

FINDING HOPE IN A CONTEXT  
OF SEVERE MENTAL ILLNESS

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A Project Report

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Doctor of Ministry

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by

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## CHAPTER ONE

### INTRODUCTION

The purpose of this project was to explore the importance and meaning of hope in the context of a group of persons who were experiencing serious mental illness. Semistructured interviews were completed to furnish data, which in turn were coded using an ethnographic research design. The study was focused around the question “How do persons with severe mental illness perceive hope?”

#### Finding Hope in a Context of Severe Mental Illness

This project studied the meaning of hope in the day-to-day lives of twenty people who carried a diagnosis of schizophrenia and were patients at a state-run psychiatric hospital. The interviews were conducted by this writer, using an interview schedule (see Appendix 2) and lasted an average of roughly five minutes. Participants were asked to recall times when they felt hopeful. They were asked about their experiences of hope on a day-to-day basis.

All of the interviews were audiotaped and transcribed verbatim. An ethnographic analysis of the text-based data was conducted by a coding team consisting of four chaplains in the Pastoral Services Department of Central State Hospital, along with one retired department chaplain. Themes that emerged through the coding process are discussed in the Project Report. They are examined and contrasted with some of the presuppositions this researcher brought to the project.

The results of the research were used by the Pastoral Services Department to

begin the development of a spiritually-based clinical pathway, which will allow the chaplains or other caregivers to nurture hope in pastoral interventions more efficiently and effectively. This stage of the clinical pathway links the patients' hope to a commitment to treatment compliance. The development of this stage has the benefit and distinction of being both patient-derived and research-based. In addition, this study fulfills Pastoral Services' ongoing commitment to performance improvement, and provides a framework for further study of hope in the context of other illnesses (i.e. Bipolar illness, severe depression) encountered in this setting. The research also met a wider hospital goal to advance the study of the efficacy of its treatment programs.

### Definitions

In the interest of clarity, brief definitions of four key terms of the study are provided. Each are discussed in depth in the chapters which follow, but it is helpful at the start of the report to give a sense of how these terms are understood and used by this writer.

#### **Hope**

Hope is a basic energy of life, by which we live out the promise and possibilities of our life in the world. For many, it is based on trust in a God who ultimately guarantees the future. In the Christian perspective held by this writer, hope is based on the promise of resurrection, which is future, but empowers life and growth in the present, and helps us to overcome the obstacles of the present moment and moves us toward the future with courage, patience, confidence and expectation. This understanding of hope provided the lens through which this researcher, and to a large extent the entire research team, viewed and interpreted the narratives of the patients. Distinctive views of hope emerged through

the study as patients spoke of their experiences. These differing perspectives were instrumental in the development of the first stage of the spiritually oriented clinical pathway.

### **Schizophrenia**

Schizophrenia is a severe mental illness, characterized by a dysfunction of the thinking process, such as hallucinations and delusions, and withdrawal from the outside world. Years of research have shown that schizophrenia is a biologically based brain disease. The most recent advances in brain imaging have confirmed imbalances of two brain chemicals, dopamine and serotonin, in those who suffer from schizophrenia. Dopamine is responsible for emotions and motivation; serotonin acts as a messenger and stimulates muscle movement, switching nerves on and off. The brains of people with schizophrenia have elevated dopamine and serotonin activity. All of the patients in the study carried a diagnosis of some form of schizophrenia.

### **Ethnographic Research**

The intent of ethnographic research is to obtain a holistic picture of the subject of study with emphasis on portraying the lived-out experiences of individuals by observing them and interviewing them and others whose lives have bearing on theirs.<sup>1</sup> In this project, the researchers used interviews with the patients as the primary source of data, but also were informed by their own experience as clinicians in the day-to-day life on the patient units. This study used ethnographic research to produce insight into ways caregivers can foster transforming interventions and alliances with people who suffer from and struggle with mental illness.

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<sup>1</sup>Jack Creswell, Research Design: Qualitative and Quantitative Approaches (Thousand Oaks, California: Sage Publications, Inc., 1994), 163.

## **Spiritually-Based Clinical Pathway**

In this project, a spiritually-based clinical pathway is defined as a set of interventions, agreed upon by consensus both of researchers and patients, that sets out a step-by-step approach for providing spiritual care. Clinical pathways identify which outcomes are most desirable and delineate the interventions (or sequence of interventions) that are necessary to achieve these outcomes effectively and efficiently. To develop the spiritually-based clinical pathway, the hope themes that surfaced in conversations with patients were ranked in terms their frequency. These rankings were used to provide the chaplain or other caregiver with first-stage information about issues that are most likely to be on the mind of a patient who is experiencing schizophrenia. If clinicians desire good outcomes for patients, they have to uncover what motivates a patient's desire to comply with treatment and move toward wellness. This is what the project does. It provides a tool for clinicians to quickly gain access to the fundamental motivational force – hope, and to link that motivational force to treatment compliance.

### **Background to the Study**

My thoughts on how we find hope in the context of persistent mental illness are focused on three distinct but mutually interlocking concepts, all of which are necessary for coping. These concepts are:

*Creativity* -- to address the problems that arise out of the tragic structure of the world.

*Compassion* -- in advocacy, fighting the destructive power of despair, and supporting those in need.

*Community* -- which creates an atmosphere of acceptance and stability and the context in which healing can happen.

My thesis is that through creativity, compassion, and community, persons with persistent

mental illnesses can build hope for fulfilling lives. I use the work of Wendy Farley<sup>2</sup> and John Swinton<sup>3</sup> to help flesh out these concepts. I set the scene in which the hope building happens, and then elaborate on the spiritual dimensions of each concept in the light of the theologians I have chosen.

My interest in the study of hope in the context of persistent mental illness arises out of my work for the past decade as a chaplain at Central State Hospital in Louisville, Kentucky, a state-run, inpatient, acute-care psychiatric hospital. Many of the patients suffer from severe, long-term illnesses. I remember being struck initially at how desperate their conditions were, and wrestling with my own feelings of hopelessness for their situation. What could I say to encourage them? I became interested in finding what enables people to hope and how to apply it to my context. The challenge for me as a pastoral caregiver seemed to be to guide the person through despair and back to hope.

My focus for this project is on schizophrenia, so it is fitting to give a little background on this illness. The challenge I encounter most in my work with patients is finding or nurturing hope in their struggle with mental illness. In my work as chaplain, I see patients everyday on the hospital units or in my office, and I wonder where they find hope to go on. Many of the patients say that hope is what keeps them going. My project goal was to provide a tool for clinicians to quickly gain access to the fundamental motivational force – hope, and to link that motivational force to treatment compliance.

Schizophrenia is a severe mental illness, one which E. Fuller Torrey calls “the

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<sup>2</sup>Wendy Farley, Tragic Vision and Divine Compassion: A Contemporary Theodicy (Louisville: Westminster/John Knox Press, 1990).

<sup>3</sup>John Swinton, Resurrecting the Person: Friendship and the Care of People with Mental Health Problems (Nashville: Abingdon Press, 2000).

most tragic disease in western civilization.”<sup>4</sup> It is characterized by a dysfunction of the thinking process, such as hallucinations and delusions, and withdrawal from the outside world. As John Swinton says,

What makes schizophrenia different from many other mental health problems is not that it is frequently serious, but that it is frequently seriously misunderstood. Unlike some other mental health problems that people seem to understand and to a degree empathize with, schizophrenia presents a challenge that seems to exceed the cognitive and compassionate capabilities of the majority of the population.<sup>5</sup>

Years of research have shown that schizophrenia is a biologically based brain disease.

The most recent advances in brain imaging have confirmed imbalances of two brain chemicals, dopamine and serotonin, in those who suffer from schizophrenia. Dopamine is responsible for emotions and motivation; serotonin acts as a messenger and stimulates muscle movement, switching nerves on and off. The brains of people with schizophrenia have elevated dopamine and serotonin activity.

Despite these findings, many people still believe poor parenting or weak willpower causes schizophrenia. Contrary to popular belief, schizophrenia is not “split personality,” and the vast majority of people who suffer from schizophrenia are not dangerous to others. While many researchers emphasize the medical/biological aspects of schizophrenia, it is also important to point out that the symptoms are experienced in a very human, very social context, which has a profound influence on how well a person is able to maintain a basic level of functioning. Where it was the early tendency of research to emphasize the social aspect to the neglect of the biological, it is now important to reassert the importance of community and context in the care of people who have mental

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<sup>4</sup>E. Fuller Torrey, Surviving Schizophrenia: A Family Manual (New York: Harper & Row, 1988), 14.

<sup>5</sup>Swinton, Resurrecting the Person, 29.

illnesses. As Swinton says,

...it is crucial to recognize that mental health problems, while quite possibly biological in origin, are also human experiences that happen to real people within specific social contexts. As such, they are open to a multitude of different understandings and interpretations, all of which have implications for the ways in which they are perceived and the forms of treatment approaches deemed legitimate for dealing with them.<sup>6</sup>

To suffer from a profound and debilitating illness in the context of a society that has little understanding often makes symptoms worse. An ethical response would call for the education not only of the one who suffers from the illness but also the society that through its lack of understanding increases the suffering of the ill person.

People with schizophrenia often experience both positive symptoms (psychological disturbances “added” as a result of the disorder, e.g., delusions) and negative symptoms (psychological capabilities the patient has “lost,” e.g., initiative). The illness appears to be cyclical, worsening in periods known as relapse and improving during remission. At times, people suffering from schizophrenia appear emotionally healthy and stable. However, during the acute or psychotic phase, people with schizophrenia cannot think logically and may lose all sense of who they and others are. For a person with schizophrenia, such everyday tasks as thinking clearly, controlling emotions, making decisions, and relating to others are challenges. Symptoms commonly associated with schizophrenia include:

*Positive Symptoms*

Delusions  
Hallucinations  
Disorganized thinking  
Agitation

*Negative Symptoms*

Lack of drive or initiative  
Social withdrawal  
Apathy  
Emotional unresponsiveness

At any given time, between 1% and 2% of the world’s population, including 1 to 2

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<sup>6</sup>Ibid., 61.

million American adults, are afflicted with schizophrenia. E. Fuller Torrey, M.D. has said, "If a worse disease than schizophrenia exists, it has not come to light."<sup>7</sup> Men and women are at equal risk for developing this illness; however most males become ill between the ages of 16 and 25, whereas females usually develop symptoms between the ages of 25 and 30.

I think of patients who come to my office--one woman who talks about going to see her children (she has none) at the adoption agencies around town, and complains about the people on the unit who keep stealing pieces of her brain. Another man, an elderly man with schizophrenia, prays every time he comes to the chapel that he will be healed from his illness. A patient on another unit believes God told him to kill his brother "like Abraham had to kill Isaac" and that the commands that God gives him (which are usually to streak or throw water on people) are punishments for not being faithful enough. Do they need therapy, better medicine, or something entirely different? Usually the best answer involves some of each.

A person who has schizophrenia sees reality differently, and may not be worried about whether his or her perceptions of what is real actually are real. While this can create considerable difficulty in accomplishing basic life tasks, it also can give rise to certain insights about God and contemporary culture. Many persons who have schizophrenia experience God's power as "not only a benevolent God of love, but also a wrathful, horrendous, punitive force. Whether He (sic) appears one or the other seems partly, but not totally, dependent on the condition of the patient."<sup>8</sup> I would add that the

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<sup>7</sup>Torrey, Surviving Schizophrenia, 66.

<sup>8</sup>David Terry Bradford. The Experience of God: Portraits in the Phenomenological Psychopathology of Schizophrenia (New York: Peter Lang, 1984), 222.

religious heritage and family function/environment give the person the words they use to convey their thoughts. Some religious traditions are fertile soil for pathology.

Whether the God a person with schizophrenia experiences is loving or wrathful (or both), the defining feature is power.

If there were a feature of God's presence more common during the religious experience of schizophrenia than for those who have not been given a schizophrenic diagnosis, it would be His (sic) horrendous, convulsive power. This may be viewed in at least two ways. It could be considered a manifestation of psychopathology specific to schizophrenia, or a reflection of the schizophrenic experience having retained a more complete array of the primordial features of the experience of God than that preserved and offered by most contemporary currents within the Judeo-Christian tradition.<sup>9</sup>

Some people who suffer from schizophrenia know how ill they are and this knowledge causes them great pain. Often patients feel like there is no place for them in the world, that no one wants them, and that things aren't going to get better, at least as far as their illness is concerned. What can the chaplain do to help them as a pastoral caregiver? Many of these feelings are rooted in reality. How can one point them to a more hopeful assessment of this situation?

Schizophrenia is a devastating illness, both for patients and for their families. My intention in my Doctor of Ministry project was to find ways in which people found hope in the context of their illnesses, so that I could point both patients and their caregivers toward these avenues of hope. Using the perspectives of patients, an initial stage of a spiritually-based clinical pathway was generated that allows the chaplain or other caregiver to nurture hope in pastoral interventions more efficiently and effectively.

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<sup>9</sup>Ibid., 222.

## CHAPTER TWO

### PROJECT CONTEXT

It is fitting at the beginning of an ethnographic study to give some sense of the context in which the study will be conducted. This is the intention of this chapter.

Central State Hospital is an acute care, 129-bed psychiatric hospital under the auspices of the State of Kentucky, Cabinet for Health Services, Department of Mental Health and Mental Retardation. Central State Hospital provides psychiatric care for residents of 15 counties, representing two mental health catchment areas:

Seven Counties Services – Jefferson, Trimble, Henry, Shelby, Oldham, Spencer,  
Bullitt

Communicare – Grayson, Hardin, Meade, Marion, Breckenridge, LaRue, Nelson,  
Washington

Central State Hospital is noted for the ability to treat persons diagnosed with severe mental illness and adult males with mental illness who are involved in the criminal justice system. The hospital follows a biopsychosocial model that includes a multidisciplinary treatment team approach with patient/family participation. This model recognizes the interrelationship of medical and physical problems; the individual's personality; and the impact of social relationships on a patient's illness and recovery. Each patient is assigned a psychiatrist, psychologist, social worker, team nurse, and an activity therapist. When indicated, other mental health professionals such as pastoral, vocational and substance abuse counselors may participate in the treatment planning.

