maximizing the Quality of a Qualitative Study

To maximize the quality, reliability, and integrity of this qualitative study, I employed the four common tests of construct validity, internal validity, external validity, and reliability (Yin, 2003) described below.

The construct validity test ensures that a researcher uses a variety of data gathering measures, follows a chain of evidence, and has a colleague or dissertation
committee member read the study. Internal validity tests are aimed at decreasing a researcher’s inferences or errors in misinterpretations and improving the analysis of the study. External validity focuses on the study being applicable to other communities and generalizable to the greater population. Reliability is an indication that any researcher can recreate or replicate the study and obtain similar results (Yin, 2003).

**Construct Validity**

The first source that I used to increase the validity of this qualitative study was a variety of data gathering measures that included interviewing 10 end-of-life service directors. The second source of information included field notes, observations, and other documents from each interview that I recorded and reviewed. The third way to increase the construct validity is to have the participants review the data for accuracy. In addition, I had my dissertation committee review the study for accurate use of methods and to assist me in producing valid research (Yin, 2003).

**Internal Validity**

Achieving internal validity is one of the most difficult aspects of conducting an interview study (Yin, 2003). According to Lukoff and Edwards (2000), internal validity is “the extent to which alternative explanations of the phenomenon can be excluded” (p. 15). To increase internal validity, Lukoff and Edwards (2000) suggested collecting data systematically, utilizing repeated measures, conducting multiple qualitative studies, collecting relevant evidence, and having trained colleagues review interpretations and conclusions. In this study, I collected relevant data from a variety of end-of-life managers and had my committee review the data and analysis.
External Validity

External validity is an indication of whether the findings in an interview study can be generalized to the greater community or extended beyond a particular interview study (Yin, 2003). This study offered a structured outline of how the data were collected and analyzed. With this outline, future studies can be made.

Reliability

Reliability is an indication that a similar study conducted with other participants would produce similar results so that later investigators can replicate the study based on the data and process that are provided in the qualitative study (Yin, 2003). To increase the reliability of this exploratory interview study, I adhered to the methods as indicated above by using a variety of data gathering measures, followed a chain of evidence, and had a trained colleague review the interview study. In addition, I had the participants review the data collected for accuracy. I analyzed the collected data systematically to ensure that no incorrect inferences were made. This minimized the likelihood of errors or biases in the collection and interpretation of data.

Confidentiality

The participants’ confidentiality was maintained by assigning an alphabetic code to the interviews such that only the researcher would know to which participant the data related. All data about the end-of-life agencies will be kept confidential as well. All transcribed data and emails between the director and myself are secured in a password-protected computer. The agency brochures are secured in a locked file cabinet in the researcher’s residence.

This study is designed to minimize as much as possible any potential physical, psychological, and social risks. Although very unlikely, there are always risks in
research, which the participant is entitled to know in advance of giving his consent, as well as the safeguards to be taken by those who conduct the project to minimize the risks. The potential risks to human participants are limited because I interviewed end-of-life service directors about the availability and quality of end-of-life care for terminally ill people with schizophrenia. The interview questions focused on the agency, service delivery, staff training and education, and community outreach. No personal questions were asked. Assigning a specific alphabetic code to represent the participant and the agency assisted in protecting the confidentiality of the participants. Each participant had the opportunity to clarify responses with the researcher during the interview session. No patients were interviewed.
CHAPTER 4

FINDINGS

Chapter 4 presents the findings from this study. I contacted 40 local end-of-life service agencies, organizations, and associations using two sources. The first source of participant recruitment was the local chapter of a national organization that provides education and a variety of end-of-life services. I selected this association because they have a large membership of end-of-life service providers, and I am a member of the association. I requested permission from the organization’s chairperson to post an invitation on the organization’s Web site for members to participate in the study. The second source was several hospice organizations that are listed on a hospice resource Web site that I retrieved from the Internet.

Of the 40 agencies contacted, 13 stated that they did not provide end-of-life services, even though they were listed as end-of-life service providers; 13 directors or agencies did not return my phone calls; 2 agencies had disconnected phone numbers; 2 service providers were not located in Southern California, even though they had Southern California telephone numbers; and 10 directors met the criteria for this study.

The research data presented in this section have been reduced from full statements into simpler statements. The full statements are available upon request.

