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# Narratives of Cancer Survivors in Religious Life

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**NARRATIVES OF CANCER SURVIVORS  
IN RELIGIOUS LIFE**

A Thesis  
Presented to  
The Faculty of the Department of Folk Studies  
Western Kentucky University  
Bowling Green, Kentucky

In Partial Fulfillment  
Of the Requirements for the Degree  
Master of Arts

By  
Andrea M. Kitta  
July 2003



**NARRATIVES OF CANCER SURVIVORS  
IN RELIGIOUS LIFE**

Date Recommended 7/23/03

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## NARRATIVES OF CANCER SURVIVORS IN RELIGIOUS LIFE

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72 Pages

Directed by Erika Brady, Tim Evans, and Chris Antonsen

Department of Folk Life Studies

Western Kentucky University

*Narratives of Cancer Survivors in Religious Life* is a careful consideration of the narratives of cancer survivors, specifically those in Catholic religious life. Through the use of interviews and secondary sources, the author addresses such issues as relationship with God, stigmatization, community life, Parson's Sick Role, and labeling theories. This thesis also considers the perceived audience during the performance of narratives, specifically, if cancer survivors in religious life perceive God to be a part of their audience and looks at the structure of narratives concerning cancer survivorship. .

# Chapter One

## Introduction:

I was introduced to cancer through personal experience, like so many people before me. Several members of my extended family were diagnosed with cancer when I was young, but it wasn't until I was a freshman in high school that my great aunt was diagnosed. It was then that I realized the gravity of this illness. As I grew older, I found that I knew more and more people who had been diagnosed with cancer. At first, many of these people were older relatives who eventually died of the disease; but increasingly over time, this group included younger individuals, including my best friend's mother. After becoming acquainted with my first cancer survivor in high school, I realized that I, like many people, had always equated cancer with death. Susan Sontag, a social historian has observed that our society looks at cancer as a terminal disease with no cure and treatments that are worse than death (1978: 7, 64). In reality, more and more people are surviving cancer everyday. Although the statistics tell us that there were 1,334,100 new cases of cancer in 2002, there are also 777,600 people who survived out of that group, meaning that they survived a one-year mark. In 1976 there was a 50% chance of five-year survival and that rate increased to 62% in 1998 (American Cancer Society 2003: 6-19). I realized that with this growing trend, there was a group of people with a variety of needs and issues that we had not seen before. These people, once thought to be as good as dead, were alive and well. Furthermore, they were not sick! They could participate in the same life activities that they had before their cancer diagnosis, but society had no way of categorizing them. I wondered, how does it feel to come that close to death? How does a person readjust to "normal" life after that? How are these people treated by others?

These questions, along with many others, made me want to do my thesis on post treatment cancer survivors. However, I had no idea of how to proceed. I could not imagine why anyone would want to talk about something so personal to someone they did not even know, much less agree to have this information about them published in a thesis. My solution was to start talking about my idea to anyone and everyone who asked. In less than four months, a person and a solution presented itself. In the spring of 2002, I was writing a paper on religious vocation for a class on folklore and belief. One of my informants, Sr. Elaine Byrne, mentioned the sisters at Mount Saint Joseph to me. She knew of several cancer survivors among the group and felt positive that they would be willing to talk to me. Sr. Elaine was a great help in the following months. We discussed what I wanted to do, and she was more than willing to contact the convent and talk to them about me. She also helped me set up my first of many meetings with some of the cancer survivors.

This thesis will primarily concern stories told by cancer survivors. Although my fieldwork focused on a specific religious group, I have also addressed stories told by lay cancer survivors through the use of secondary sources. (I use the Catholic terminology “lay” and “religious” to distinguish between those who have not responded to a specific religious call and have taken vows in contrast with those who have, respectively.) I have decided to use these secondary sources instead of interviews with lay cancer survivors for a number of reasons. To begin with, privacy issues for most lay cancer survivors are much more involved than some of the issues that I have encountered with cancer survivors within a religious group. Since the survivors in the religious group do not have to deal with issues such as employment and insurance, they are more willing to discuss

these private matters. By using already published resources, I am ensuring that I do not place any informants in harm's way by accidental disclosure. In addition, since I am using these secondary sources only as a means of finding general themes and not specific ones, I feel I am comparing seemingly universal themes and not personal themes.