## Physical Settings

The Central State Hospital campus covers 70 acres, with 16 buildings totaling 373,000 square feet. The following facilities are located on campus:

- Modern facility of five treatment units with 100 beds
- A self-contained, secure, forensic unit with 29 beds
- Therapeutic activities building accessible through an enclosed walkway to main hospital
- Large gymnasium
- On-site laboratory, radiology, pharmacy, and dental services
- An intermediate care, 50-bed facility that provides residential and respite services for adults with developmental disabilities
- The Center for Human Resources Development
- The Center for Rehabilitation and Recovery, a 38-bed personal care home operated by Seven Counties Services, Inc., a local non-profit mental health services provider.
- Offices for community mental health consumer and family organizations, such as the National Alliance for the Mentally Ill, Louisville Chapter, the Kentucky Consumer Advocates Network (KyCAN), and other government offices

## Demographics

### **The Neighborhood**

It is interesting to note that Central State Hospital used to be as far away as one could get from Louisville and still be in Jefferson County. It is no wonder, then, that this

is where the “Central Kentucky Lunatic Asylum” would come to be. The facilities, initially used for the housing and rehabilitation of juvenile delinquents, were taken over for the care of persons with mental illnesses in 1873. How ironic that this part of Jefferson County is now a very wealthy area, populated with residents who often complain about the presence of a mental hospital which was here long before their houses were even built.

### **The Patients**

The individual most likely to receive treatment at Central State Hospital is a thirty-one to thirty-five year old white male, involuntarily committed, at the hospital a median length of fourteen days, experiencing an acute episode of a major mental illness, such as schizophrenia. Patients chosen for this study were all current patients at the time of the interviews and carried a diagnosis of schizophrenia. Out of thirty-seven possible candidates for the study, twenty participated. Of the patients who participated, fourteen of the patients carried a diagnosis of paranoid schizophrenia, and the other carried a diagnosis of schizophrenia NOS (not otherwise specified).

Since 1873, Central State Hospital has been committed to serving the special needs of those experiencing the pain and difficulties of mental illness. Our current staff continues this tradition of excellence, dedication, and service to provide patients with the highest quality of psychiatric care and treatment available. Working with our patients, our common effort is toward easing the troubling thoughts, feelings, and behaviors which bring them to the hospital, so that they may rejoin their family and friends in the community as soon as possible.

## Pastoral Services

The primary mission of the Pastoral Services Department is to provide informed religious/spiritual care and counseling for adults with mental illness, chemical dependency, or mental retardation during their stay in the hospital. Furthermore, the department provides spiritual care for the hospital staff through support ministry and referral to other resources

### **A Brief History of Pastoral Services**

Although very little source material exists, it appears that religious services have been provided at the Hospital since its inception in 1873. One source says that during the superintendence of H. K. Pusey, M.D., (1882-1896) "On Sunday the same room (as used for the Asylum Balls) serves as a chapel where Catholic, Methodist, Presbyterian, & Baptist services are held in rotation. Attendance is not compulsory, the patients being allowed to go or remain as they please."

In the Twenty Seventh Annual Report of the Central Kentucky Asylum for the Insane, September 30, 1899, one can read that:

Religious services have been conducted regularly every Sunday afternoon by members of the different Protestant denominations and once a month by Rev. McParland of the Catholic Church, for his members. There has been a good attendance and close attention. Lasting truths have been taught by preachers and priests. The interest and devout attention shown by these unfortunate ones is an evidence that religion is a vital subject that should engage the individual conscience of every one.<sup>1</sup>

Not much is known about the early 1900's, except that in the 1920's there were allegations of abuse and neglect, with employees challenging the sanity of the hospital's director, and officials questioning the integrity of employees.

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<sup>1</sup> "Twenty Seventh Annual Report of the Central Kentucky Asylum for the Insane" (Annual Report, dated September 30, 1899), Archives, Central State Hospital, Louisville.

The 1940's brought the beginnings of nationwide mental health reform, and renewed interest in the support of the community. A clinically trained chaplaincy training came as a result of the collaboration of Richard V. Wood (a dedicated Presbyterian layman) and Wayne E. Oates of the Southern Baptist Theological Seminary. In 1946 Wayne E. Oates first came to Central State Hospital. He was an instructor at the Southern Baptist Theological Seminary, and held worship services in the hospital's dining room. At that time the hospital had reached its highest census -- 3200 patients. He served as part-time chaplain from September 1946 until May 1947, and established what is now known as Clinical Pastoral Education in a series of courses he taught at Southern in 1948. Clinical Pastoral Education continued at Central State Hospital until 1997, when it was discontinued due to lack of funding. There is hope that it will be resurrected in the near future.

From 1950 to the late 1980's the number of Pastoral Services staff averaged between two and four, supplemented by varying amounts of students from Louisville Presbyterian Seminary, Southern Seminary, and other nearby seminaries. Presently, the staff has two full-time state employees, one full-time Seven Counties Services employee, and another part-time employee provided through funds administered by the Archdiocese of Louisville.

The chaplains of Central State Hospital are trained in the field of psychiatric pastoral care, a highly specialized field of ministry. As psychiatric chaplains, we are required to develop expertise in the psychology of religion, knowledge encompassing both psychological and spiritual dynamics. This knowledge includes spiritual formation and faith development, healthy and pathological religious forms and expressions, the

interplay between abnormal psychology (Axis I and II disorders) and the spiritual life, and religious/cultural beliefs and traditions which impact positively and negatively on emotional/psychological health. We are also required to develop expertise in the art and science of pastoral care and counseling. This is not simply praying and reading religious texts with people. This is a specialized form of counseling which seeks to provide a creative collaboration in which innovations, inventions, and the discovery of new alternatives is a daily event. This kind of creative relationship engenders hope. It utilizes and enhances the spiritual dynamics and religious perspectives of persons experiencing mental illness to facilitate their recovery. This type of counseling is not only about specifically religious concerns. Rather, we meet patients in their life concerns:

- Navigating difficult relationships,
- The impact of living with chronic mental illness on issues of hope, meaning and purpose in life,
- The pursuit of a higher quality of life
- Dealing with grief, bereavement and loss
- Processing anger and resentments
- Feelings of guilt and shame
- Moral and ethical decisions and concerns
- Feelings of loneliness and alienation
- Anxieties and fears about life

Each of our chaplains are ordained, endorsed members in good standing in their religious communities. A faith community has examined them for having the appropriate "gifts and graces" –aptitude and ability—for pastoral ministry. Each of our full-time chaplains

holds at least a master's degree from an accredited divinity school or seminary. Each of our full-time chaplains chose pastoral care and counseling and/or the psychology of religion as their specialty area in academic training. This includes training in individual and marital/family pastoral counseling. Some of our chaplains have extensive post-master's graduate education in the field. Each of our full-time chaplains has extensive clinical training in psychiatric chaplaincy through the Association for Clinical Pastoral Education. Each of our chaplains is eligible for certification by the Association of Professional Chaplains. Most of our chaplains have served in some academic teaching or training capacity with seminaries, some holding positions as adjunct professors, academic and coursework small group instructors, or approved field education/supervised ministry supervisors.

### **Programs and Services**

As psychiatric chaplains, we offer a wide range of programs and services for patients, families and staff. We serve as members of treatment teams, with all the privileges and responsibilities associated with patient care. We also receive and follow through on hospital-wide requests for pastoral counseling with patients. Chaplains lead on-unit and hospital-wide therapeutic groups for patients at the hospital.

Administratively, chaplains are very involved with the progress our hospital is making in raising performance improvement standards hospital-wide. We serve on the Executive Staff Committee, Management Staff Committee, Clinical Executive Staff Committee, and Ethics Committee. We have chaired the Patient Rights Committee, addressing immediate needs of patients hospital wide, and we are actively involved in the strategic planning teams involving reworking the hospital's philosophy of treatment, the

human resources functions and processes, and the hospital's internal and external research programs.

We are active in support of employees. We offer day to day support of staff through pastoral care. Chaplains are active with staff during critical occasions in their lives. We often visit, call or write staff members who are hospitalized or whose families have suffered loss. We perform weddings, funerals and memorial services for staff and their family members. We provide support on a day to day basis with stretched, stressed staff who need some time to ventilate or express their feelings, and more on-going support for staff who have personal, work-related, or family problems. We are active, creative members of the hospital's employee recognition initiatives, and also host events to promote morale among employees and call them to their best selves.

Chaplains also plan, organize, and lead chapel services. We currently conduct two formal services every week. In addition, we conduct services during holiday seasons, write meditation booklets for patients and staff geared toward the psychiatric community, write and lead services targeted toward specific spiritual dynamics assessed in our patient contacts, and hold special occasion services centered around hospital events. For those patients who are unable to come to the chapel for services, we conduct on-unit services and communion opportunities. In addition, we are in contact with faith groups and leaders in the community, which extend not only spiritual resources, but also social and financial resources, for our patients in the hospital. We lead spirituality groups on each of our six patient units, nurturing those whose illness prevents them from leaving the units to participate in other activities.

## **Community Involvement**

Our chaplains represent Central State through speaking engagements with religious and community groups and agencies. We train personal care home providers and new staff orientees in human rights. We speak on mental health issues as guest speakers for seminary classes. We help clergy and laypersons confront their own prejudices and fears about mental illness through sermons and educational programs, and offer them perspectives from the best in our collective religious traditions. In our roles as chaplains, we have access to a grass roots community not always afforded to mental health professionals, a unique opportunity to provide advocacy and mental health education to groups not usually tapped by other professions.

### **Chapter Summary**

Chaplains have played a role in the provision of care at Central State Hospital since its beginnings in 1873, and continue to provide informed religious/spiritual care and counseling for adults with mental illness, chemical dependency, or mental retardation during their stay in the hospital. Pastoral Services has in place a constant process of review, and it continually strives to find the best ways to meet the needs of our constituency. Chaplains lead worship, offer counsel, facilitate groups, chart on patient progress and attend committee meetings, just as they have done for the past 133 years.

There is hope that the ministry will continue to grow here, adding more volunteer churches, possibly getting the CPE program up and running again, and eventually attracting marriage and family therapy students who desire acute care mental health experience. The chaplains are devoted to the ministry here, and feel that God has called them to this place, to this ministry, and to these people.

CHAPTER THREE  
THEOLOGICAL FOUNDATIONS

Hope: A Theological Frame

Hope is a basic energy of life, by which we live out the promise and possibilities of our life in the world, based on trust in a God who ultimately guarantees the future.<sup>1</sup> Hope is as necessary to human life as breath,<sup>2</sup> so necessary that its diminishment or absence has been linked to mental illnesses,<sup>3</sup> physical illnesses, and premature death. Lack of hope can be woven into one's own way of looking at the world, which evidences itself as despair. From a more positive point of view, hope helps us to remain healthy<sup>4</sup>, and in fact gives us the motivation to do so. What are we as pastoral caregivers to do when hope falters? Jurgen Moltmann offers help here. Moltmann's experience of three years as a prisoner of war informed his theology of hope, as he saw first hand how hope and its absence affected the lives of people around him. His insights are useful in pastoral work with people who suffer from serious mental illness. In Moltmann's understanding, Christian faith is expressed in hope for the future of human beings and this world; a hope that is promised by the God of history both in the exodus and the

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<sup>1</sup>A. Jack Davis, "The Chaplain as Minister of Hope" (Training document, Pastoral Services Dept., Central State Hospital, Louisville, 1989).

<sup>2</sup>Emil Brunner, Eternal Hope, trans. Harold Knight (Philadelphia: Westminster Press, 1954), 7.

<sup>3</sup>Ezra Stotland, The Psychology of Hope (Chicago: The University of Chicago Press, 1979), 153-163.

<sup>4</sup>Karl Menninger, "Hope." Pastoral Psychology 11 (April 1960), 11-24. Reprinted from the American Journal of Psychiatry 116 (December 1959), 481-491.

resurrection of the crucified Jesus. For Moltmann, eschatology expresses the attitude of expectancy that underlies all of faith. This faith is not some vague, generic sense of good that will come in the future; it is based in present reality, and based on that reality it is projected into the future. As Moltmann says, it sets out from a "reality in history" and announces "the future of that reality, its future possibilities and its power over the future."<sup>5</sup> This is very useful to the pastoral caregiver because it gives hope for an alternative and redemptive reality, one different from the ever-present suffering of the seriously mentally ill. This hope indeed is the motivating force behind all liberating effort in the world. It is the force behind the creativity that caregivers bring into their work, not simply reframing impressions of reality, but transforming them. As Moltmann says, "the theologian is not concerned merely to supply a different *interpretation* of the world, of history and of human nature, but to *transform* them in expectation of a divine transformation."<sup>6</sup> This transformation occurs in real time, in the present day lived-out reality of our lives, broken as they are by illness, and is informed as much by accurate diagnosis as it is by eschatological hope.

In the case of someone who suffers from a severe mental illness, it is of paramount importance not to encourage unrealistic expectations. Often recovery is a slow process, and often entails an increasing level of dependence on the community, along with a decrease in one's own sense of independence. It is within this context that we talk about hope. Moltmann's Christian eschatology is about hope and the new creation, anchored in the risen Christ, and provides a reality based grounding for a truly

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<sup>5</sup>Jurgen Moltmann, Theology of Hope, trans. by James W. Leitch (New York/Evanston: Harper & Row, 1967), 17.

<sup>6</sup>Ibid., 85.

creative, transforming hope.

Hope is something people do all through their lives. As Jack Davis, a former colleague at Central State Hospital, says, “The fact that we do something rather than nothing in the unreflective living of our daily lives is evidence of rudimentary degrees of hopefulness. We act, hoping all the while that our actions will bring about some hoped for result. Or, lost in daydreams, we exercise our work-tired minds and build the foundations of our hope. In the fantasy of our daydreams, attending to the images of what life outside our present reality could be, we often find creative solutions or hidden longings toward a more creative future.”<sup>7</sup> These wishes and fantasies may become the seedbed from which mature hope grows.<sup>8</sup>

Mature hope is what gets us through life’s most difficult trials. The call of the pastoral counselor is to stand with the suffering person in a time of need, and if it is possible, to help think of creative solutions to life problems. As Wayne Oates says:

A part of the professional competence of a pastoral counselor is to provide the creative kind of relationship in which innovations, inventions, and the discovery of new alternatives is a daily event. In short, this creativity engenders hope. When a counselee says: ‘There is nothing else I can do,’ often the very process of counseling itself is that ‘something else’ that opens new avenues to hopeful existence.<sup>9</sup>

Creativity is as much a function of hope as it is a producer of hope. The counselor and the counselee engage one another in the hope of effecting change, to understand and adapt to life, creatively addressing its concerns.

Difficulties can arise in this therapeutic process if the counselee has an

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<sup>7</sup>A. Jack Davis, “The Contributions of Rollo Reece May and Gabriel Marcel to a Pastoral Theology of the Hoping Self” (Th.M. thesis, The Southern Baptist Theological Seminary, 1989).