The objectives of this study were to explore what end-of-life agencies are providing palliative and end-of-life care to persons with schizophrenia, what services are being provided to dying persons with schizophrenia, and what measures directors in the end-of-life service industry believe can help increase or improve the awareness of and amelioration of this situation.
The data in this section are divided into four main groups: participant demographics; admission criteria; staffing, training, and education; and mental health and community outreach. Overall, the interview content for some of the questions asked is consistent with each director due to the agencies following similar end-of-life standards of care.

Participant Demographics

The directors were asked a series of questions to determine the demographics of their agencies. This category focused on data from the following interview questions:

- How many years has your agency been in operation?
- Who are your referral sources?
- What funding sources does your agency accept?

Each of the directors stated that they follow Medicare guidelines. The agencies had been in business for an average of 10-12 years. According to the participants, the referral sources are generally hospitals, skilled nursing facilities (SNFs), physicians, family members, other hospices, and assisted living centers. The funding sources accepted are Medicare, Medi-cal, insurances, and private pay. Some patients are nonfunded. See Table 1 for the demographic data.
Table 1

*Agency Data*

<table>
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<th>Participant</th>
<th>Years in Business</th>
<th>Referral Sources</th>
<th>Funding Sources</th>
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<td>Hospitals, SNF, physicians, family, assisted living centers</td>
<td>Medicare, Medi-cal, insurance, private pay, nonfunded</td>
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</tbody>
</table>
Admission Criteria

The directors were asked a series of questions regarding the admission criteria for their agency. This category focused on data from the following interview questions:

- What is the criterion for admission to your agency?

- Does your agency admit patients with “mental illnesses” such as schizophrenia, bipolar illness, recurrent major depression, or dementia such as dementia of the Alzheimer’s type?

  If you do not accept terminally ill patients with secondary diagnosis of a “mental illness,” to what kinds of facilities do you refer such patients?

- Does your agency obtain a psychosocial history and within what time frame? Who generally obtains the psychosocial history?

- In your opinion, are people with schizophrenia capable of making end-of-life decisions about their care?

Nine of the 10 end-of-life service directors stated the criteria for admission to their end-of-life care agency was a terminal illness with a prognosis of six months or less. Two physicians must certify this, usually the patient’s primary doctor and the medical director of the agency. The family, conservator, or patient must give informed consent. One director stated that the only requirement for admission to her agency was that the patient needed care-taking services due to the physical or cognitive impairments that interfered with the patient’s ability to feed him- or herself and attend to grooming and hygiene. All of the directors stated that they admit patients with a secondary diagnosis of a “mental illness”, as long as the primary diagnosis is a terminal illness.

The 10 directors stated that their agency obtains a psychosocial history with timelines ranging from 1-5 days after admission. Nine of the 10 directors stated that Master’s level or licensed clinical social workers obtain the psychosocial history. One director stated that she obtains the psychosocial history for her agency. Although the 10 directors stated that they accepted patients with a secondary diagnosis of “mental
illness”, specifically schizophrenia, 9 of the 10 stated that they did not have any data on the number of people with schizophrenia for whom they had provided services. One director stated that all medical and psychiatric diagnoses are listed on the patient’s fact sheet, and all of the others stated that the insurance companies only allow billing for a primary diagnosis so there is no reason to keep data on secondary diagnoses. In addition, the 10 directors stated that having a secondary diagnosis of schizophrenia is not a reason to withhold end-of-life care from someone who has a terminal illness.

The directors had a variety of responses to the question, “Are people with schizophrenia capable of making end-of-life decisions about their care?” Only 3 directors said yes. However, the responses were followed up with comments to the effect that this is true only if the people with schizophrenia are taking their medication and are stable. Three directors did not feel qualified to answer the question. Five stated that the patient would generally have a durable power of attorney or conservator to assist with or make end-of-life care decisions for the patient.

Staffing and Training

The directors were asked a series of questions about staffing and training. This category focused on data from the following interview questions:

- What disciplines make up the end-of-life care team?
- Has your staff had training and education about schizophrenia or other psychiatric conditions? If so, what kind? Who provides the training? Are your social workers Bachelor or Master’s level?
- How does your staff manage any psychiatric escalations with the patient?
- Does your agency have a consulting psychiatrist or consulting psychiatric nurse to evaluate and manage psychiatric episodes?
- If one of your patients is taking psychotropic medications to improve the quality of life, who manages the psychotropic medications?
Nine of the 10 directors stated that the end-of-life care team consisted of a medical director, registered nurses, licensed vocational nurses, social workers (Master’s level and licensed clinical social workers), chaplains, home health aids, and volunteers. Two of the 10 directors stated that they also contracted with a massage therapist and a music therapist. One participant stated that her agency contracts with an occupational therapist, physical therapist, and speech therapist. One of the 10 directors stated that her staff consisted of a director and caregivers. One of the 10 participants stated that the agency program director was a psychologist. Staff trainings and in-services were reported as very minimal. One of the 10 directors stated that weekly trainings are conducted by the program director, who is a psychologist. All 10 directors stated that the staff had the greatest knowledge about depression, anxiety, and dementia but very little to none of the staff had training in schizophrenia or other psychiatric conditions. All 10 directors stated that they did not have a psychiatrist or psychiatric nurse practitioner on staff. Three directors stated that they either contracted with outside sources or consulted with the skilled nursing facilities’ physicians.