Investigations of these sources suggest some themes I have found concerning body image, relationship with God and others, and perception of stigmatization that lay cancer survivors typically experience. Through the use of interviews, I have been able to compare the themes of lay cancer survivors in secondary sources to my interviews with cancer survivors in religious life.

I would also like to address the effect of living in a community has on a cancer survivor. Since each of these sisters were already in religious life when they were diagnosed with cancer, they had the experience of living within this community before, during, and after their treatment. I hope to explore how this affected their attitudes, their survival, and their current life. I hope to contrast this to lay cancer survivors and their experience as well, both as a member of a different kind of community and within other interpersonal relationships.

Most accounts, including stories concerning cancer survival, are told to an audience. I am particularly interested in the perceived audience during the performance of these narratives. Specifically, I hope to see if cancer survivors in religious life perceive God to be a part of their audience. Since many of the Sisters have already told me they consider God to be a witness to all they do, I also hope to explore their conversations with God, not only in everyday life but also during prayers. Although many may consider talking with God to be an internal monologue and an example of a unicultural expression,

I wish to show that if the person thinks of God as a separate entity, then these discussions are actually between two people, thereby being an example of a dyad instead of an example of a unicultural expression. People who pray or speak to God do not think of themselves as participating in an internal monologue, but as participating in a conversation between two people. Therefore, as folklorists, we should recognize engaging in a conversation with an entity perceived to be listening and participating in the dialogue is an example of a dyad. This particular form of prayer or conversation is not the same as internal monologues or beliefs that we tell ourselves without discussing them with others.

I will also look at labeling theories, which concern how people are labeled as sick or healthy. Although medical sociology has many theories on labeling, there are very few de-labeling theories or theories on how an individual can either change or lose his or her current label. In this thesis, I will address why there is a lack of de-labeling theories and the effect that lack has on people who no longer fit their label. I would also like to consider ideas such as stigmatization and how it might affect these women. I hope to show if the effects of stigmatization are greater, the same, or less on the general public than on people in religious life.

### Folklore and Medicine:

Since this project deals with both medicine and belief, I feel it is an appropriate area of research for a folklorist to consider. Although other fields have performed research on the link between spirituality and medicine, a folklorist will ask different questions and be more open to some of the possibilities that exist. The real question,



according to David Hufford, is “Do folklorists have something special to offer in this work?” (Hufford 1997: 65). Hufford then states that he firmly believes “Folklore’s ethnographic methods, the field’s emphasis on narratives, and its natural populist orientation all allow folklorists to make special contributions to this kind of research and teaching” (Hufford 1997: 65).

This research is important in general since surviving cancer is becoming more common recently than it was in the past. Since we now have a groups of people who are surviving illness that were once thought to be a death sentence, we need to look at how they readjust to society and how society readjusts to them. Not only is this important to the people involved and many other fields, I feel it is also potentially important to folklore as a discipline specifically because it will show the importance of belief within a group and explore the relationship between a person and God.

In addition, work in folklore may complement the field of medicine. In order to better understand how folklore and medicine can help each other, a brief history of folklore and medicine is necessary.

In the area of folklore, the beginnings of studies in medicine can be seen in the works of Wayland Hand, who used a catalogue approach typical of the historic-geographic methods popular at the time. Later, the 1972 work of Don Yoder emphasized the relationships between definitions of what constituted folk medical practices. Yoder also challenged the notion that only the uneducated used alternative health practice, which opened up the study of medicine in folklore (Yoder 1972: 191-215).

David Hufford has also contributed much to medicine and folklore since his dissertation in 1974. He has addressed such topics as doctors’ understanding of folk

health belief systems, the patient-doctor relationship, and the importance of folk health belief systems in a patient's conventional care. Hufford states "the ultimate goal of folklore applied to health care . . . is to help official medicine to recognize its cultural location within the community and to discover the means for interacting as effectively as possible with those additional resources with which it coexists" (Hufford 1994: 128).

Bonnie O'Connor has also made contributions to folklore and medicine, especially in the area of alternative medicine with her book *Healing Traditions* and a variety of articles used in this thesis. Her consideration of how people's experience, belief, and values influence their health care choices in addition to the importance of working with both biomedical health belief systems and vernacular health belief systems are very important to the field.

There have also been several collections of articles on folklore and medicine, such as James Kirkland et al. *Herbal and Magical Medicines: Traditional Healing Today*, which looks at a single region and a variety of topics instead of topics that concern unrelated regions as well as containing articles written by people from a variety of disciplines and Erika Brady's *Healing Logics*, which address many modern day issues in health and belief, including the use of alternatives therapies, the new-age dilemma, and the healer healed.