<sup>8</sup>Ernst Bloch, The Principle of Hope, vol. I (Cambridge, Massachusetts: MIT Press, 1986), 87-88.

<sup>9</sup>Wayne E. Oates, Protestant Pastoral Counseling (Philadelphia: Westminster Press, 1962), 160.

impairment that prevents a typical, insight-oriented pastoral conversation. As Andrew Lester says,

On the downside, the person who cannot “re-collect” a self out of the past is a psychologically disabled self whose personal boundaries are difficult to establish and who is thus vulnerable to many mental health problems.<sup>10</sup>

John Swinton offers help here in emphasizing that we are beings created for relationship, created in the image of God. Our ability to reason is not what defines our status in relationship to God. If that were the case, only those with high intellectual functioning would be close to the image of God. As one receded from the boundaries of “normal” intellect, one would become more animal, and further from God. Such misunderstandings have been present in the care of the mentally ill, even to the point of belief that the ones who were the most ill were Satanic. It has been the downfall of the Western tradition to locate a human’s worth in her or his ability to reason alone. He says, “The problem appears to be that if human beings are defined by something within themselves, this inevitably leads to the exclusion and alienation of the weakest members of society.”<sup>11</sup> The image of God is something we all carry within us, regardless of our ability to “recollect a sense of self,” as Lester would say. Our worth is not based in our ability to reason, but our ability to relate. This offers hope for those who, for reasons of disease or disability, are no longer able to relate in “rational” terms. In the final analysis, ability to relate is more important than ability to reason, and the ultimate criterion of any theology is whether it can be applied to those who are most vulnerable.

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<sup>10</sup>Andrew Lester, Hope in Pastoral Care and Counseling (Louisville: Westminster/John Knox Press, 1995), 34.

<sup>11</sup>John Swinton, From Bedlam to Shalom: Towards a Practical Theology of Human Nature, Interpersonal Relationships, and Mental Health Care (New York: Peter Lang, 2000), 26.

Some people have suffered abuse at the hands of those who were entrusted with their care. They may no longer be able to recollect the perpetrator or tell what exactly happened. Some others have an illness, like schizophrenia or dementia, which makes them either unable to think clearly or remember past events. In both of these cases, it is clear that the task of the counselor is two-fold. As Nancy Ramsay says:

It poses a two-fold task for effective care and counseling. On the one hand, we must offer a clear and credible affirmation of God's love as tender and powerful. On the other we must incarnate such love in ways that counter the isolating bondage of fear and shame.<sup>12</sup>

### Understanding Suffering

The whole process of counseling is rooted in hope. The very activity of counseling is hopeful. But what does one do in the cases where hope seems so elusive? Often the only way around despair is through it. Wendy Farley offers help by offering a theoretical basis for understanding suffering in Tragic Vision and Divine Compassion: A Contemporary Theodicy.<sup>13</sup> Suffering, in her view, is not something to be explained as much as it something to be resisted. The conceptual environment of her reflections is governed by *tragedy* rather than *the Fall*. In other words, she takes a more intuitive, existential (phenomenological-descriptive, in her words) approach rather than the theoretical, almost math-like solution of classical Christian theology. There is nothing more offensive to someone who is suffering than having someone explain "why" or try to figure out "what you did to bring this on yourself." Countering a time-honored

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<sup>12</sup>Nancy Ramsay, "Compassionate Resistance: An Ethic for Pastoral Care and Counseling," The Journal of Pastoral Care, 52:3 (Fall 1998), 214-226.

<sup>13</sup>Farley, Tragic Vision and Divine Compassion, 19.

theological tradition, she places suffering at the center of the problem of evil, rather than sin. This is a helpful shift for pastoral caregivers because it makes an important distinction that not all suffering results from personal choices.

The two faces of human evil, sin and suffering, must be permitted to emerge in their distinctiveness. To reduce the problem merely to dissolving suffering into the guilt-sin category or moral dualisms is not to understand the complexity of sin and suffering.<sup>14</sup>

In the context of an acute care mental hospital, this has been very useful in counseling those who think that their illnesses are a result of sin in their lives.

Farley is attempting to construct "a response to the problem of suffering and evil on the basis of a phenomenology of divine love."<sup>15</sup> Clearly it is not good enough to respond to suffering with facile explanations. It must be addressed thoroughly if any healing is going to happen. Farley's thesis is that redemption and, eventually, healing, come through our confrontation of evil.

Hope often arises in a context of suffering, which is why I included both hope and suffering in building the theological foundations for my project. It was my intention to observe the ways in which people who experience serious mental illness are able to access hope in the midst of the suffering that their illness brings. My expectation was that in this process I would find useful and practical ways for pastoral caregivers to address the problems that come in living with a mental illness. This study produced insight into ways caregivers can foster transforming interventions and alliances with people who suffer from and struggle with mental illness, in ways that are creative, compassionate, and rooted in community.

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<sup>14</sup>Ibid., 52.

<sup>15</sup>Ibid., 14.

## Creativity, Compassion, and Community

Creativity, compassion, and community are all concepts present in Farley's and in Swinton's work. I will show how they are brought to bear in the context of schizophrenia.

### **Creativity**

In Farley's view creativity would be what one must use to thwart the tragic character of the cosmos. Tragedy, as Farley understands it, brings a sense of the irrational into our experience of suffering. It is the part of suffering that can admit no explanation. More concretely, life presents itself with many difficulties, some of which seem insurmountable. The creativity that results from the soul's attempt to make sense of reality, or to adjust to it, gives it hope to go on. In the case of a person with a severe form of schizophrenia, one must realize that often the person's mental capabilities may be so impaired that they are unable to reason out the cause of their suffering, let alone come to an understanding of it. Creativity would have to merge with community and compassion in this case, as other persons would be called in both to provide care for the person and advocate for their fair treatment. My correspondence with Farley confirmed this:

I would think *any* form of suffering calls forth a compassionate response...I think that any situation that defrauds us of our agency, hope, etc. is one of real suffering and pathos, generating suffering loved ones as well as the one who suffers most immediately.<sup>16</sup>

This suffering is distinguished from radical suffering, at least in Farley's understanding. Radical suffering, as she presents it, has almost a willful character to it. It is an assault on one's personhood, often at the hands of a perpetrator.

The fact that there is no identifiable "perpetrator" to resist in many cases of

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<sup>16</sup>Wendy Farley, email message to author, April 17, 1999.

mental illness makes a hopeful, pastoral response difficult. If, as Farley says, “the power to *resist* suffering distinguishes meaningful suffering from radical suffering,”<sup>17</sup> there must be room in the argument for resisting a different sort of perpetrator. A person suffering from a degenerative and incurable illness has no human perpetrator to fight against. Schizophrenia is like Alzheimer’s or dementia, in that it is mostly irreversible. One creative response, taken by the medical community, is to view *biology* as the perpetrator, and mobilize forces of science to fight it. Research in psychopathology has made strides in understanding schizophrenia, and there is hope that more research can help find better ways to treat the illness. If a person is being assaulted by biology, it can seem like there is no future, no meaning, and no relationship, but a creative and compassionate response from a dedicated community can bring results that help and inspire hope.

Swinton speaks to the issue of suffering and hope in a different and also very helpful way. He maintains that people with mental illnesses are not only suffering from the biological effects of the disease itself, but also from the sociological effects of a diseased society’s lack of response. He points toward friendship and relationships as key ingredients in the inspiration of hope and healing in the lives of those who suffer from schizophrenia, saying, “One of the primary ways in which hope is inspired within human beings is through personal relationships.”<sup>18</sup> He combines his voice with the voices of other researchers in saying that recent research suggests “...that the ability of the sufferer to develop some degree of hope is fundamental to the recovery process. The primary

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<sup>17</sup> Farley, Tragic Vision and Divine Compassion, 57.

<sup>18</sup>Swinton, Resurrecting the Person, 139.

way in which hope is engendered within an individual is in and through personal relationships.”<sup>19</sup> The humanizing aspect of friendships helps to counter the ill person’s internalized sense of defectiveness and diminished self-esteem, and is seen as one of the most important factors in the recovery process.

### **Compassion**

Compassion finds its calling in its resistance to tragic suffering. In the face of the tragic character of mental illness, it doesn’t lose hope--it is ethical, not nihilistic. It calls out for justice and resistance. The cosmos is sometimes savage and cruel, but something in the hoping person remains untainted and keeps hope alive. Compassion resists suffering instead of trying to justify it. Compassion is seen as a power rather than an emotion or something interior. It is something that gets acted on; it *is* action.

Compassion is a here-and-now way to address the problem of suffering.

In order to act with compassion, one must have some knowledge of another person’s suffering, even though there is no way to fully know it. In the case of schizophrenia, one needs to be educated in the positive and negative symptoms of the illness, and have some small sense of how difficult it is to have the illness. Farley’s idea of sympathetic knowledge captures this. "Sympathetic knowledge is an apprehension of a situation or experience precisely as belonging to someone else, qualified by the other's interpretation of it, within the perimeters of the other person's frame of reference."<sup>20</sup> It allows another to "taste" what the sufferer endures, and it is a prerequisite for compassion. Compassion is not limited to sympathetic knowledge. It is a disposition

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<sup>19</sup>Ibid., 139.

<sup>20</sup>Farley, Tragic Vision and Divine Compassion, 71.

that motivates a healing response to a suffering world, a commitment to resist suffering. Love effects this transformation, and it sees its duty first and foremost as preserving human dignity. Swinton says, “one of the most significant interventions in the treatment of mental health problems is understanding. While pharmacology and therapy may well be useful in the treatment of mental health problems, understanding is a vital form of intervention that is fundamental to the process of rehabilitation.”<sup>21</sup>

Compassion finds its work in two areas. The first is highlighted in the section on creativity. The medical community is seeking a creative response as it researches ways to manage, if not cure, the illness. The relational community addresses the second work of compassion. Community-based services help persons with mental illnesses to integrate their lives to the extent that they are able. They help to find jobs, churches, and provide a place where a person can “belong.” They create a holding environment that can allow growth, change and adaptation, and they act as safeguards of a person’s human dignity, advocating strongly for rights. Swinton calls the Christian church to act prophetically in this regard, saying,

In terms of pastoral care at a congregational level, this is a very important point. Hope lies at the heart of the message of the gospel—hope for the broken-hearted; hope for the afflicted; the poor; the marginalized; those whom society casts aside. Likewise, hope and the inspiration and maintenance of hope lie at the heart of the church’s ministry of mental health care. The Christian community, as a community of memory, resurrection, and hope, has the potential to make a valuable contribution...If congregations can be enabled to offer this type of hope-bringing relationship, it will not only benefit people with mental health problems, but it will also empower church communities to become hopeful communities that are able to care effectively for ‘the outcast and the stranger.’<sup>22</sup>

## **Community**

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<sup>21</sup>Swinton, *Resurrecting the Person*, 141.

<sup>22</sup>Ibid.

If creativity and compassion are the works that *nurture* hope, community is the *agency* of hope. If we ask the question, “How does God save those who have been disenfranchised?” we see that God responds by raising up a community<sup>23</sup> (family, place of worship, assisted-living environment) that can:

- 1) Physically, incarnationally, demonstrate the reality of a God who cares.
- 2) Provide a refuge, a safe, holding environment for those who are unable to cope with their illness.
- 3) Provide the gift of enduring presence and shared journey.
- 4) Provide accountability and support.
- 5) Provide a promise of growth.

These provisions are absolutely essential in the life of a person who suffers from an acute mental illness such as schizophrenia. The community is the agent of hope in the life of an ill person, embodying God in acts of compassion and creativity, helping to create power to live a fulfilling life rather than trying to control it.

"Notwithstanding the damning evidence against God," Farley's attempt in her work is "to show that divine love is deeper even than the evil that tears creation, and that God is neither indifferent nor powerless before evil."<sup>24</sup> The love that is shown through the action of the community is evidence of this. With love as a paradigm of divine power, there will always exist the possibility of evil, because love leaves freedom and the future undetermined. In Farley's words, "there is 'room' in creation for that which utterly resists

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<sup>23</sup>Loren Townsend, “Creative Theological Imagining: A Method for Pastoral Counseling,” in The Journal of Pastoral Care 50:4 (Winter 1996), 362.

<sup>24</sup>Farley, Tragic Vision and Divine Compassion, 95.

and thwarts the will of God. Evil is that which has successfully resisted God."<sup>25</sup> If one imagines divine power through the symbol of love, one can account for evil without having to justify it. Of course when evil happens, it is tragic, but one must also keep in mind that love can be a “fierce tenderness,”<sup>26</sup> which symbolizes the power to oppose evil and, even more, to empower and redeem.

There is no way to eradicate suffering, but in the paradigm of love, this is not the fault of God; it is more a fact of life. God is the one who through the power of compassion empowers people to confront the reality of suffering and evil, and to do works of redemption in resistance to them. We are called to embody and incarnate the hope that inspires hope. Swinton says that to the extent that we participate in this cycle of reciprocity, “we will have moved toward the type of resurrection that is fundamental to effective mental health care.”<sup>27</sup>

#### Chapter Summary

Creativity can be blocked by evil. Compassion can be thwarted in its attempt to liberate and redeem. Community can fail in its responsibility to help those who need it. All of this has been seen to happen in history, both in the context of the individual and the institution, but as much as evil has shown itself in history, so too has redemption. As pastoral caregivers we are given the high calling of working for this redemption. Work such as this, in creativity, compassion, and community, gives us a taste of the love of God for the world.

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<sup>25</sup>Ibid., 97.

<sup>26</sup>Ramsay, “Compassionate Resistance,” 224.

<sup>27</sup>Swinton, Resurrecting the Person, 141.

## CHAPTER FOUR

### METHODOLOGY

#### Choice of Methodology

This study followed the tradition of ethnographic research. The design emerged from the field of anthropology, primarily from the contributions of Bronislaw Malinowski, Robert Park and Franz Boas.<sup>1</sup> The intent of ethnographic research is to obtain a holistic picture of the subject of study with emphasis on portraying the lived-out experiences of individuals by observing them and interviewing them and others whose lives have bearing on theirs.<sup>2</sup> An ethnographic study includes in-depth interviewing and on-going participant observation of a situation<sup>3</sup> and in attempting to capture the whole picture reveals how people describe and structure their world.<sup>4</sup>

#### Role of the Researcher

In the most traditional fields of ethnographic research, fieldworkers often live among the subjects they are studying, engaging in participant observation as they gather relevant data. Research in this project was performed chiefly by one person (this writer), who has worked among this group and carefully observed it for over ten years, investing a considerable amount of time in the provision of pastoral care, religious rituals,

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<sup>1</sup>Evelyn Jacob, "Qualitative Research Traditions: A Review," Review of Educational Research 57:1, (1987), 10.