The directors stated that they manage behavioral or psychiatric escalations by using a variety of resources. First and foremost, they assess the escalating patient to see whether there might be a physical reason, such as pain, for the escalation. They would rule out if the person were getting close to dying and determine whether the escalation was the normal progress toward death. End-of-life staff would also use medication (Haldol, Prozac, Ativan), massage, or music to calm the person’s escalation. The directors overall stated that at the end of life, patients typically deal with many emotional and psychological factors such as fear, unresolved issues, and family dynamics. When a psychiatric evaluation is needed, 2 of the 10 directors stated they would call a psychiatric
team to evaluate the person for safety. Overall, most of the directors stated that the medical director of the agency or the patient’s family physician monitors all psychotropic medications. Two of the 10 directors stated that Hospice Pharmacia manages their patients’ medication, always monitoring for interactions and possible side effects. One of the 10 directors stated that the family or patient manages all of the patient’s medication.

Mental Health-Related Questions

The directors were asked a series of questions pertaining to patient mental health. This category focused on data from the following interview questions:

- In your opinion, are the hallucinations and delusions of a person with schizophrenia different from visioning or near-death awareness hallucinations and delusions? If so, how are they different?
- Does your agency do outreach work in the community to group homes, board and cares, shelters, prisons, or psychiatric facilities?
- Do people with mental illness present different challenges than people without mental illness?
- Do you have any suggestions you would like to share about improving the service delivery for people with a terminal illness and schizophrenia?

Most of the directors had a difficult time answering the following question: In your opinion, are the hallucinations and delusions of a person with schizophrenia different from visioning or NDA hallucinations and delusions? Five of the 10 directors did not feel qualified to answer the question. The responses of the remaining five directors were fairly similar. They stated that people with a terminal illness and schizophrenia experience hallucinations and delusions as generally disturbing and frightening. In contrast, the directors stated that in general, for the dying person who did not have schizophrenia, the hallucinations and delusions were calming. Interestingly, the five directors did not consider visioning or NDA to be hallucinations or delusions. One
director stated that her staff used diversion techniques with people who have a chronic mental health history, such as schizophrenia. Diversion techniques include, but are not limited to distracting the person, changing the subject, or assisting the person in engaging in an activity.

In general, the 10 directors stated that visioning or NDA is a normal part of the dying cycle. The staff generally joins in or encourages the dying patient, as it seems to keep the person in a more peaceful state. The five directors who stated that they did not feel qualified to comment on hallucinations and delusions of someone with a history of schizophrenia were very comfortable and confident in discussing visioning and delusions related to the dying process. Table 2 shows the directors’ responses to the question, In your opinion, are the hallucinations and delusions of a person with schizophrenia different from visioning or NDA hallucinations and delusions?
<table>
<thead>
<tr>
<th>Participant</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>I’m not the right person to ask this question to.</td>
</tr>
<tr>
<td>B</td>
<td>With schizophrenia, the hallucinations and delusions are frightening and disturbing. Visioning is comforting and calming to the dying person. It is a relief for them.</td>
</tr>
<tr>
<td>C</td>
<td>I don’t feel qualified to answer this question.</td>
</tr>
<tr>
<td>D</td>
<td>When people who are dying have hallucinations and delusions are hopeful. The staff joins in with the person. It seems to keep them in a more peaceful state. They can be very comforting. Hallucinations and delusions of schizophrenia, we use diversion tactics. Sometimes we join in to, but if the person is distressed we divert their attention.</td>
</tr>
<tr>
<td>E</td>
<td>I can’t answer that. The nurses have more experience at that than I do.</td>
</tr>
<tr>
<td>F</td>
<td>Schizophrenia has not come up. Visioning is very calming and comforting to people without schizophrenia. The person is in between this world or the other world.</td>
</tr>
<tr>
<td>G</td>
<td>I understand it is different. The person having visioning is having it for different reasons then the person with schizophrenia. The person with schizophrenia is frightened and upset by hallucinations.</td>
</tr>
<tr>
<td>H</td>
<td>I’m sure they [hallucinations and delusions] are different, but I don’t have enough experience with these people [schizophrenia] to have an opinion about it.</td>
</tr>
<tr>
<td>I</td>
<td>Yes, they are different. Sometimes sorting out what is mental illness and what are end-of-life issues can be difficult.</td>
</tr>
<tr>
<td>J</td>
<td>I’ve haven’t encountered that. Maybe someone else can answer that question.</td>
</tr>
</tbody>
</table>