### Discussion of Literature:

In this thesis, I plan on using literature from a variety of disciplines, including folklore, sociology, anthropology, and medicine. Many useful theories on stigmatization and labeling come from sociology, including books on general medical sociology such as

William Cockerham's 2001 textbook entitled *Medical Sociology*. I have also used Erving Goffman's ideas of stigmatization and how they might apply to cancer survivors from his 1963 book *Stigma: Notes on the Management of Spoiled Identity*.

I also consider the way that illness narratives are presented, especially as regards Arthur Kleinman's *The Illness Narratives: Suffering, Healing, and the Human Condition* (1988) and Cheryl Mattingly and Linda Garro's *Narrative and the Cultural Construction of Illness and Healing* (2000). In addition to Kleinman's work on illness narratives, I will also use his book *Writing at the Margin* (1995) to discuss the border between social and medical problems.

In the field of folklore, I will use Diane Goldstein's work on patients with HIV entitled *Talking AIDS* (1991) as well as Bonnie O'Connor's *Healing Traditions* (1995). In discussions of unicultural expressions, I will use Primiano's 1995 article "Vernacular Religion and the Search for Method in Religious Folklore." I will also consider the topic of representation in regards to Susan Ritchie's 1993 article "Ventriloquist Folklore: Who Speaks for Representation?"

### The Importance of Narratives in the Medical Field

David Hufford has stated,

Many scholarly approaches to narrative and experience interpret the stories of ordinary people as creative works imposing a subjectively satisfying order on a past remembered through cultural filters that "color" the "facts". That is also the way physicians tend to interpret the stories of patients... But sick people, it turns out, often do know exactly what has been happening to them, what it feels like, and when it happens, and there is nothing fictional about it. (Hufford 1997b: 118)

Many physicians assume they know exactly what the patient is experiencing since they know and understand the symptoms. However, every person's experience is different and is based on the experiences they have had in the past. No one person, even if her or she has had the same type of illness, can truly understand what another person is going through. The only insight we can hope for is the insight we can gain through their narratives.

Not only are narratives important from a medical perspective for the diagnosis and reporting of symptoms but they are also important for making sense of events and healing. Kleinman states:

One of the core tasks in the effective clinical care of the chronically ill – one whose value it is all too easy to underrate – is to affirm the patient's experience of illness as constituted by lay explanatory models and to negotiate, using the specific terms of those models, an acceptable therapeutic approach. Another core clinical task is the empathetic interpretation of a life story that makes over the illness into the subject matter of a biography. Here the clinician listens to a sick individual's personal myth, a story that gives shape to an illness so as to distance an otherwise fearsome reality. The clinician attends to the patient's and family's summation of life's trials. Their narrative highlights core life themes – for example, injustice, courage, personal victory against the odds – for whose prosecution the details of illness supply evidence. (Kleinman 1988: 49)

In addition to the medical diagnosis, a physician could attempt to treat what the patient feels is wrong and help that patient correct the wrongs they feel have happened to them. A physician also can acknowledge that different patients are going to have different interpretations of their illnesses. When considering a disease such as cancer, which has no one known cause, patients often try to discern why they contracted this disease. Many doctors discourage this practice for a variety of reasons, mostly because they feel it is futile to try to determine why this happened (Weil 1995: 60). This non-holistic approach

often discourages patients; after all, not only do people want to get better, they also want to prevent their disease from coming back. Most physicians tell people that after they are successfully treated, they do not need to do anything; however most patients feel that there is something that they can do to prevent further reoccurrences (Weil 1995: 60). Many physicians do not realize this opportunity as a way they can help their patients in long-term healthy lifestyle decisions. Dr. Andrew Weil, the author of *Spontaneous Healing*, states “A larger subject is the problem of making doctors more conscious of the power projected onto them by patients and the possibilities for reflecting that power back in ways that influence health for better rather than for worse” (Weil 1995: 64). If a patient decides his or her illness was caused by diet and that improving the diet might help them to ward off disease, a physician could explain to them that this is not a fool-proof way of preventing disease, but it is a good idea. By listening to a patient’s illness narratives and discussions of the cause of their disease, a physician can come to an understanding of the personal and relational factors which underlie lifestyle choices.