<sup>2</sup>Creswell, Research Design: Qualitative and Quantitative Approaches, 163

<sup>3</sup>Jacob, Qualitative Research Traditions, 14.

<sup>4</sup>Creswell, Research Design: Qualitative and Quantitative Approaches, 1-2

celebrations, and occasional meals in the cafeteria. Additional research assistance came from four other chaplains, three who were employed at the hospital, along with one who had retired.

Interviews were conducted and data was collected from October through November, 2006. During the course of the interview process, the interviews were audiotaped using a digital recorder and in turn de-identified (stripped of any identifying information—see Appendix 7) and transcribed. The de-identified transcriptions were then distributed (as Microsoft Word Documents) to the members of the coding team, which then had the opportunity to examine them according to the steps that Renata Tesch describes:<sup>5</sup>

1. Get a sense of the whole. Read through all of the transcriptions carefully. Perhaps jot down some ideas as they come to mind.
2. Pick one document (one interview)—the most interesting, the shortest, the one on top of the pile. Go through it, asking yourself, What is this about? Do not think about the “substance” of the information, but rather its underlying meaning. Write thoughts in the margin.
3. When you have completed this task for several informants, make a list of all topics. Cluster together similar topics. Form these topics into columns that might be arrayed as major topics, unique topics, and leftovers.
4. Now take this list and go back to your data. Abbreviate the topics as codes and write the codes next to the appropriate segments of the text. Try out this preliminary organizing scheme to see whether new categories and codes emerge.
5. Find the most descriptive wording for your topics and turn them into categories. Look for reducing your total list of categories by grouping topics that relate to each other. Perhaps draw lines between your categories to show interrelationships.
6. Make a final decision on the abbreviation for each category and alphabetize

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<sup>5</sup>Renata Tesch, Qualitative Research: Analysis Types and Software Tools. (New York: Falmer, 1990), 142-145

these codes.

7. Assemble the data material belonging to each category in one place and perform a preliminary analysis.
8. If necessary, recode your existing data.

Using this method of coding resulted in a distillation of the data that presented a richer analysis, one which safeguarded the identity of the patients and deepened understanding of them. While much of the work in the analysis process consisted of ‘taking apart,’ (for instance into smaller pieces), the final goal was the emergence of a larger, consolidated picture.<sup>6</sup> To strengthen reliability and internal validity, transcriptions were read by various members of the coding team to look for themes and interpretations that were present across the spectrum of patients interviewed and agreed upon by the members of the coding team.

### Research Design

Since ethnographic research is conducted among living human subjects, the utmost care was taken to safeguard the privacy of the persons being studied. It was imperative that this researcher made his research goals clear to the patients, to the clinical members of the hospital community, and to the academic institution for which the research will be evaluated. The research prospectus had to be approved not only by the Institutional Review Board of the Louisville Seminary, but both the Director and the Supervisor of the Pastoral Services Department, along with separate meetings of the Executive Leadership Committee and Medical Staff Committee of Central State Hospital. In addition, the fact that the study was to be conducted among mentally ill patients necessitated convening the Internal Review Board of the State of Kentucky in Frankfort,

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<sup>6</sup> Tesch, Qualitative Research: Analysis Types and Software Tools, 97.

which deliberated for nearly two hours before granting permission to go forward with the study. Part of the length of the deliberation was due to the State's interest in protecting the needs of patients. This researcher, along with the State Ombudsman and the Chair of the Institutional Review Board (who were very familiar with the details of the project proposal), assured the Board that the informed consent of the patients would be obtained, and that patients would be informed that only basic themes derived from analysis of their conversations with the researcher would be used in the reporting of the research, and that any identifying information they reveal in the interview process would be filtered out.

### **Instrumentation**

All patients were provided with a copy of the Authorization and Consent Form (Appendix 1), along with the Patient Interview (Appendix 2). These are described in detail later.

All interviews were recorded digitally using a password-protected Pocket PC running Microsoft Windows Mobile compatible software. Digital recording software used was Yoho™ Version 2.03, created by Pocco Software, which recorded the interviews as .wav files. All data was recorded during the interview, and then was transferred immediately from the Pocket PC to the researcher's password protected desktop computer, where it was then transcribed and identity stripped according to JCAHO/HIPAA standards. All recording and transcribing took place with patients' written consent and within the physical confines of Central State Hospital.

### **Selection of Researchers**

Researchers were chosen for this project primarily for their familiarity with the patient milieu, and for reasons of both confidentiality and convenience, restricted to

current or former employees of the Pastoral Services Department of Central State Hospital. The researchers' experience ranged from six years to nearly thirty five. The researchers' faith affiliations ranged from conservative Catholic to liberal Baptist; namely, one solidly conservative Catholic (a permanent deacon), one conservative Baptist, one moderate Baptist, and two liberal Baptists. Distinctions such as these are difficult to draw with any great certainty, but the diversity and difference of perspective within the research team was an asset, having a tendency to strengthen reliability and internal validity.

### **Selection and Protection of Research Candidates**

The interviews were conducted by this writer, using a structured interview and lasted no more than fifteen minutes. Interviews were conducted only with approval of the patients' treatment teams. The signature of the parent or guardian (if necessary) was obtained on the Authorization and Consent Form (Appendix 1) prior to obtaining the signature of the subject and a copy of the consent form was given to the patient and guardian for their own records. Necessary care was taken to identify appropriate patients and to keep them safe. The eligibility criteria for the study were:

1. An individual.
2. A Central State Hospital patient.
3. A diagnosis of schizophrenia.
4. Experience of symptoms that have been protracted over the course of a year or more.
5. Determination by patient's treatment team that the study posed no threat to the patient.

Patients' eligibility for the study was discussed with and approved by their treatment

teams before they were approached. Pending approval of family or guardian (if applicable), they were presented with the consent form, which clearly and simply stated the goals of the project, and that their identity would be safeguarded. If they were agreeable, the patients read and signed the consent form (see Authorization and Consent Form, Appendix 1), and this was noted in the patient's treatment record along with notation that the patient was notified of benefits, risks, and offered the opportunity to refuse participation in the study (see Informed Consent, Appendix 3). After this preliminary preparation, the interview process commenced, with the clear understanding that all of the information would be held in strict confidence (see Confidentiality and Confidentiality of Behavioral Health Records, Appendices 4 & 5) and that it would be used only for the purposes of learning. All interviewees provided authorization and consent to have their interviews taped (see Recording/Filming Appendix 6), and received written assurance that any identifying information would be removed from their data during the coding process.

According to current Central State Hospital regulations, a researcher holding protected health information may only use the information as long as it has been de-identified. Based on HIPAA (Health Insurance Portability and Accountability Act), health information that is individually identifiable protected health information can be reclassified by removing all 18 of the specified identifiers (name, address, age, data of birth, etc.) as outlined below (see De-identification of Patient Information, Appendix 7) and in the federal Privacy Rule §164.510(a).

Information about patients was gathered at the time of interview. During the coding process of the research, all the data were de-identified. Records that have been

de-identified are no longer considered individually identifiable health information and can be used or disclosed freely without a patient's authorization. The de-identified interviews served as the text the researchers used during the first and second levels of the coding process. These are discussed in the fourth chapter.

## Limitations

### **Limitations of Research Methodology**

Decisions about the focus of this project and the boundaries that have been set have involved compromises along the way. These limitations are inevitable, and are present to varying degrees in any study. Ethnographic research has as its goal an attempt to understand the culture of a group by entering into it and participating in the day to day experiences of the patients. One typical criticism of ethnographic research is that it leads to in-depth understanding only of a certain context, and is not easily applied to other situations. To be certain, this writer made the attempt to understand hope in a context of severe mental illness, through a multi-layered analysis of the culture of a very circumscribed group of individuals; namely, persons experiencing symptoms of schizophrenia who were undergoing intensive treatment at a state psychological hospital. So from the very beginning one can see limitations both of lack of breadth and lack of generalizability. What follows is a more in-depth discussion of some of the limitations of the project.

### **Limitations of Sample**

Ethnographic research generates so much data that a small sample size is necessary. The study had at its commencement the possibility of interviewing as many as thirty seven patients, but eventually the field of potential candidates was narrowed down

to twenty. This proved to be a sufficient number to achieve a saturation point with the data, i.e., a point at which a sense of redundancy was achieved in terms of frequency of themes. More patients would have brought a greater diversity of perspectives, but would also have created a data set that would have been overwhelming given the time constraints of the project.

### **Limitations of Data Analysis**

The researcher chose to use open-ended questions as a way of eliciting responses around patients' experiences of hope. This of course entailed a restriction of the data analysis merely to what was said and transcribed. An attempt was made to convey some of the body language of the patients while they were interviewed, but much of that was lost in the process of the recording. Ability to speak is not a prerequisite for ability to hope, but it was to a large extent a prerequisite for participation in the project interviews.

Some of the interviews were very short, due in part to the varying degrees of cognitive functioning of the participants. The researcher had to counter a natural (pastorally-oriented) attempt to get patients to "say more." The survey itself is limited by the questions it asks, as well as the questions it neglects to ask. It may have been useful to "try out" the questions on a few participants as a systematic way to derive a better set of questions. As it stands, though, the data produced by the questions used was rich with information, some which could have been predicted by the team before it began, but also some that the team had not predicted. This will be discussed in more detail in the findings.

### **Limitations of Researchers**

The identity of the researcher as both chaplain and researcher could also be

considered a factor that might influence the resulting conversation. Patients might feel compelled to portray themselves as more hopeful than they truly felt because of the presence of a representative of the sacred. This researcher did not find that compulsion borne out in the study.

As a group of pastoral caregivers, the Pastoral Services Department is limited by its own sectarian biases and theological understandings. Five researchers were used during the coding process. More researchers would have brought a better diversity as well as stronger reliability and internal validity, but would have proved unwieldy for a study of this size.

### **Limitations of the Literature**

There were limitations of literature in the study in that there is little that has been written about the particular sample group studied in this project. This is due in part to the length of time it takes to conduct such a study, and also in part to the difficulty in obtaining approval and consent. On the other hand, this is what makes a study of this kind so crucial. The clinical community, with chaplains and pastoral caregivers in particular, need to have research-based, patient-derived, clinical pathways to help them facilitate healing and wholeness in their areas of endeavor.

### **Benefits of the Project**

The benefits this project provides to knowledge and practice include the following:

- A. The project facilitates communication and dialogue on the subject of nurturing hope in a context of persistent mental illness.
- B. The project creates an easily replicable method for nurturing hope among patients, which can be of use to chaplains, pastoral counselors and

psychotherapists.

- C. The project itself as well as the newly formed research-based, patient-derived clinical pathway, may be used in further application and dialogue in the field of pastoral counseling and psychotherapy. This dialogue may lead to formation of other tools for spiritual intervention or critical thinking in this area.
- D. The project provides a framework for further study of hope in persons with diagnoses different from schizophrenia. In this writer's current context, it could be extended to the other major mental illnesses treated by Central State Hospital; namely, bipolar illness and severe depression.
- E. The project fulfilled a performance improvement initiative taken on by the Pastoral Services Department of Central State Hospital, in keeping with the Hospital's vision to provide professional education and research, and to advance the study of the efficacy of its treatment programs.

### Chapter Summary

This project was designed to examine some of the presuppositions this researcher brought to the research, to suggest new ways pastoral caregivers might think about hope, and to develop an initial stage of a spiritually based clinical pathway for use in ministering to persons who are experiencing symptoms of schizophrenia. Hypotheses were not tested as much as were presuppositions in this type of study. Although ethnographic fieldwork does not usually call for the generation and testing of hypotheses, it does require both theoretical and empirical foreknowledge. Aspiring to enter the field

devoid of any preconceived ideas of what one might be looking for, or might expect to find, in order to fulfill a purist conception of scientific objectivity or impartiality was neither warranted nor realistic.<sup>7</sup> To this end, this researcher brought the expectation that even though his theoretical and empirical foreknowledge came from a wealth of clinical experience, some of his presuppositions would be challenged, and if found wanting, revised.

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<sup>7</sup>Renee Fox, "Observations and Reflections of a Perpetual Field Worker," *The Annals of the American Academy of Political and Social Science* 595 (Sept. 2004), 315.

## CHAPTER FIVE

### THE PROJECT

#### Descriptive analysis of the data

##### **Data collection**

Initial data collection took place in October 2006, after the study was approved by the Institutional Review Board of the State of Kentucky. In coordination with the Medical Records and Social Work Departments of the Central State Hospital, a list of thirty-seven patients who carried a diagnosis of schizophrenia was generated. Five of the patients were under guardianship status, and as an interview with any of them would involve the additional burden of obtaining both the consent of the patient and the guardian, they were not interviewed. Not surprisingly, patients under guardianship status often lack the ability to participate in even an open-ended conversation. Of the thirty two remaining patients, twenty gave consent to be interviewed, six declined any interview, and six were determined by the treatment team to be too disorganized to approach with a request for an interview.

##### **Interviews**

All the interviews except for one were conducted on the treatment units, wherever patients felt most comfortable. Occasional interruptions occurred, but steps were taken to safeguard the patients' privacy and sense of security. Typical places for interviews included patient rooms, in the courtyards, and in various semi-private rooms on the unit. One interview took place in the chaplain's office, as the patient desired more privacy and

had earned the privilege to be escorted off the treatment unit. Length of interviews ranged from as long as thirteen minutes, sixteen seconds to as short as two minutes, nine seconds, reflecting both the cognitive functional level and the comfort level of those interviewed. Care was taken by the interviewer to let patients answer in their own words, with any additional questions asked more to clarify than to lead. Excerpts from the transcribed, data-stripped interviews are discussed in the section describing the coding process.

### Interpretive Data Analysis

The data provided through the interviews were distributed to the research team members in early November, 2006 for the first level of analysis, during which each researcher read through the interviews with the instruction to take note of themes which might emerge from the reading. These findings were compiled through notes taken at a staff meeting in late November, 2006. Five primary themes were distilled from the data. These became the basis for the second level of analysis, which was to read back through the interviews with the five themes in mind, taking note of each time the researchers noticed an instance of a theme in an interview. This provided a way to rank the themes in order of their prevalence in the minds of the patients. This information became the basis for the development of the spiritually-based clinical pathway.