Nine of the 10 directors stated that they do community outreach with residential care for the elderly board and cares, medical clinics, and group homes. No community outreach is done in psychiatric facilities, prisons, or homeless shelters. One participant said the agency was planning to have an open house soon but that was all the community outreach that her agency had done so far. One director said that she was conducting teleconferences for the public. This led to the question of, Do people with mental disorders present different challenges than people without mental disorders? The 10
directors answered, yes, that they felt people with mental disorders do present different challenges than people without mental disorders (see Table 3). The factors included poor psychotropic medication compliance, increased psychiatric symptoms, a tendency for people with mental disorders to wander away from the facility, increased family dynamics, and poor coping skills. One director felt that she did not have enough experience to comment on this question.

Table 3

*Participant Responses: Do People with Mental Disorders Present Different Challenges Than People Without Mental Disorders?*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Yes, they [people with mental disorders] do not want to take their medications. They wander off and don’t want to stay on hospice. We will refer them to home health if this happens.</td>
</tr>
<tr>
<td>B</td>
<td>Yes, if they [people with mental disorders] don’t want to take their medications. It is difficult to work with them.</td>
</tr>
<tr>
<td>C</td>
<td>Yes, at end-of-life, there is so much going on with the patient and the family. Family dynamics can increase. Some do not want the patient on hospice and other do. It is a challenging time.</td>
</tr>
<tr>
<td>D</td>
<td>Yes, due to increased symptoms, makes it difficult to work with them [people with mental disorders.]</td>
</tr>
<tr>
<td>E</td>
<td>Yes, the family can make it very difficult. Sometimes the family is a wreck. It’s like a ripple in the water.</td>
</tr>
<tr>
<td>F</td>
<td>Yes, their [people with mental disorders] perception of reality of what is happening and how the family deals with it is really different.</td>
</tr>
<tr>
<td>G</td>
<td>Yes, if they [people with mental disorders] are not medicated, they are a challenge.</td>
</tr>
<tr>
<td>H</td>
<td>I’m sure they [people with mental disorders] do, but I don’t have enough experience with these people to have an opinion about it.</td>
</tr>
<tr>
<td>I</td>
<td>Yes, sometimes sorting out what is mental illness and what are end-of-life issues can be difficult.</td>
</tr>
<tr>
<td>J</td>
<td>I think all people at end-of-life have a variety of challenges whether they are mentally ill or not.</td>
</tr>
</tbody>
</table>

The final question asked whether the participants had any suggestions for improving service delivery to people with a terminal illness and schizophrenia. Six of the 10 directors mentioned the need to educate the medical community and the public in
general about end-of-life care. Two directors stated that there is a need to create an end-of-life team or program that includes mental health staff. One director said that she did not have any suggestions and that she never thought about it. One director recommended using less medication. See Appendix C for more extensive responses.
CHAPTER 5
DISCUSSION

The objectives of this research study were to (1) explore what end-of-life care agencies are providing end-of-life services to persons with schizophrenia, (2) gain an in-depth understanding from end-of-life service providers on what services are being providing to persons with schizophrenia, and (3) increase the awareness of end-of-life service providers of possible underservice to people with schizophrenia.

As a mental health professional working with persons who experience schizophrenia, I am interested in exploring who provides end-of-life care to people with mental disorders such as schizophrenia. This chapter summarizes the findings presented in Chapter 4.

As a reminder, end-of-life care is a philosophy of care and not a place where a person goes and stays until death. An important factor to remember in reviewing these findings is that end-of-life care is provided wherever the person calls home.