The personal narrative does not merely reflect illness experience, but rather it contributes to the experience of symptoms and suffering. To fully appreciate the sick person’s and the family’s experience, the clinician must first piece together the illness narrative as it emerges from the patient’s and the family’s complaints and explanatory models; then he or she must interpret it in light of the different modes of illness meaning – symptom control, culturally salient illnesses, personal and social contexts. (Kleinman 1988: 49)

Physicians, just like their patients, have their own cultural biases and stereotypes for a variety of reasons. O’Connor looks at the education and training of health professionals. She states that doctors should not project their beliefs and values about the illness onto the patient. She also discusses the idea that by teaching health professionals about ethnicity, we may help to inspire even more stereotyping. Instead, she suggests we

must teach doctors ethnographic methods so that they can address each patient as a unique person with different values and beliefs from any other person from that age, ethnic group, or gender (O'Connor 1995: 176-181). Not only are cultural biases present with doctors, they are also present with patients. Throughout my interviews and research, I often heard doctors being referred to as "foreign," "Indian," "Jewish," "young," "old," and "male" showing age, gender, and ethnicity of doctors is very important to the patient.

Ethnicity, both of the patients and the doctors, is an issue that is often debated in folklore literature (O'Connor 1995, Hufford 1997b). In my later discussion on alternative therapies, this will also prove to be true. Many doctors do not realize that by listening to their patient's narratives about their beliefs and values they can find the help they might need in persuading the patient to accept their treatment. Although I certainly would not suggest teaching doctors how to understand their patient's beliefs and values as a way to coerce their patients to accept their treatment, it could be a way to understand why a patient may accept or reject different types of treatment. By understanding their motivation, compromises can be made that would benefit both parties. Kleinman states,

Clinicians (and researchers, too) need to unpack their own interpretive schemes, which are portmanteaus filled with personal and cultural biases. They also must rethink the versions of the clinical world they create. They must be certain where therapeutic interests are being altered by concerns of theory validation, research publication, or just plain making a living and advancing a professional career. The professional biases that underwrite invidious stereotypes of certain categories of chronic patients... are another example. These human interests need to be the subject of ongoing self-reflective sorting by the interpreters of patient accounts to be sure that the interpretations they render are not tendentious delegitimations of the illness experience, obstacles to effective care. This is a simply enormous problem in clinical practice and research with chronic patients that has not been adequately addressed. (Kleinman 1988: 53)

Some physicians do not like dealing with chronic conditions since they tend to be more complicated and difficult, if not impossible, to cure. Kleinman states:

The upshot is that practitioners, trained to think of “real” disease entities, with natural histories and precise outcomes, find chronic illness messy and threatening. They have been taught to regard with suspicion patients’ illness narratives and causal beliefs. The form of those narratives and explanations may indicate a morbid process; the content may lead them astray. The way of the specialist diagnostician, which is not to credit the patients subject account until it can be quantified and therefore rendered more “objective,” can make a shambles of the care of the chronically ill. Predictably, the chronically ill become problem patients in care, and they reciprocally experience their care as a problem in the health care system. (Kleinman 1988: 17)

As we see here, the care of the chronically ill is complicated and difficult to deal with from a physician perspective. However, it is infinitely more difficult to understand the experience of a patient. Some doctors do not want to lose their objectivity since they see it as a removed scientific way of diagnosis. However, it can make them seem less human to their patients, as if the doctors do not care about them. This perceived lack of concern can be difficult for patients and can lead to their telling their narratives in different and less revealing ways.

### The Importance of Narratives to Patients

In their book *Narrative and the Cultural Construction of Illness and Healing*, Cheryl Mattingly and Linda Garro state, “Narrative is a fundamental human way of giving meaning to experience” (Mattingly and Garro 2000: 1). It is through telling narratives that many people explain their experience not only to themselves but also to others. People tell others and themselves that they tell stories for a variety of reasons. Max Lerner discusses a few of them in his book *Wrestling with the Angel*:

This is one man's journey away from death, toward life. It is at once a narrative of a cluster of illnesses and a meditation on them. There are many reasons a man gives himself for writing a memoir about an illness: his friends have egged him on; he wants to reach other sufferers; he thinks his example may do something to change the climate within which life-threatening illnesses are treated. There is a kernel of truth for me in each yet my real reason is an experiential one. I passed through a searing experience that tested and changed me in ways I never foresaw. And like the Ancient Mariner I want to tell my story, to whatever listeners it finds.