### **Description of the First Level of Analysis**

The first level of analysis was conducted in November, 2006 with a meeting of the Pastoral services staff. Copies of the interviews were distributed to all researchers prior to the meeting, along with an instruction sheet (see Appendix 8) to assist them in finding themes as they analyzed the interview data. An additional meeting was held at

the home of a retired chaplain near campus. This researcher took notes during each of the meetings. Many themes came through the reading. The themes discussed were as follows:

- Hope is relational—it emerges through discussion.
- Illness colors what patients talk about, and it affects their capacity to articulate hope.
- Illness may affect the character of the hope.
- Hope requires community.
- Hope needs encouragement.
- Hope for release
- Hope is important all the time—right now
- Hope for agency—ability to do things
- Hope is fundamental, truth comes through experience
- Hope is expectation of good and preparation for misfortune
- We (chaplains) are harbingers of hope
- Hope comes through the interview process (sense of connectedness)
- Hope for my own life, my own apartment.
- In spite of my illness, I am a human being
- Hope for normalcy
- Hope for a better life
- Hope comes in the midst of despair
- Hope is right now—most valued in the present
- Hope for future wholeness, promise of a better tomorrow

- Hope for nothing worse
- The dark is light enough
- Hope to help others
- Hope to get out (of the hospital)
- Hope for a normal life/restoration of the past hope for recovery
- Hope to have something to offer
- Hope crosses denominations and faiths
- Hope and self esteem are inseparable
- We (chaplains) embody hope
- Hope is presently important
- Hope for a better life
- Family is important in sustaining hope
- Hope for recovery
- Hope in systems of support
- Hope is always important
- Hope that if I pray, God will take my illness away
- Hope that God will forgive and educate
- Hope for happiness in the next life
- Hope for world peace
- Hope for success in life
- Hope for recovery/restoration
- Hope to be with community, friends
- Hope to get out (of the hospital)

- Hope is important now
- Hope to get out
- Hope comes through other people
- Hope is destroyed by other people
- Hope for recovery

### **Description of the Coding Process**

The primary researcher read through these themes after the conversations with the other researchers, and categorized them according to those which were the most prevalent, coding them by number. They are as follows:

1. Hope to do what I want (power/agency/self-esteem).
2. Hope to be restored to community (family/friends/therapeutic community).
3. Hope to be sustained in the present/right now.
4. Hope to get out of the hospital/back to normal.
5. Hope for a better life.

The themes arose out of the context of the interview process, so it is fitting at this point to discuss the themes more deeply, using excerpts of dialogue to support selections. Each of the themes are discussed in detail, along with excerpts (single spaced) from the conversational contexts in which they arose. There is some thematic overlap present in the chosen passages, but that is inevitable to a large extent. Passages have been chosen which represent the best and most representative iterations of the themes. The themes are discussed in the order that they were eventually ranked in the second level of the analysis. In all the conversations quoted, “D” represents the interviewer, and any other letters represent patients.

## Hope for a Better Life

Hope for a better life is a theme that seems always on the minds and in the conversations of patients. They want lives that are fulfilling, and their hope is quite possibly the only thing that gets them through the difficulties posed by their illnesses.

Sometimes that hope is expressed as simply as it is in the following passage:

- D** ok..alright, it looks like we're recording...first question is, How do you define hope? ...and there's no right or wrong answers, you just answer whatever you want to.
- B** It's hope?
- D** uh huh
- B** (ten seconds pass) Something that, uh...(5 sec.) hmm....that would have me feeling like I'm striving to get somewhere...
- Mental Health Tech** (walking past) Reverend Dave's the best!
- B** oh yeah... striving to do something...
- D** uh huh
- B** ...and eventually I'll make it I guess.
- D** ok...What do you hope for?
- B** A better life. I gotta have more hope in doing what, you know, getting this done, so I can live a better life for myself.

The patient understands hope as striving to do something, and has the insight that following the advice of his treatment team is part of what has helped him get well. He understands that compliance with his treatment at the hospital and follow up in the mental health community after he is discharged (referred to as “getting this done”) is of paramount importance to living “a better life.”

Other patients are sustained by the belief that things will get better, perhaps buoyed by a trust in a God who ultimately guarantees the future:

- D** Let's see if this thing's working—ok--How do you define hope?
- J** Well by scripture it's 11 Hebrew 1, isn't it? The absence of something special, the evidence of things not seen. (chuckles, pleased with herself)
- D** (laughing, too) Well, there you go. And that's kind of how it works for you in your life, too?
- J** Yeah.
- D** ok...What do you hope for?

**J** A brighter future, a better future, a better world.

This patient, despite her misquote of scripture, is comforted by the belief that faith is the substance of things hoped for, the evidence of things not seen. She may not understand what the passage means literally, but her attempt to link her hope to a Christian sacred text suggests a type of hope that is mediated through a religious tradition. Her hope comes from the Christian perspective which holds that hope is based on the promise of resurrection, which happens in the future, but empowers life and growth in the present. It helps people to overcome the obstacles of the present moment and moves them toward the future with courage, patience, confidence and expectation. Often patients make incorrect references to their religious traditions, either through their own ignorance or the severity of their cognitive impairment. This is not evidence of unhealthy spirituality. Inability to articulate hope adequately cannot be equated with inability to experience it. Ability to experience hope for a better life transcends education, illness, and tradition.

Not all expressions of hope come out of a particular tradition, but are more general. The following are representations of this.

Patient one:

**D** What helps you keep going day after day?

**R** Knowing I have a better tomorrow. Knowing the promise of a better tomorrow.

Patient two:

**D** ok...How does hope help you cope with your illness?

**A** Well, you hope to get well and you look forward and, the future, uh, like that.

The ambiguity present in these expressions of hope does not necessarily imply that they are not strongly felt. Patients are not always able to express their beliefs with clarity, but

this is also true of those who are supposedly “sane.” Scholars and saints have struggled with this same issue down through history. Our worth is not based in our ability to reason, but in our ability to relate. This offers hope for those who, for reasons of disease or disability, are no longer able to relate in “rational” terms. In the final analysis, the ability to relate is more important than the ability to reason, and the ultimate criterion of any theology is whether it can be applied to those who are most vulnerable.

Another issue is raised by the following short interchange:

- D** ok How does hope help you cope with your illness?  
**d** Wishing for the best for myself.

One might ask whether “wishing” is actually hoping at all. Is it not actually the very opposite of hoping? Oftentimes, wishful thinking is based on an unrealistic assessment of the way things are. In the case of someone who suffers from a severe mental illness, it is of paramount importance not to encourage unrealistic expectations. Often recovery is a slow process, and entails an increasing level of dependence on the community, along with a decrease in one’s own sense of independence. It is within this context that we talk about hope. The paradox of hope, it seems, is that people tend to hope whether or not they have good reason. In the particular context of this patient’s interview, he was actually hoping, not wishing. He was misusing the word. It is usually clear to a pastoral caregiver from the context of a narrative whether encouragement of healthy hope or redirection of false hope is indicated.

Some patients are able to articulate more fully what they mean by hope, as the next excerpt shows:

- M** I define hope as something that is spiritually defined as a manner of situations in life where there’s a destiny that has an end of reality of being uh  
 ....subtly defined more as a destiny -- like if you have a dream and it

doesn't come true, if it doesn't come true, you can hope more that if it don't come true, at least you tried, and if it does come true, you've got the benefit of the doubt, you can say to yourself, my dream came true, so I'm satisfied.

**D** Huh. Ok that's good...Let's see.... What do you hope for?

**M** I hope for my future that, even though I'm mentally ill, and I have nothing but a hospital bed most the time instead of a home to lay my head down every night that one day even though I guess my destiny is mainly to stay on my medications, to stay out of trouble, to stay away from the spread of anger in this world of violence, this world...of...hatred this world of ignorance that says because you're schizophrenic bipolar you're not normal. I just hope one day, even if they can't find a cure, at least I can say, before I pass away, that I am a human being.

**D** So, how does hope help you cope with your illness?

**M** Hope tells me that I might be having a hard time sometimes, it's difficult sometimes in my life, but trusting that there's a better, there's a promise for a better tomorrow, is how hope helps me.

**D** ok

**M** Knowing that there's a better tomorrow, another day.

**D** ok

**M** Or if not at least as good if it wasn't better at least nothing worse.

One sees in this interchange a hope that, in some ways, endures "in spite of" all the difficulties that life presents, be they medical, spiritual, or socio-economic. It is a hope that asserts that in spite of all these afflictions, "I am a human being." In addition, the patient has a hope that is informed by a realistic assessment of his situation. He hopes that if things don't get better, that at least they won't get any worse. He knows that this is a possibility, but chooses to move forward with his life rather than remain mired in despair.

A younger patient sees his hope for a better life intertwined with his relationships; his life, his career, someone to share it with, and even with the wonder of creation.

**D** What do you hope for?

**W** uh...personally—a good life, a good life, a career, maybe a marriage when I get older. Maybe a relationship, but there's so many women out there it's hard for me to choose which one I want.

**D** (chuckles)

**W** It's like I have a long time to find one.

**D** You're young. Ok...What helps you keep going day after day?

**W** A lot of things...Love for everything I have and everything I see. Just the beauty of it, and the amazingness of it.

This is the kind of person for whom hope has a very holistic, relational character to it.

This relational character figures heavily in the analysis of the next theme.

Hope to be Restored to Community (Family/Friends/Therapeutic Community)

Hope is relational in character, and is often experienced through other people, so it is not surprising that the second most prevalent theme would be a hope centered around getting back to family, friends, and faith communities. John Swinton was quoted earlier, saying "...that the ability of the sufferer to develop some degree of hope is fundamental to the recovery process. The primary way in which hope is engendered within an individual is in and through personal relationships."<sup>1</sup>

Sometimes hope is mediated through friendships:

**D** Hope is the main thing, ok...Have there been times when you felt more hopeful, or less hopeful?

**A** Ah yeah, I felt less hopeful when I'm alone, more hopeful when I've got people around and I'm thinkin' straight.

For this patient, who has a thought disorder and suffers from paranoia, the humanizing aspect of friendships helps to counter his internalized sense of defectiveness and diminished self-esteem, and is seen as one of the most important factors in the recovery process.

For others, family sustains them. For the following two patients, their experience of family has provided a strong sense of hope through the years.

First patient:

**R** It's like--well love keeps me going

**D** OK, love from...?

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<sup>1</sup>Swinton, Resurrecting the Person, 139.

- R** Family  
**D** Family—is your family pretty close?  
**R** Yeah.  
**D** That’s good.

Second Patient:

- D** Who or what provides you with strength and hope?  
**W** My family  
**D** your family  
**W** yeah -- on occasions  
**D** yeah  
**W** on certain occasions they’ve helped me out a lot.  
**D** yeah  
**W** But they’ve had me since I was a kid and so it’s like I don’t know if they’re still willing to take care of me as it were when I was younger. As I’ve gotten older I want to stand, you know, to get, not necessarily to get my own place, but like a mindset from like peer mediators, you know—like peers always assume that you’ll leave when you get older  
**D** yeah  
**W** I know how that works—I’ve grown up, I mean—I’m only 19, but...  
**D** Everybody’s on their own schedule...  
**W** Yeah everybody’s on their own schedule, and I can’t really define how I’m going to leave, or where I might go, or...  
**D** yeah  
**W** I’ve always got my family. Family, and my mom and all them. They’ve always been there for me  
**D** ok... What helps you keep going day after day?  
**W** I like different things – You know I guess it goes back to the relationship thing. I want to get a relationship some day and have kids  
**D** uh huh  
**W** I’m far from it now, I’m still young, like you said

The second patient, even though he eventually wants to leave home and begin new relationships, still has a strong relational bond to his family, and feels that “they’ve always been there for me.” That experience of being cared for in the past informs his confidence of being cared for in the future.

One patient’s connection to her children fueled her desire to get well:

- M** There’s been a time in my life when hope, and faith, failed me.  
**D** Oh really? How did you make it?  
**M** By having my children to love, and being with me all the time, and not in an

orphan home.

Family, friends, and communities not only can be the ones who provide care; they can also provide the reason an ill person has to get well. All too often, patients who suffer from severe mental illnesses believe that they have nothing to offer. Friends, families, and faith communities remind them that they are needed, and give them motivation to move to wholeness.

The same is true of another patient who had been estranged from his family for nearly twenty years. Social workers were able to track down his children, and once he had a chance to talk to them, he experienced a rise in hope unlike any other:

**D** ok...Have there been times when you felt more hopeful, or less hopeful?

**B** Like just yesterday I got in touch with my family after 20-some years,

**D** yeah

**B** and I felt like I had to go through with the program. I know I had to go through it before I got in touch with them, but since I got in touch with them, I found out that my kids have grown up and they've got grandkids, and now I *know* that I got to get finished the program, and it's like I got more hope *in* finishing the program, cause I got more reasons to want to finish the program, not only just for seeing my kids and my grandkids, but for myself.

Often just talking to family and friends is enough:

**D** I guess this is a question about times you felt more hopeful, or are there times when you felt less hopeful?

**J** lemme think...well, yeah, there've been down moments, yeah.

**D** And what got you through those times?

**J** Oh, the spirit and reading my King James, talking to family and, you know, friends, people who understand what you understand, you know.

**D** So you had a good network of...

**J** communication

**D** community, and church and stuff.

**J** I talked to family and some of them been to church and some of them don't go.

**D** ok

**J** We sort of all get together and talk about things.

Faith communities can bring a very strong sense of belonging, and lend a blessing to

what may have been a very traumatic journey. Communities are absolutely essential in the life of a person who suffers from an acute mental illness such as schizophrenia. The community is the agent of hope in the life of an ill person, embodying God in acts of compassion and creativity, helping to create power to live a fulfilling life rather than trying to control it. One man, a Muslim, told of his wandering in and out of illness and addiction through the years, alongside his crises of faith.

**D** Now, have there been times when you felt more hopeful, or less hopeful?

**Y** There's been times when I gave up.

**D** Gave up?

**Y** Gave up at certain times

**D** yeah

**Y** You know, uh, gave up, you know, but then again, you know things God speaks to you, speaks to us, you know well everybody has done wrong, we all got sin, good and bad in us. You know, I've done wrong. You know, but it says in the Qur'an that he may lead you off into wrongdoing and guide you back for you to have experience and see what that is, because he may have another purpose for you.