A finding I highlight first is the common characteristics and similarities of the participants. This is very important factor of end-of-life care because in general the director sets the tone for the staff and the agency. The directors were articulate, compassionate, gracious, empathetic, with a genuine interest in assisting with this study. The directors were all women. They presented themselves with the utmost professionalism. I was greeted in a friendly manner at the interview site, which was the directors’ offices. The agencies were neat, clean, organized, and decorated with peaceful, meaningful artwork. The directors gave me brochures, informational flyers and other informative, end-of-life care resources about their agency, staff, and the dying process. Each director was relaxed and willing to talk as long as was needed.
Overall, I was impressed with each director’s deep desire to provide comfort and care for the dying persons and their families. Each director communicated staff dedication in educating the community about end-of-life care and how they can work side-by-side with other healthcare professionals to provide the best possible care for the dying and their families and friends. At the end of the interview session, each director stated that she had increased in awareness about providing end-of-life care for terminally ill patients with a history of schizophrenia. With this awareness, the directors were open to a dialog about how the service delivery could be improved.

A second significant finding is that the directors stated that their agencies are willing to provide end-of-life care to terminally ill persons with a secondary diagnosis if the person is referred to their agencies. The directors also stated that they would not discriminate against those who have a secondary diagnosis of schizophrenia.

The third finding is that all of the directors stated that their agencies’ funding sources include Medicare, Medi-cal, insurances, private pay, and donations. This is an important finding because most terminally ill people with schizophrenia subscribe to Medicare, Medi-cal, and many individuals have private insurance.

The forth finding is that there are no statistical data that document secondary diagnoses of complex mental disorders, such as schizophrenia. Therefore, there is no way to validate or challenge the directors’ claims that their agencies provide end-of-life care for terminally ill persons with schizophrenia.

A fifth finding is that the directors stated that they provide services to terminally ill patients with schizophrenia; however, the majority of the staffs have had no training with schizophrenia or other complex mental disorders. In addition, the agencies have no psychiatrists, psychiatric nurse practitioners, or mental health staff who specialize in
schizophrenia or other complex psychiatric disorders. The only end-of-life care staff training is on managing depression-, anxiety-, and dementia-related diseases relevant to the dying process. According to 9 of the 10 directors, the end-of-life care social workers do not have extensive experience working with complex psychiatric cases. As a result of these findings, I conclude that the staff would have a difficult time effectively assessing and managing psychiatric escalations and symptom management of terminally ill persons with schizophrenia.

The sixth significant finding is that most of the directors indicted that they did not feel qualified or know the distinction between hallucinations and delusions of someone experiencing schizophrenia and someone who was experiencing visioning or NDA hallucinations and delusions. In general, most of the directors who were able to discuss the difference between the two stated that visioning or NDA is a normal progression of the dying process and that the staff does not interfere with this process. In contrast, the directors felt that persons who experience schizophrenia hallucinations and delusions need to be contained, distracted, diverted, and assessed for possible safety risks to the staff.

As mentioned in the review of the literature, medical staffs often are not trained or equipped to manage disturbing behavior. Some staff members feel that “there is no way [a person with schizophrenia] will come here and die here” (Felker et al., 1996; McGrath & Jarrett, 2007, p. 22). Often the medical staff has a difficult time understanding the complexity of how mental disorders influence the behavior of a person. This lack of understanding can “lead to anger and frustration on the part of the healthcare providers” (Goldenberg et al., 2000, as cited in Baker, 2005, p. 300). Given the findings mentioned
above, we must wonder how likely end-of-life service providers are to address the mental health needs of the terminally ill person with schizophrenia.

We must wonder why one set of hallucinations and delusions is normalized and the other set of hallucinations and delusions treated differently from the ones that are normalized. We must also wonder whether end-of-life service providers feel safe in the presence of people with a secondary diagnosis of schizophrenia. How likely are terminally ill persons with schizophrenia to be admitted into an agency if they are psychiatrically unstable, especially if the staff has not had any training in schizophrenia or other complex psychiatric disorders? It is imperative to explore these questions to disclose possible biases or barriers that some end-of-life service providers may experience.

Other findings were that all of the directors stated that the referral sources were hospitals, skilled nursing facilities, physicians, family members, and assisted living centers. The criteria for admission to hospice or other end-of-life service agencies are a terminal illness, two physicians having certified that the person has six months or less to live, and the patient’s understanding that no curative treatment will be provided. In addition, with the normal progression of the terminal illness, the person will continue to decline with a negative outcome eventually causing death. Patients must sign forms indicating that they understand the nature of hospice and that no curative measures will be administered. Another factor for admission is that a psychosocial history be obtain by a social worker within 1 to 5 days of admission. Nine out of 10 directors stated that the disciplines of the end-of-life team consist of a medical director, registered and vocational nurses, home health aids, chaplains, social workers, and volunteers. One director stated that her staff consisted only of caregivers. Overall, the greatest suggestion that most of
the directors shared with me was the importance of increasing education about the nature of hospice and how it works in conjunction with other healthcare providers.