The austere medical scientists call this kind of evidence "anecdotal" as distinguished from the rigorously "experimental," where you have "populations" being studied statistically along with their "control groups." I don't mind the designation but suggest that the "narrative" mode is better. It is a term emerging in literary criticism which has spread to other human disciplines as a legitimate method of getting at some essential truths. (Lerner 1990: 20)

As Lerner says, he wants to tell his story and let people come to their own realizations and conclusions. He wants it to speak to people in their own meaningful way and not in a way that is prescribed or predetermined. Many survivors feel that way about their stories. Several of the sisters when asked why they wanted to tell their stories responded with ideas that it might be able to help people in some way, primarily as an example. They felt by telling their story, they might be able to help other people through their own experiences and offer them a sense of hope. They wanted to reach out to others and say, "See, I did it. You can do it, too."

I felt I should warn the sisters that they might experience some mental anguish since they were bringing up bad memories. However, all of them felt talking about their experiences could only be helpful. I did insist that if they ever felt any stress from the situation that they tell me and discuss the matter with a trained professional, whom they had on site. None of the sisters, to my knowledge, experienced any trauma through their storytelling events. This does not mean, however, that there were not some tears and



some painful memories. However, after these moments, the sisters reported feeling better. One of them said to me, “Whew! I guess I was holding that in for awhile. Well, now that it’s out there, it’s no longer hurting me in here” she said, pointing to her chest (Name withheld by author 2003).

Narratives of illness do often disturb other people since they remind us we are not immune to disease and we are mortal according to Max Lerner:

In our time we are coming to understand that none of us is immune from the necessity of facing – at one or another point in our histories – some life-threatening episode. Cancers, strokes, heart ailments, Parkinson’s, Alzheimer’s, multiple sclerosis, AIDS – the disease that beset us are varied, and their treatment has been the subject of intensive, experimental study. Now, increasingly, the responses of the patients to their ailments are capturing attention in and out of the medical profession. In a curious sense, medical advances, even as they have heightened expectation, have not lessened anxieties; as hope has risen, the fear of missing out becomes sharper. And the pale rider on his pale horse becomes all the more the apparition to overcome. (Lerner 1990: 26-26)

Many cancer survivors are often very aware of the situation they put themselves in when they tell their stories. Like telling any story, they let themselves be open to criticism and interpretations. This place is a hard one in which to be. Often times, survivors feel they are opening themselves to be analyzed. So many times in these various narratives I heard and read phrases that devalued their experience so they would not be judged. Above all else, it seems cancer survivors hate to be judged by their disease or have motivations explained by their disease. Many time phrases like “You might think I’m crazy, but. . .” and “This might sound silly, but. . .” were used. In a way, this protects the survivors from opening themselves up too much and also protects them from our “traditions of disbelief,” Hufford’s idea that in our culture we have a tendency to believe

or disbelieve our own experiences based on what we are told are the correct things to believe in (Hufford 1982).

These qualifiers may also serve another purpose. In Erika Brady's article "The Beau Geste: Shaping Private Rituals of Grief" she observes, "... while qualifying the action and the performance as unusual, the narrator is seldom entirely self-deprecatory: there is a sense of pride and completion in the telling, conveying the narrator's conviction that the action was beautiful and appropriate, although liable to be misconstrued" (Brady 1987: 30). Even though these stories are phrased in this way, it does not necessarily mean that any of these sisters thought that they were crazy or silly; it only means that they think someone else might misconstrue their stories. They may also have a sense of pride in their stories and what they have survived, but are more motivated by their own concern about being misunderstood.

Another reason why cancer survivors may want to discuss their experiences is because they have been silenced for so long, not only from a medical standpoint but also from a personal one. Often when a person is experiencing an extreme situation that requires a great deal of concentration or effort, they have a tendency to be silenced so that they can "just get through it." They are not told the whole truth about their illness or told only, "what they need to know." Max Lerner refers to this as a "communication crisis" saying:

A mortally sick person suffers repeatedly from a communication crisis. The only people who can tell him what is happening objectively are in the business of arresting and postponing his death. They are not in the business of communicating much to him, and in my experience rarely is it the whole truth at all times. This applies especially in a diagnostic crisis when the authorities themselves don't yet know the truth and don't want to frighten the patient. (Lerner 1990: 33)

As Hufford states, most ill people want to know exactly what is happening to them (Hufford 1997b: 118). Since they understand and know how they feel, they often tell their stories to others so they might get some of the truth they are missing. Cancer survivors are often more than willing to share information about testing, drugs, and their other experiences so others who are going through the same thing do not feel as marginalized or misinformed. One of the sisters said to me, “I wish they would have told me what to expect. I could have handled it. I just wanted to know what was going to happen. It was scarier not knowing. So, now whenever someone tells me that they are having their first mammogram, I tell them exactly what to expect. I don’t want anyone to be as worried or scared as I was for no reason” (Sr. Angela 2003). She then asked if I had ever had a mammogram and if I ever did self-exams, stressing the importance of both and making sure I knew exactly what the experience was like.