**D** huh. So you—wow.

**Y** I had stopped praying for many times but, you know, but this man named Dr. Siddiq Ali, he come from Bangladesh who I met at the mosque, he told me he said that, uh, things might not happen in salaah in attending to in prayer you may want things to happen in a week or two it may take five or six years for things to happen, but a Muslim knows his duty is if a person says he's a Muslim, and follows Muhammad, he knows that he has five prayers to meet the day. (he says a words here that are garbled on the recording)...in prayer. Then if he guided, if he shows interest, overall interest like even if he's out of this culture, and shows overall evidence of coming to salaah til Juno, and praying and praying, God will take that burden off of him.

He found a hope-giving passage from within the sacred texts of his tradition that helped him make sense of the agony he had gone through, i.e., that Allah had led him “off into wrongdoing” and guided him back, so that he might deepen his understanding. In addition, he was able to use the teachings at the mosque he attended to help him learn patience, and in so doing to restore a sense of hope.

For some, going home is equated with being restored to their families and communities, and being restored to health:

- D** What helps you keep going day after day?  
**L** Hope that I'll be going home, that's one thing that helps get me through being here, being here, the hope of going home.  
**D** Are you getting out of here pretty soon?  
**L** I have a hearing which is supposed to be here, and it's supposed to be on Thursday.  
**D** They're usually on Wednesday or Thursday  
**L** It's supposed to be Thursday  
**D** OK...So home is a big one, I think that's true for a lot of people. I'd wanna get home as soon as I could!  
**L** Yeah...And hopefully never ever have to come back to a hospital again, I hope.

Hope for restoration of relationships is often what sustains hope in the present. This will be examined in the analysis of the next theme.

#### Hope to be Sustained in the Present/Right Now

The hope to be sustained in the present was one of the surprises of the interview process. Rather than focusing on whom or what their hope was focused, patients spoke to the very character of their experience of hope. This may have to do with the temporal nature of the question, "Can you tell me about a time when hope was important to you?" A few patients took the question as an invitation to reflect on times in the past when hope sustained them, but even those patients affirmed along with the others that while hope has gotten them through things in the past, it is also getting them through things right now, as the excerpts bear out:

- D** Okay. Can you tell about a time when hope was especially important to you?  
**M** Uh. (pause) I think right now actually. Being here, I don't have much freedom. Hope is real important right now because of what I'm facing.  
**D** Right  
**M** I don't know when I'm getting out, so hope is real important.  
**D** Okay. What helps you keep going day after day?  
**M** (pause) I'd have to say God. That's what gets me through

**D** Lots of people say that.

**M&D** (chuckling)

**D** Okay...Have there been times when you felt more hopeful? And have there been times when you felt less hopeful?

**M** Oh yeah.

**D** Tell me about the more hopeful time first.

**M** Alright. Well—there are times when...Well actually, they kind of go hand in hand, because at times when, whenever I feel like I just can't do it anymore, I just can't go on, something happens, something else happens that picks me up. Like in the holy Qur'an they talk about patience—patience is real important. And that as soon as you think you're not going to be able to do something any more—or you're at your wit's end, Allah comes in, and, you know, helps. The help of Allah. That's happened to me here a few times. There were times that I felt that I couldn't go on, and God helped me.

**D** So those times you are in the greatest need were also the times that you opened up to the possibility of hope, even more.

**M** Yeah.

This patient finds hope from within his religious tradition and deepens his characterization of it by saying that he experiences hope most fully during times of limitation. Hope comes in the form of deliverance. This hope for deliverance was also true for another Muslim patient, who was quoted earlier:

...Then if he guided, if he shows interest, overall interest like even if he's out of this culture, and shows overall evidence of coming to salaah 'til Juno, and praying and praying, God will take that burden off of him.

The same patient talked of his hope in the present:

**D** ok...Can you tell about a time when hope was important to you?

**Y** Hope--hope is always important. ...Hope is always important. Hope—hope is when, like, you... Hope is always important, it's just the prayer thing, you know, like praying we ask God to do things, we call that a personal doula, as we get finished making our salaats in between coming to the end of our four prostrations, you know, we ask god to do certain things for us. This may not happen in a week's time...

**D** yeah

**Y** It may not happen in a month's time but you know that you're a Muslim you've got to pray five times a day and ten salaats 'til Juno which is the Friday evening assembly...that's hope there. Hope, hope, hope for a better world and in the hereafter and on up.

Not enough Muslim patients were interviewed to draw any conclusions, but it was of interest that both of the Muslim participants had both hope to be sustained in the present as well as hope for deliverance on the future.

Most answers to the hope question, “Can you tell about a time when hope was important to you?” had a sense of immediacy, and were not constrained to age, gender, or race:

A forty-something white male:

**R** When hope was important to me? Uh...well right **now** hope is very important to me.

**D** So definitely now and at times in the past, has hope been important to you?

**R** Yes sir.

A sixty-ish white female:

**M** It's guided me all my life.

An African-American man in his forties:

**M** It's all my life hope has been important.

An African-American man in sixties:

**B** Hope is always important to me. I don't know just from any time, it's always important to me.

**D** yeah. Ok. That's something I'm really seeing a lot with people. It isn't any just one time that hope is important—it's always important. What helps you keep going day after day?

**B** The hope that I'll get better.

It is clear from this that people of all types in the group studied tend to think that hope is always necessary, not simply for deliverance in the future but for sustaining grace in the present.

Another patient had a sense of the immediacy of hope in his desire to do something to get himself out of the hospital:

**R** (looks back at the sheet) Can you tell about a time when hope was important to you? Right now it is, because I need to get out of here, cause I can't do anything.

Hope not only sustains people in the present and assures them of future security, it gives them power to act (“to do” something) in the present. This theme is discussed in what follows.

#### Hope to Do What I Want (Power/Agency/Self-Esteem)

The hope “to do what I want” is fundamentally the hope for agency, for ability to have creative control over one’s own life. Simply defining it as power “to do” may make it appear less frequently in the raw data of the transcriptions, but it remains a fundamental subtext to many of them. In the case of a persistent, severe mental illness, daily life presents many difficulties, some of which seem insurmountable. The creativity that results from the soul’s attempt to make sense of reality, or to adjust to it, gives it hope to go on. In the case of a person with a severe form of schizophrenia, one must realize that often the person’s mental capabilities may be so impaired that they are unable to reason out the cause of their suffering, let alone come to an understanding of it. Creativity has to merge with community and compassion in this case, as other persons are called in both to provide care for the person and advocate for their fair treatment. My correspondence with Farley, mentioned earlier in this report, confirmed this:

I would think *any* form of suffering calls forth a compassionate response...I think that any situation that defrauds us of our agency, hope, etc. is one of real suffering and pathos, generating suffering loved ones as well as the one who suffers most immediately.<sup>2</sup>

This excerpt is from a man who suffers from paranoid schizophrenia, and has a sense that he ought to be “doing something” about his condition:

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<sup>2</sup>Wendy Farley, email message from author, April 17, 1999.

- D** Have there been times when you felt more hopeful? And have there been times when you felt less hopeful?
- R** Can I read that myself? (reaching for the questions) Want me to answer these real quick? Let's see. Hope is an emotion or feeling for the promotion of oneself when one does not feel as, for lack of a better word, prominent, doesn't feel good about themselves, doesn't feel the situation is going that great, otherwise doesn't actually they have the ability to feel like they're going to get much further in life as far as the situation goes that I'm in right now as far as that statement is concerned I don't actually have much hope of getting out any sooner than is proposed, since I'm having to stay here because of court, so anyway they are trying to keep me here two weeks longer
- D** Oh really
- R** Instead of letting me out earlier, like the court said they could. On the other hand, as far as I define hope, that's about the only definition I can think of right now
- D** That's a good one.
- R** I guess I don't have a dictionary to define it –that's what I said a minute ago. What do I hope for? Well, I hate to say cause I'd be afraid someone might do something to the contrary to keep me from having what I hope for.
- D** I could see that.

He talks about feeling like there's nothing he can do to better his situation, and that even if he spoke out his hope, that others might try to prevent him from attaining what he wants. He eventually says what he wants in the following passage:

- R** Actually I'd like to be able to have my own life, and be able to do what I want to do and need to do in my life, for the betterment of myself. And also, I kind of like other people, but then again on the other hand there are some people I don't. There are lots of different careers and jobs, and people in the world, and I really can't do what I was thinking a long time ago—I've changed a little bit since I was younger. So what I hope for now is a little different than when I was younger.

He wants a sense of creative control of his life, and perhaps a relationship and meaningful work, but his hope (as has been seen in others' stories) is shaped by the real limitations he experiences in the present; namely "I really can't do what I was thinking a long time ago." There is a sense of grief that any forty-something male has over opportunities that have come and gone, and perhaps a sense of anger over the fact that opportunities have

been stolen by his illness. He also has a sense that he needs to be “doing” to be worthy (also not unusual in men his age):

**R** I feel like I’ve been laying around here for 24 hours a day for thirty days, and I can’t do anything. People keep hauling me all over the place, giving me pills that I can’t take.

**D** Well, what helps you keep going day after day?

**R** Well, I don’t know. I think I’ve got a physical problem here

**D** But you seem to do, I mean... pretty well—you’re not in the hospital all the time like some people I’ve seen—so something must be helping you to hang in there ...

**R** Well I can’t name all that stuff.

**D** Well, have there been times when...

**R** I don’t know. I know I need to do stuff. I’m just sitting around, and people are doing stuff.

It is clear that until he regains his sense of creative direction over his life he will be dissatisfied. The role of the pastoral caregiver in this situation is to encourage him in the things he does have control over, so that he may increase in creative self control.

Other patients express their hope simply as just doing what they want, or doing whatever is within their legal right.

First patient:

**d** (long pause) Doing my best. ... (pause)

**D** Doing your best...looking forward to things?

**d** Yeah.

**D** Like what?

**d** Just...like doing what I want.

Second patient:

**D** What do you hope for?

**M** OK, I hope that no nobody turn against me. Cause I don't need no player-haters, hating my lifestyle. I can't just go straight forward, and expect everybody to move out of my way--"I'm comin' through," you know, but what I need to do is not every time, like "may I," you know, I don't like that.

**D** uh-huh.

**M** I hope that what I can, everything legal, that I'm doing, I can get it did, you know, without everybody trying to stop me. That's that answer.

It is not unusual for people who suffer from severe mental illnesses who experience institutionalization to feel as if they are trapped in a system where everybody is telling them what they need to do. This is often experienced as an assault on the creative control they want to have in their lives. It is clear from this study that effective treatment for this sort of patient has to involve finding ways to link the motivational power of hope to treatment compliance.

Hope “to do” has been seen so far as power to have creative control over one’s own self-development, but other patients see it as a way to be an agent of hope for others:

**D** Have there been times when you felt more hopeful?

**R** Yeah, like when I’m able to help somebody else, and they don’t know exactly how I’m helping them, cause the voices say I’m their—the only begotten son

**D** Huh.

**R** So I can help people cause I know my life that well—I know what they need

This patient probably has something like a Christ delusion, but he also derives a sense of well-being and hope from being able to help others. All too often patients believe themselves to be in such a state of spiritual poverty that they have nothing to give. Long periods of illness have a way of convincing them that they can only be “taken care of.” When patients are reminded through relationships that they are necessary and have something of value to offer, their hope increases.

#### Hope to Get Out of the Hospital/Back to Normal

The hope for eventual release from the hospital, even if it does not come up in conversations, is one that most patients hold. For some of them, their whole idea of hope is linked to getting out, because it signals a return to normalcy:

First patient:

- D** What do you hope for?
- M** I hope that I'll be getting out of here soon, and that it won't be where people play jokes and think my life means nothing

Second patient:

- D** What helps you keep going day after day?
- L** Hope that I'll be going home, that's one thing that helps get me through being here, being here, the hope of going home.

In some ways this theme is linked to the second theme (Hope to be restored to community), but often enough patients did not explicitly mention a desire to be with other people, they just said that their hope was to be out of the hospital. The next three excerpts are examples of this:

First patient:

- D** What do you hope for?
- G** To get myself outta here, to be well, and on my own

Second patient:

- D** ok...Can you tell about a time when hope was important to you?
- A** Well, maybe when I was in jail, I had a hope that I'd get better, get out of here in the hospital, that the medicine helps me get my mind, my actions, and my speech—my words—all equaled out to be normal.

Third patient:

- D** The first question I've got is, How do you define hope?
- d** Definition of hope?
- D** Yeah. Just whatever comes to mind
- d** Uh. A purpose for something to come
- D** ok ...A purpose for something to come?
- d** yeah.
- D** ok. What do you hope for?
- d** I hope I get out of here. (laughs)
- D** A lot of people hope for that! (laughing)

At face value, one might think that patients are offering glib responses to deep questions

about hope, but here again, one must remember how significant an accomplishment it is to get out of a hospital after having gone through an acute episode of a major mental illness. It is evidence to them and to the larger community that they are able to function on their own. This is often a well-deserved cause for an increase in self-esteem and optimism.

While some patients spoke of their desire to simply get out of the hospital, others both spoke of their desire to be both out of the hospital and restored to loved ones:

**D** What do you hope for?

**S** to get out of this hospital by next week.

**D** yeah

**S** I guess the doctors, the social workers been workin on it—I think the social workers could be workin' a little harder—find other places—right now one of them's found me one place, a place that she thinks I could get in, I think she could work a little harder to get me somethin' else cause I know I could always go back to this place called the xxx xxx, here in Louisville, it's a mission, for women, I gotta keep in mind you know with the holidays coming up, I got family I want to be around, and I'm not trying to be here for them.

This patient wants to get out of the hospital as soon as possible, but also has a motivating factor of wanting to be able to visit with her family over the holiday season. She also suspects that the hospital staff are not working hard enough with regard to her placement.

These excerpts give some sense of how the themes arose out of the conversations, and how they became useful in the second level of analysis.

### **Description of the Second Level of Analysis**

The second level of analysis was conducted in January, 2006. Copies of the interviews were redistributed to all researchers, along with an instruction sheet (see Appendix 9) to assist them as they analyzed the interview data. The coding team took the themes that were found most prevalent in its analysis of the interviews, and read back

through the interviews and ranked the themes in terms of their prevalence. They read through the interviews, and every time they took note of one of the themes coming through a patient's narrative, they put a mark in the column of the corresponding theme. Once they finished, the primary researcher examined the combined scores and formed a ranking of the themes that were of greatest importance to the patients.

Ranking the top hope themes (out of 280 total votes)

1. Hope for a better life.  
(with a score of 81, or 29% of the total)
2. Hope to be restored to community (family/friends/therapeutic community).  
(with a score of 66, or 23.5% of the total)
3. Hope to be sustained in the present/right now.  
(with a score of 49, or 17.5% of the total)
4. Hope to do what I want (power/agency/self-esteem).  
(with a score of 47, or 16.8% of the total)
5. Hope to get out of the hospital/back to normal.  
(with a score of 37, or 13.2% of the total)

The initial stage of a spiritually-based clinical pathway for intervention with patients who have schizophrenia is derived from these findings.