Limitations and Delimitations

The results of this qualitative study are subjective. It is important to note that there is no way for me to know whether a director presented truthful information or whether the remarks made may have concealed an organization’s tendency to underserve patients in the end-of-life care system. Without end-of-life service providers collecting data on secondary psychiatric diagnoses, there is no evidence whether they do or do not provide end-of-life services to people with a secondary diagnosis of schizophrenia. Another limitation is that the sample size is fairly small, considering that there are thousands of end-of-life agencies and organizations all over the world. The participants were randomly selected from a variety of end-of-life agencies and organizations in the Southern California area. Finally, a limitation of this study is that more research is needed to continue to gather data on the likelihood of people with a terminal illness and a secondary diagnosis of schizophrenia getting referred for end-of-life care. This is my fourth study on this subject and I still do not feel confident that people with mental disorders such as schizophrenia are being referred for end-of-life care.

An important delimitation of this study is that the participants were randomly selected to participate in this study. I elected to interview managers instead of nurses, social workers, or caregivers because managers may have the most extensive and comprehensive knowledge about their organizations. Another delimitation is the focus on what services are being provided to people with schizophrenia. There are many other mental health disorders that I could have explored in this study, such as mood disorders or chronic substance abuse. However, based on my previous work (Madrigal, 2006,
2007), there appears to be a tendency to underserve people with schizophrenia. The purpose of this study was to explore whether this population is underserved.

Future Research

The suggestions presented by the directors in this study prompted various ideas for future research. We know that to be referred for end-of-life care, a person must have a terminal illness with a life expectancy of 6 months or less. Two physicians must certify this, usually the patient’s primary doctor and the medical director of the agency. Therefore, the availability and quality of end-of-life care begins with physicians referring people with schizophrenia to end-of-life service providers. Without a physician referral, the end-of-life service provider cannot provide services. Therefore, a suggested area for future research is to explore how often physicians refer terminally ill patients with schizophrenia for end-of-life care.

Another area of research might focus on developing an end-of-life care educational program for medical schools. The goal would be to educate medical students on the importance of working collaboratively with end-of-life service providers to improve the patients’ quality of care and quality of death. The directors stated that very often the physicians wait too long to refer the patient for care. By the time the patient is referred, they may only have a few days before they die. Again, if physicians were educated on the benefits of referring a patient earlier, they could greatly improve the quality of care and the quality of death for the patient.

Finally and most important, a study that would greatly improve service delivery for terminally ill people with schizophrenia would be the development of a pilot program that includes mental health service providers and end-of-life service providers. This comprehensive team would include end-of-life service providers to provide end-of-life
care while the mental health staff attends to the person’s mental health issues and overall end-of-life psychological needs. This pilot program could spur the creation and training of other comprehensive specialized teams to provide quality of care for terminal ill patients with a secondary diagnosis of schizophrenia. I believe a program like this would have improved the quality of life and quality of death for Judy and countless others who have not received referrals for end-of-life care. Again, it seems that the process needs to begin with the medical physicians referring the patient for end-of-life care. Once the patient is admitted for end-of-life care, a comprehensive team such as this could be contracted with or sent to provide the specialized services needed at the patient’s end of life. This would help us move toward a situation in which people would not die alone or in pain because they would be receiving the humane care that many people receive at the end of their lives.
References


APPENDIX A

INTERVIEW QUESTIONS

Interviewee’s Code:

Title:

1. How many years has your agency been in operation?

2. Who are your referral sources?

3. What are the criteria for admission to your agency?

4. Does your agency admit patients with “mental illnesses” such as schizophrenia, bipolar illness, recurrent major depression, or dementia such as dementia of the Alzheimer’s type?

   If you do not accept terminally ill patients with secondary diagnosis of a mental illness, to what kinds of facilities do you refer such patients?

5. What funding sources does your agency accept?

6. Who obtains a psychosocial history and within what time frame?

7. What disciplines make up the end-of-life care team?

8. Do you have data that shows how many people who had a terminal illness and a secondary diagnosis of schizophrenia has your agency provided services?

9. In your opinion, are people with schizophrenia capable of making end-of-life decisions about their care?

10. Has your staff had training and education about schizophrenia or other psychiatric conditions?

    If so, what kind?

    Are your social workers Bachelor or Master’s level?

    Who provides this training?

11. How does your staff manage any behavioral or psychiatric escalations with people?

12. Does your agency have a consulting psychiatrist or consulting psychiatric nurses on staff to evaluate and manage psychiatric episodes?

13. If one of your patients is taking psychotropic medications to improve the quality of his/her life, who manages these psychotropic medications?
14. In your opinion, are the hallucinations and delusions of a person with schizophrenia different from visioning or near-death awareness hallucinations and delusions? If so, how are they different?

15. Does your agency do outreach work in the community to group homes, board and cares, group homes, shelters, prisons, and psychiatric facilities?

16. Do people with mental illness present different challenges to services than people without mental illness?

17. Do you have any suggestions you would like to share about improving the service delivery for people with a terminal illness and schizophrenia?

Is there anything else you would like to share with me?
APPENDIX B

INFORMED CONSENT FORM

**Title of Study:** Availability and Quality of End-of-Life Care for Persons with Schizophrenia

**Principal Researcher:** Mary Madrigal
Doctoral Candidate, Saybrook Graduate School and Research Center
Contact information: 714-504-8840 (cellular)
E-mail address: Mmadrigal2@socal.rr.com

**Brief Description of Proposed Research:**

This purpose of this research project is to explore the availability and quality of end-of-life care for persons with schizophrenia. The participants will be directors, managers, or administrators of end-of-life care agencies who can provide the greatest range of information about the end-of-life services that the agency provides to the community. Mary Madrigal, a graduate student of Saybrook Graduate School and Research Center, is conducting the interview and research as part of her doctoral dissertation.

**Procedures of the Study:**

You will participate in an interview ranging from 20-30 minutes. You will be asked a series of 17 questions that focus on the services that your agency provides and the training of the agency staff. The discussion will be tape-recorded and transcribed to a computer program. The content of the discussion will be clarified with the participant and transcribed within 24 hours. A summary of the interview will be available upon your request. This is a ground-breaking study that has never been conducted before. Your participation in this research study will provide vital information in determining the availability and quality of end-of-life care for persons with schizophrenia. The relevant legal consent forms will be completed with you before the interview begins.

**Potential Benefits of the Study:**

The anticipated benefit of participating in this research study is the opportunity to participate in a ground-breaking study that will gather vital data about the availability and quality of end-of-life care for persons with schizophrenia. In addition, what is learned from the study may assist in the development of specialized programs, greater community awareness of a potential underservice to people with schizophrenia, and to the end-of-life and mental health literature.

**Risks of the Study:**
The study only gathers information; therefore, no risks are expected from this study. If you have questions or concerns that arise during this study, please let the researcher know immediately. You can decide to end your participation in this study at any time. If there is any question you do not want to address, the question can be skipped.

Confidentiality:

All of the information obtained during this study is strictly confidential. A unique letter of the alphabet will be assigned to you on the day of the interview. All of the written, transcribed, and tape-recorded information will be stored in a locked filing cabinet. Only the researcher and dissertation committee will have access to your information. Any research summary reports that are sent to you will have no identifying information.

Summary Report:

Upon conclusion of this study, a summary report of the general findings will become available. If you would like a copy of the report, please provide the address to which you would like it sent (your e-mail or postal address):

[---Postal address---]

[---City, State, Country, Zip---]

Participation Statement

Mary Madrigal has reviewed the above information with me. I understand what is involved in this study. I am signing this consent form voluntarily. I understand I can change my mind at any time during the study. If I have any further questions or concerns, I may contact:

Mary Madrigal at [redacted] or e-mail address: [redacted] if I have further questions. If I am still concerned about the study I will contact:

Dr. Tom Greening, Dissertation Committee Chair, [redacted] or [redacted]
Consent of Principal Investigator:

I have explained the above procedures and conditions of this study, provided an opportunity for the research participant to ask questions, and have attempted to provide satisfactory answers to all questions that have been asked in the course of this explanation.

______________________________________________________
Signature                              Date

______________________________________________________
Print name

Consent of the Participant:

If you have any questions of the principal researcher at this point, please take this opportunity to have them answered before granting your consent. If you are ready to provide your consent, read the statement below, then sign, and print your name and date on the line below.

I have read the above information, have had an opportunity to ask questions about any and all aspects of this study, and give my voluntary consent to participate.