#### Development of Spiritually-Based Clinical Pathway

Clinical pathways identify desired client outcomes and provide the sequence of events necessary to achieve these outcomes with optimal efficiency. To develop the spiritually-based clinical pathway, the ranked hope themes were used to provide the chaplain or other caregiver with first-stage information about issues that are most likely

to be on the mind of a patient who is experiencing schizophrenia. If clinicians desire good outcomes for patients, they have to uncover what motivates a patient's desire to comply with treatment and move toward wellness. This is what the project does. It provides a tool for clinicians to quickly gain access to the fundamental motivational force – hope. Not all patients are the same, to be sure, but the project has shown that these five themes are ones worthy of consideration:

1. Hope for a better life.
2. Hope to be restored to community (family/friends/therapeutic community).
3. Hope to be sustained in the present/right now.
4. Hope to do what I want (power/agency/self-esteem).
5. Hope to do get out of the hospital/back to normal.

This is the first stage of the spiritually-based clinical pathway, in which the chaplain or caregiver establishes a connection to the sources of motivation for the patient, with a view toward linking that hope to a treatment plan that will move him or her toward wholeness. The outcome of this Doctor of Ministry project is only the first stage of a multi-stage process that Pastoral Services will be working on in the coming months.

#### Presentation of the Stage to Pastoral Services Staff

At a staff meeting in early February 2006, this researcher presented the results of this study to the other researchers in the department, explaining how the two levels of analysis worked together to produce the first stage of the spiritually-based clinical pathway. It was explained at the time that although the study in itself was useful in the development of the initial stage of the spiritually-based clinical pathway, more work would be necessary if a full clinical pathway were to be developed. Initially the

departmental plan was to develop a full spiritually-based clinical pathway, but as the study progressed it became obvious that what was emerging was a not a full pathway but rather a first stage. The other researchers discussed their perceptions of the project. Among the items discussed were how difficult chaplaincy can be, how chaplains are often a physical embodiment or representative of hope for patients, and how the interview process itself has a potential to increase a patient's sense of hope and well-being.

### Chapter Summary

The project has involved the gathering of data through interviews of twenty patients carrying a diagnosis of schizophrenia. All were patients at a state-run psychiatric hospital. The interview data was de-identified according to HIPAA guidelines, and distributed to a team of researchers, who, in a first level of analysis, looked for themes of hope in the data. These themes were discussed among the researchers, and five prevalent themes were chosen. In a second level of analysis, the researchers returned to the data, reading back through it with the five prevalent themes in mind, noting where and how often they saw these themes in the data. Those findings were brought together and scored to produce a priority ranking of the themes. This ranking in turn became the basis of the development of the first stage of a patient-derived, research-driven, spiritually-based clinical pathway for the pastoral care of patients suffering from symptoms of schizophrenia. The project found ways to link the motivational power of hope to effective treatment compliance. These results were presented to the Pastoral Services' staff of researchers, as an introduction to development of further stages of the spiritually-based clinical pathway.

## CHAPTER SIX

### EVALUATION—CONCLUSION AND DISCUSSION OF DATA ANALYSIS

#### Difficulty of Conducting Research in a State-Run Facility

Any research involving human subjects involves a considerable amount of preparation, collaboration and accountability. This project was conducted with the blessing of the Pastoral Services Department, the approval of the Executive Staff and the Medical Staff committees, the approval of the Institutional Review Board of the Louisville Presbyterian Theological Seminary, and the close scrutiny of the Institutional Review Board of the Commonwealth of Kentucky. Having five different levels of liability increased the time and effort required to bring the project to light, but given the especial vulnerability of the group studied, it was not unwarranted.

#### Sample Size

This has been discussed earlier in the limitations section, but at various times in the research, this writer wondered if the sample size was large enough to provide an accurate picture of what hope looks like in the lives of people who have schizophrenia. Time did not permit a long-term study, but it would be interesting to see whether a large sample size would have an effect on the results. Other benefits of a larger sample size might be the possibility of determining the effect that various religious or secular traditions have on patients' experiences of hope. Of interest in this area were the two Muslim patients who both emphasized ritual prayer as way to gain Allah's favor and obtain deliverance from their illnesses. One said that if he continued to do his daily

prayers that “God might take this burden off me.” This caused the researchers to wonder whether this is a theme common to many Muslims, or just a similarity between the only two Muslim participants in the study. Of interest for further research would be inquiry into how race, class, gender, age or ethnicity might have an effect on one’s experience or expression of hope. Time and scope of the project limited the project’s ability to address issues such as these.

#### Issues of Consent with Suspicious People

Before the writing of the project prospectus, much consideration was given to the possibility that, even after all the necessary approvals had come from the various hospital, state, and institutional review boards, patients might refuse to be interviewed. Over the course of the study, it was noted that even some of the most paranoid people will give consent to an interview if the clinician has established a good amount of therapeutic rapport, and given ample assurance that the confidentiality of the patient will be secure. Maybe it is the lack of threat patients experience when speaking on the subject of hope, or it could be the personality of the interviewer, or the non-threatening prospect of being interviewed by a chaplain. Over half of the patients who gave consent to the interviews had a diagnosis of paranoid schizophrenia. It could be that they were getting well enough that they were experiencing diminished symptoms of paranoia. The primary researcher had at least some clinical pastoral involvement with at least half of the patients, either as a worship leader, or in a more engaged role as counselor.

#### Spiritually-Based Clinical Pathway

At the outset of the project, it was thought that an entire spiritually-based clinical pathway would be developed, but as the study progressed it became apparent to this

writer that what the project achieved was better understood as a first stage of a therapeutic intervention plan, one which has as its desired outcome treatment compliance. In this stage, a patient's sense of hope is linked to compliance with treatment, be it biological, psychological, sociological, or spiritual, or some combination of those. It is a good first stage, one that lays the groundwork for further research.

### The Immediacy of Hope

One theme that came rather unexpectedly through the course of the interviews was how much hope is of immediate concern to patients in this setting. Patients could think about times in their lives when hope was important to them, but seemed much more interested in speaking of or longing for an immediate hope, one that could sustain them through their daily lives. Often when the fifth question of the interview (Can you tell about a time when hope was important to you?) was asked, the answer would be along the lines of, "Hope is important to me *now*." Upon reflection, the idea that hope is never more important than it is "right now" might seem rather obvious, especially in the midst of the difficulties that patients go through while hospitalized. It certainly makes sense, and points out the value of simply asking patients what their needs are, rather than assuming that they are self-evident.

### Chaplains as Embodiment of Hope

One of the ideas that surfaced in the discussions of the interviews was not so much a theme to be distilled as a phenomenon to be observed, that chaplains and pastoral caregivers embody hope for patients. The interviews themselves became an opportunity for therapeutic intervention, a time of clarity in the midst of confusion, one in which the existential power of shared humanity created a spiritual renewal. Patients often thanked

this researcher for interviewing them, even though they were aware that more thanks were due to them for making the effort to let down their guard. One explanation for this is that often patients in the mental health system think that a hospital is a place where things are done *to* them rather than done *with* them. An interview that doesn't feel like an interrogation can have the effect of creating a sense in patients that they have something of value to offer. That feeling has a profound effect on their sense of optimism, self-esteem, and hope. An excerpt from an interview with one of the patients gives some sense of this:

**M** I'd say hope was important to me when I was a little kid because what it was-- when I first got diagnosed that I had a chemical imbalance I didn't have no hope. I was suicidal, I felt down and out. The dream of being normal like everybody else was on my mind. So I figured that if I just gave up on life there'd be no way out, but now with doctors, nurses, nurse practitioners, mental health techs in the hospitals, chaplains like you -- 'cause there is a hope. Sometimes I think God has to work through mankind through the doctors, the nurses, the mental health techs, and the nurse practitioners and the doctors themselves and the physical therapists that have the means that when somebody with a drug problem or an alcohol problem or been a car accident victim-- See God could use his power to work through mankind cause see God gives mankind the power to work, see if God can give mankind the power to build a house, to build a building, or build a vehicle or...weapons of mass destruction like we have going to war with in this world, then God can use mankind ...to build a dream.

**D** Alright! That's beautiful.

This patient not only sees the *chaplains* as incarnations of hope, but he broadens it to include the wider collaboration of the entire hospital staff -- a diverse group of professionals, all working together to bring about healing and wholeness. Each made a decision at some point in their lives to help patients find hope in a context of severe mental illness, and in this patient's words, "with doctors, nurses, nurse practitioners, mental health techs in the hospitals, chaplains like you...there is a hope."

## Chapter Summary

In summation, it seems fitting to reiterate what has already been said earlier in the project, because throughout the project, its truth has been borne out: Creativity can be blocked by evil. Compassion can be thwarted in its attempt to liberate and redeem. Community can fail in its responsibility to help those who need it. All of this has been seen to happen in history, both in the context of the individual and the institution, but as much as evil has shown itself in history, so too has redemption. As pastoral caregivers we are given the high calling of working for this very redemption. Work such as this, in creativity, compassion, and community, gives us a taste of the love of God for this world we live in.



## APPENDIX 1



COMMONWEALTH OF KENTUCKY  
**Cabinet for Health Services**  
 Department for Mental and Health and  
 Mental Health Retardation Services



**An Equal Opportunity Employer M/F**

**AUTHORIZATION AND CONSENT FORM**

**DATE:** \_\_\_\_\_

**CLIENT NAME:** \_\_\_\_\_

**PROJECT:** *Finding Hope in a Context of Severe Mental Illness*

I hereby consent to participate in the research project, *Finding Hope in a Context of Severe Mental Illness*, conducted by the Pastoral Services Department of Central State Hospital. I understand that my participation in this research is completely voluntary. Refusal to participate or discontinuing my participation at any time will involve no penalty, and participation will not affect my treatment or length of stay in the hospital in any way.

In signing this consent document, I also authorize the use, disclosure, and release by Central State Hospital and its employees of my medical records, including health information protected by federal or state regulations or statutes, to Chaplain David Dillard for research purposes. I understand that I may revoke this authorization in writing at any time by mailing or delivering a written revocation to Chaplain David Dillard

I also grant the Pastoral Services Department of Central State Hospital permission to audiotape me and to use said audiotape in connection only with the research project, *Finding Hope in a Context of Severe Mental Illness*. The purpose and use of these recordings is limited to research regarding the Pastoral Services Department's ongoing Performance Improvement goals. The recorded data gained from these interviews will be transcribed after audiotaping, and any identifying information will be removed according to the Health Information Portability and Accountability Act. Access to raw data will be restricted to the research team. I understand that if I reveal any information that poses a direct threat to myself or others, or involves proposed criminal activity, the researcher is required to report this to authorities.

If I have questions about this study, I can contact the researcher, Chaplain David Dillard, M.Div., at (502) 253-7068. If I have any questions about my rights as a research volunteer, I can contact the Cabinet for Health and Family Services Institutional Review Board at 502-564-5497 x4102.

I have read this agreement before signing below, and I have been given a copy of this authorization and consent form.

\_\_\_\_\_  
**(Signature of Client)**

\_\_\_\_\_  
**(Date)**

\_\_\_\_\_  
**(Signature of Client Parent/Legal Guardian)**

\_\_\_\_\_  
**(Date)**

\_\_\_\_\_  
**(Principal Investigator)**

\_\_\_\_\_  
**(Date)**



APPENDIX 2  
Central State Hospital  
Pastoral Services Performance Improvement Project  
July, 2006  
Finding Hope in a Context of Severe Mental Illness  
Patient Interview

**Interview questions**

The following questions are centered around your understandings and experiences of hope in the context of your illness. Answers will be audiotaped and the interviewer may take a few notes, but no identifying information will be made public. Answer as freely and honestly as you feel comfortable.

1. How do you define hope?
2. What do you hope for?
3. Who or what provides you with strength and hope?
4. How does hope help you cope with your illness?
5. Can you tell about a time when hope was important to you?
6. What helps you keep going day after day?
7. Have there been times when you felt more hopeful? Less hopeful?

Thank you for your time and interest. You are helping Pastoral Services provide better care for patients.

## APPENDIX 3

## CENTRAL STATE HOSPITAL

**JCAHO Function:** Ethics, Rights and Responsibilities (RI)  
**Standard of Practice:** RI - 110  
**Subject:** Informed Consent  
**Effective Date:** 03/30/05  
**Supersedes:** HH 7.50 (04/21/93, 06/24/97, 04/15/03)

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**STANDARD STATEMENT:**

Patients' participation in care, treatment and service processes and procedures is evidenced in the following manner.

**PROCEDURE:**

<b>Voluntary Admissions</b>	The form, <i>Application and Request for Voluntary Admission</i> , is explained to and signed by the patient. The physician's signature attests that the patient meets the criteria for voluntary admission and is capable of making an Informed Consent decision.
<b>Voluntary Treatment With Psychotropic Medications</b>	<p>The physician documents in the medical record that the individual being treated has been informed of the purpose, benefits, risks, side effects and alternatives relative to the medications administered or prescribed and that the individual is able and willing to give Informed Consent for their use.</p> <p>Informed Consent is obtained for use of psychotropic medication except in emergency situations (as defined by 908 KAR 3.010, Sec. 2(2)(c)) or when effecting court orders for involuntary administration of psychotropic medications.</p>
<b>AMA Discharges</b>	<p>The patient and physician complete and sign the <i>Discharge Against Medical Advice</i> form which documents:</p> <ul style="list-style-type: none"> <li>• the patient's request for discharge against this advice</li> <li>• the physician's assessment that the patient does not meet the criteria for involuntary hospitalization</li> </ul>
<b>ANI (Admission Not Indicated)</b>	Documentation is maintained when individuals are released with medications or prescriptions following evaluation.
<b>HIV/AIDS Testing</b>	The form, <i>Obtaining Consent for Blood Analysis for HIV Diagnosis</i> , is completed and signed, following explanation by the physician.
<b>Participation in Research Study Projects</b>	<p>The physician documents in the medical record that any patient who agrees to participate in a research project has been provided with:</p> <ul style="list-style-type: none"> <li>• a description of the expected benefits</li> <li>• a description of the potential discomforts and risks</li> <li>• a description of alternative services that could also prove advantageous</li> </ul>

- an explanation of the procedures to be followed, especially any that are experimental in nature
- an opportunity to refuse to participate and assurance that their refusal will not compromise their access to services
- institutional approval of the research

### **ECT Treatment**

The physician explains to the patient, family and/or significant other the nature of the treatment, purpose of the treatment, possible side effects, risks and potential complications. The physician then pursues completion of informed consent for ECT treatment. A form consenting for ECT treatment at other facilities is signed by the patient or authorized party in the presence of the physician. The patient is given a copy of the signed consent. A copy is filed in the chart and the original is sent to the treatment site.

### **Recording/Filming**

In order to minimize the risk of compromising a patient's privacy or confidentiality, consent is obtained before recording or filming for purposes other than patient identification, diagnosis or treatment.

### **Patient's Participation in Treatment Plan**

For the Individual Treatment Plan and Treatment Plan Reviews, the patient's signature serves as documentation of participation in development of the plan.

The physician's signature indicates that the following elements have been discussed with the patient:

- nature of the proposed care, treatment, services, medications, interventions or procedures
- potential benefits, risks or side effects, including possible complications
- likelihood of achieving care, treatment and service goals
- reasonable alternatives to the proposed care, treatment and service as well as relevant risks, benefits and side effects associated with those alternatives, including the possible outcome of not accepting care, treatment and services
- legal criteria, when noted, that would take precedence over the patient's confidentiality privilege.

To augment the various forms and to provide a more complete picture of the patient's understanding of treatment and capability to give Informed Consent, entries describing interactions and activities pertaining to Informed Consent are recorded on an ongoing basis in the medical record.

Specific instances when this documentation is appropriate include, but are not limited to, noting discussion of:

- when the patient inquires about and receives answers regarding treatment
- when the patient meets with staff regarding progress made and/or revisions in the plan of care.

## APPENDIX 4

## CENTRAL STATE HOSPITAL

**JCAHO Function:** Ethics, Rights and Responsibilities (RI)  
**Standard of Practice:** RI - 160  
**Subject:** Confidentiality  
**Effective Date:** 10/15/04  
**Supersedes:** B21, B32, W2, W3, W7, W9, W15 (05/27/94), RI-150 (06/01/97, 07/10/97, 11/14/03, 10/15/04)

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**STANDARD STATEMENT:**

All information identified by Federal and State regulations and hospital standards as confidential is not disclosed, or caused to be disclosed, by current or former hospital employees without prior consent of the appropriate authority(s) of Central State Hospital. All hospital staff, volunteers, students, Governing Board members, community agency representatives working in liaison with the hospital, and visitors are informed of the confidentiality regulations and are required to sign and abide by an agreement to assure confidentiality.

**PROCEDURE:****Confidentiality of Patient Records**

Patient information, whether accessed through direct contact, observation, conversation with secondary sources, written documents, or electronically stored, is confidential and is not disclosed outside the scope of assigned job duties without prior authorization of appropriate hospital authorities. This includes:

- patients who are seeking or have sought admission to the hospital
- current or former patients of the hospital
- patients' diagnostic and assessment information
- patients' treatment plans and response to treatment
- patients' discharge plans and circumstances surrounding discharge

If usefulness of the information related to the patient's health can be maintained, personal identifiers are removed whenever possible.

**Confidentiality of Employee Information**

Information about hospital staff, whether accessed through direct contact, observation, conversation with secondary sources, written documents, or electronically stored, is confidential and is not disclosed outside the scope of assigned job duties without prior authorization of appropriate hospital authorities. This includes:

- pre-employment background checks, evaluations, testing, interviews
- information collected on state and hospital HRIS data bases or printed reports generated therefrom
- health information, including wellness information, worker's compensation health reports, ADA health reports, FMLA health reports
- employee-initiated actions such as grievances and their resolutions, Personnel Board appeals and their resolutions
- employee performance reviews, investigatory information, disciplinary actions

**Confidentiality of Hospital Administrative Documents**

Hospital administrative documents, whether accessed through direct contact, observation, conversation with secondary sources, written documents, or electronically stored information, is confidential and is not disclosed outside the scope of assigned job duties without prior authorization of appropriate hospital authorities. This includes:

- incident reports
- investigatory reports

- administrative correspondence and memoranda

**Controlled Access to Patient Information**

Only employees who are directly involved in a patient's care and treatment have access to the patient's medical record or other treatment information.

Telephone access to information about hospitalized patients is controlled through utilization of a unique patient identification number (PIN) assigned to each patient upon admission. Acknowledgment of a patient's admission and contact with the patient is granted only when the PIN number has been correctly given.

Visitors to the hospital are notified about their obligation to maintain patient confidentiality through the visitor registration process at the hospital's entrance.

Dissemination of information contained in patient medical records, hospital reports or electronic data collection systems is governed by federal and state regulations and hospital operating procedures. Authorization must be obtained through the Health Information Services Director prior to any copying or dissemination of patient records to ensure compliance with these regulations and tracking of disclosures.

Upon admission, all patients are provided with a "Notice of Privacy Practices", informing them how the hospital may use and disclose their health information without requesting an additional signed release of information.

Upon admission, all patients are asked to sign a "Consent to the Use and Disclosure of Psychiatric, Drug, Alcohol and Medical Information for Treatment, Payment or Healthcare Operations", enabling the hospital to follow the scenarios of the Notice of Privacy Practices.

**Controlled Access to Employee Information**

Only employees who are directly involved in creating and maintaining employee information have access to such information (i.e., personnel files, electronic records and information, personnel reports, supervisory files, investigatory information). Documents maintained in employee personnel files may only be inspected and copied after a written request is made under KRS 18A.020. Other written information pertaining to employees may only be inspected and copied after a written request is made under KRS 61.884 to the proper custodian.

**Controlled Access to Hospital Administrative Documents**

Administrative information about the internal operations of the hospital is not disclosed without the prior authorization of the Hospital Director. Citizens, or hospital employees who do not have access to such documents within the scope of their assigned job duties, must request access to hospital administrative documents in writing according to Kentucky's Open Records Law (KRS 61.870 to 61.844). A determination as to whether the request is permitted or denied will be issued in writing within three working days of the receipt of the request.

Employees are not permitted to disclose to the media, community agencies or in public forums hospital administrative documents, policies, or processes without prior permission of the Hospital Director.

**Controlled Computer Access**

Each employee requests access to the hospital's computer network, containing patient- and employee-related information, by means of an employee sign-on/password request form. The request is initiated by the employee's supervisor and reviewed for approval or denial and level of access by Management Information Services. Employees who allow others to use their password, who seek to gain unauthorized access to confidential information outside the scope of their job duties, or who provide unauthorized access to confidential information to others, will be considered in violation of the hospital's confidentiality agreement.

**Penalties**

Violation of the hospital's standards of practice on confidentiality will result in disciplinary action up to and including dismissal and may be subject to applicable criminal and civil action.

## APPENDIX 5

## CENTRAL STATE HOSPITAL

**JCAHO Function:** Ethics, Rights and Responsibilities (RI)  
**Standard of Practice:** RI - 165  
**Subject:** Confidentiality of Behavioral Health Records  
**Effective Date:** 03/02/06  
**Supersedes:** B 21 (05/27/94), RI-150 (06/01/97), RI – 165 (06/01/97)

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**STANDARD STATEMENT:**

Staff protects the confidentiality of patients' behavioral health records at all times.

**PROCEDURE:**

1. All medical records, including the unit chart and green folder, are confidential patient records to be used only by persons involved in the direct care of the patient or involved in assessing care provided.
2. Information is not provided to anyone other than persons directly involved in the provision or review of care unless specific release of information is obtained from the patient and entered into the record.
3. HIPAA Privacy and Security is taught in orientation to all employees and the Cabinet and hospital policies are reviewed and signed. Patient Rights is also taught to all new employees. Their understanding of both topics is evaluated through written tests.
4. The patient or the patient's guardian has the right to view the medical record, unless a physician documents that such access could harm the patient.
5. Requests for release of information are processed by the Health Information Management Department.

## APPENDIX 6

## CENTRAL STATE HOSPITAL

**JCAHO Function:** Ethics, Rights & Responsibilities (RI)  
**Standard of Practice:** RI - 320  
**Subject:** Recording/Filming of Events Unrelated to Identification, Diagnosis or Treatment  
**Effective Date:** 03/30/05  
**Supersedes:** HH 7.40 (06/01/94), RI-160 (06/01/97 – deleted 05/07/03)

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**STANDARD STATEMENT:**

The patient's consent is obtained prior to recording/filming with photographic, video, electronic or audio equipment for purposes other than identification, diagnosis or treatment.

**PROCEDURE:**

**Documentation of Consent** When the product is to be used exclusively for internal purposes such as Performance Improvement, education or training, a Consent to Record/Film form is presented for signature at the time the project is discussed with the patient.

Within a reasonable period, patients have the right to rescind their consent.

**External/Public Access** Any external or public presentation of material lending itself to visual or voice recognition of a patient requires a specific, separate consent, in writing, of the patient and the Hospital Director.

**Recording/Filming Without Signed Consent** If consent of every patient involved in any activity or session has not been obtained in advance of filming/recording, the product must remain in the hospital's possession and cannot be used for any purpose unless or until consent is obtained. If consent cannot be obtained, the product must be destroyed or the non-consenting patient(s) must be edited out.

**Confidentiality** Visitors and staff are not permitted to photograph, record or film in patient areas without treatment team and patient approval. All requirements stated above apply.

Anyone who photographs, films or records any activity, event or situation where patients can be seen or heard must sign a confidentiality statement.

## APPENDIX 7

**De-identification of Medical Information**

To de-identify a record, the following information must be removed from all forms of the medical information:

- A. Names;
- B. All geographic subdivisions smaller than a State, including street address, city, county, precinct, zip code, and their equivalent geocodes, except for the initial three digits of a zip code if, according to the current publicly available data from the Bureau of the Census:
  - 1. The geographic unit formed by combining all zip codes with the same three initial digits contains more than 20,000 people; and
  - 2. The initial three digits of a zip code for all such geographic units containing 20,000 or fewer people are changed to 000.
- C. All elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date, date of death; and all ages over 89 and all elements of dates (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older;
- D. Telephone numbers;
- E. Fax numbers;
- F. Electronic mail addresses;
- G. Social Security numbers;
- H. Medical record numbers;
- I. Health plan beneficiary numbers;
- J. Account numbers;
- K. Certificate/license numbers;
- L. Vehicle identifiers and serial numbers, including license plate numbers;
- M. Device identifiers and serial numbers;
- N. Web Universal Resource Locators (URLs);
- O. Internet Protocol (IP) address numbers;
- P. Biometric identifiers, including fingerprints and voiceprints;
- Q. Full-face photographic images and any comparable images; and
- R. Any other unique identifying number, characteristic, or code, except for an algorithmic derivation code or an encoded security code that could allow for the record to be re-identified using the key.

## APPENDIX 8

### **Finding Hope in a Context of Persistent Mental Illness Coding and Analysis, First Stage**

#### *A description of our process so far:*

Interviews have been conducted and data has been collected during October, 2006. During the course of the interview process, the interviews have been audiotaped and in turn de-identified and transcribed. The de-identified transcriptions are now available (as Microsoft Word Documents) to the members of the coding team, which has the opportunity to examine them according to the steps that Renata Tesch describes:<sup>1</sup>

1. Get a sense of the whole. Read through all of the transcriptions carefully. Perhaps jot down some ideas as they come to mind.
2. Pick one document (one interview)—the most interesting, the shortest, the one on top of the pile. Go through it, asking yourself, What is this about? Do not think about the “substance” of the information, but rather its underlying meaning. Write thoughts in the margin.
3. When you have completed this task for several informants, make a list of all topics. Cluster together similar topics. Form these topics into columns that might be arrayed as major topics, unique topics, and leftovers.
4. Now take this list and go back to your data. Abbreviate the topics as codes and write the codes next to the appropriate segments of the text. Try out this preliminary organizing scheme to see whether new categories and codes emerge.
5. Find the most descriptive wording for your topics and turn them into categories. Look for reducing your total list of categories by grouping topics that relate to each other. Perhaps draw lines between your categories to show interrelationships.
6. Make a final decision on the abbreviation for each category and alphabetize these codes.
7. Assemble the data material belonging to each category in one place and perform a preliminary analysis.
8. If necessary, recode your existing data.

Using this method of coding will result in a distillation of the data that will present a richer analysis, one which safeguards the identity of the patients and deepens understanding of them. While much of the work in the analysis process consists of ‘taking apart,’ (for instance into smaller pieces), the final goal is the emergence of a larger, consolidated picture.<sup>2</sup> To strengthen reliability and internal validity, transcriptions will be read by various members of the coding team to look for themes and interpretations that seem to be present across the spectrum of patients interviewed and agreed upon by the members of the coding team.

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<sup>1</sup>Tesch, *Qualitative research: Analysis types and software tools*, 142-145.

<sup>2</sup>Ibid., 97.

**Benefits of the project:**

The benefits this project may provide to knowledge and practice include the following:

- A. The project may facilitate communication and dialogue on the subject of nurturing hope in a context of persistent mental illness.
- B. The project may create an easily replicable method for nurturing hope among patients, which can be of use to chaplains, pastoral counselors and psychotherapists.
- C. The project itself, as well as the newly formed research driven, patient derived spiritually-based clinical pathway for pastoral intervention may be used in further application and dialogue in the field of pastoral counseling and psychotherapy. This dialogue may lead to formation of other tools for spiritual intervention or critical thinking in this area.
- D. The project may provide a framework for further study of hope in persons with diagnoses different from schizophrenia. In this writer's current context, it could be extended to the other major mental illnesses treated by Central State Hospital; namely, bipolar illness and severe depression.
- E. The project will fulfill a performance improvement initiative taken on by the Pastoral Services Department of Central State Hospital, in keeping with the Hospital's vision to provide professional education and research, and to advance the study of the efficacy of its treatment programs.

## APPENDIX 9

**Finding Hope in a Context of Severe Mental Illness  
Coding and Analysis, Second Stage**

The following themes are the ones the coding team found most prevalent in its analysis of the interviews. Our task now is to read back through the interviews and rank the themes in terms of their prevalence. In other words, read through the interviews, and every time you hear one of the themes coming through a patient's narrative, put a mark in the column of the corresponding theme. Once we have finished, we will combine our scores and have a good picture about what is most important to the patients. Our spiritually-based clinical pathway for intervention with patients who have schizophrenia will be based on what we find.

1. Hope to do what I want (power/agency/self-esteem).
2. Hope to be restored to community (family/friends/therapeutic community).
3. Hope to be sustained in the present/right now.
4. Hope to get out of the hospital/back to normal.
5. Hope for a better life.

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