______________________________________________________
Signature                              Date

______________________________________________________
Print name
## APPENDIX C
### DETAILED RESPONSE MATRIX

<table>
<thead>
<tr>
<th>Participant</th>
<th>Criteria for Admission</th>
<th>Does Your Agency Admit Patients With a Mental Disorder?</th>
<th>Does Agency Obtain a Psychosocial History? If so, who obtains it and within what time frame?</th>
<th>Are People With Schizophrenia Capable Of Making End-Of-Life Decisions?</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Terminal Illness that is certified by two physicians with 6 months or less to live. Signed consents that no curative measures will be administered.</td>
<td>Yes</td>
<td>Yes Social worker and nurses obtain the psychosocial within 48 hours of admission</td>
<td>I’m Not Qualified to answer that question</td>
</tr>
<tr>
<td>B</td>
<td>Terminal Illness that is certified by two physicians with 6 months or less to live. Signed consents that no curative measures will be administered.</td>
<td>Yes</td>
<td>Yes Director obtains the psychosocial within 24 hours of admission</td>
<td>Yes, If Stable and medicated</td>
</tr>
<tr>
<td>C</td>
<td>Terminal Illness that is certified by two physicians with 6 months or less to live. Signed consents that no curative measures will be administered.</td>
<td>Yes</td>
<td>Yes Social worker obtains the psychosocial within 3-5 days of admission</td>
<td>Yes, Sometimes they have a DPOA or Adv. Dir.</td>
</tr>
<tr>
<td>D</td>
<td>Terminal Illness that is certified by two physicians with 6 months or less to live. Signed consents that no curative measures will be administered.</td>
<td>Yes</td>
<td>Yes Social Worker, Nurses, or Director obtains the psychosocial upon admission.</td>
<td>I’m Not Qualified to answer that</td>
</tr>
<tr>
<td>Participant</td>
<td>Criteria for Admission</td>
<td>Does Your Agency Admit Patients With a Mental Disorder?</td>
<td>Does Agency Obtain a Psychosocial History? If so, who obtains it and within what time frame?</td>
<td>Are People With Schizophrenia Capable Of Making End-Of-Life Decisions?</td>
</tr>
<tr>
<td>-------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------</td>
</tr>
<tr>
<td>E</td>
<td>Terminal Illness that is certified by two physicians with 6 months or less to live.</td>
<td>Yes</td>
<td>Yes  Social worker obtains the psychosocial within 5 days</td>
<td>No. They usually have a conservator</td>
</tr>
<tr>
<td></td>
<td>Signed consents that no curative measures will be administered.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>Terminal Illness that is certified by two physicians with 6 months or less to live.</td>
<td>Yes</td>
<td>Yes  Social worker and obtains the psychosocial within 3 days of admission</td>
<td>No. Due to their mental illness the family makes decisions or the person has a DPOA</td>
</tr>
<tr>
<td></td>
<td>Signed consents that no curative measures will be administered.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>G</td>
<td>Terminal Illness that is certified by two physicians with 6 months or less to live.</td>
<td>Yes</td>
<td>Yes  Social worker obtains the psychosocial within 5 days</td>
<td>I don’t feel qualified to answer that question.</td>
</tr>
<tr>
<td></td>
<td>Signed consents that no curative measures will be administered.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>H</td>
<td>Terminal Illness that is certified by two physicians with 6 months or less to live.</td>
<td>Yes</td>
<td>Yes  Director obtains the psychosocial upon admission</td>
<td>Yes, when they are Okay</td>
</tr>
<tr>
<td></td>
<td>Signed consents that no curative measures will be administered.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>Terminal Illness that is certified by two physicians with 6 months or less to live.</td>
<td>Yes</td>
<td>Yes  Social worker or nurses obtain the psychosocial upon admission</td>
<td>Most have a family member of DPOA</td>
</tr>
<tr>
<td></td>
<td>Signed consents that no curative measures will be administered.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant</td>
<td>Criteria for Admission</td>
<td>Does Your Agency Admit Patients With a Mental Disorder?</td>
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</tr>
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<td>-------------</td>
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<td>-------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------</td>
</tr>
<tr>
<td>J</td>
<td>Terminal Illness that is certified by two physicians with 6 months or less to live. Signed consents that no curative measures will be administered.</td>
<td>Yes</td>
<td>Yes Social worker or nurses obtain the psychosocial within 24 hours of admission</td>
<td>Depends on the doctor making the decision</td>
</tr>
</tbody>
</table>