Narratives can also help the patient to restore order in his or her life. The act of telling a story puts the experience in a box that can be accessed at any time, but does not necessarily need to be thought about often. Telling a story over and over again can detraumatize the event, making it less painful. As Mattingly and Garro state, “Creating a narrative, as well as attending to one, is an active and constructive process – one that depends on both personal and cultural resources. Stories can provide a powerful medium for learning and gaining understanding about others by affording a context for insights into what one has not personally experienced” (Mattingly and Garro 2000: 1). Many people are surprised at the offhanded way that cancer survivors report their experiences, as if they are bored by the details and the facts. They often are. Just as any of us would tire of talking about the same thing over and over again, survivors also get tired of telling

their stories. Often times they will tell their stories only if they feel that it will help someone (Name withheld by author 2003).

Survivors also feel that their stories are their own and dislike it when they are told how to feel. One of the sisters mentioned how much she hates it when people tell her she should be thankful she had cancer. She said, “One person actually told me I should think of it as a gift! As if God would want to hurt us! I told her, ‘God is good and God does not want us to suffer.’ That shut her up” (Name withheld by author 2003). Many survivors have stories like this one, in which someone tried to make them feel better about their illness and failed. Sr. Agatha said, “I know they are trying to help and it’s hard to know what to say. That’s why I just tell people not to say anything and just pray for me. People say really strange things when they don’t know what to say, but feel they should say something” (Sr. Agatha 2003).

Of course, in any narrative, one must be careful about the exact intention of writing and the expressed intention of writing which are not always the same intention. In the case of autobiographies, especially celebrity autobiographies, there may be more reasons for publishing such a work than the reasons stated. As is the case with all narratives, we should realize that people often have both conscious and unconscious motivations and modes of self-preservation.

Cancer survivors tell their stories for a variety of reasons, some of them personal and some to help others that may be experiencing the same thing. Autobiographies written by cancer survivors are on the rise and more and more people are starting to feel more comfortable about writing their stories. This sharing of narratives is one way that some cancer survivors feel will help eliminate the problems with stigmatization, which

will be discussed in Chapter Five. The more others are exposed to the reality of cancer survivorship, the more they will be willing to accept and even laud survivors for their strength and courage.

## Chapter Two

### Methodology:

My informants all live at the Ursuline Sisters of Mount Saint Joseph Convent in Mount Maple, Kentucky. They are all post-treatment cancer survivors. I was first introduced to the idea of working with cancer survivors in religious life by Sr. Elaine Byrne, who is involved with the Newman Center on the campus of Western Kentucky University. Although I already knew Sr. Elaine from attending mass at the Newman Center, I grew to know her much better after she became one of my informants for a term paper on religious vocations. She first mentioned the sisters at Mount Saint Joseph to me in the spring of 2002, and we discussed the possibility of interviewing these sisters over the summer. In addition to Sr. Elaine's introducing me to the community, she also offered to act as a liaison if necessary since she already familiar with ethnographic research. This will help in the project if any of the sisters decide to contact her in the case of any confusion instead of directly contacting me.

Sr. Elaine took me to my first visit at Mount Saint Joseph where I spent two days talking to five survivors. Other members of the community found these survivors, contacted them, and asked them if they would mind talking to me. During this time, I also had the opportunity to experience life at Mount Saint Joseph. I attending mass and meals with the sisters and participated in one of the retreats that they sponsored. After spending only a short time with the sisters, I could already see how strong their sense of community is, which led me to wonder what it might be like to live in a community and experience a serious illness under these circumstances.

All of the sisters who wished to participate signed a consent form. I took a generous amount of time to explain the consent forms to them and answered any questions they had. I also left this form with them so they could look over it further before they signed it or if they wished to refer to it at a later time. I also made a few copies in a larger font in case any of the sisters had visual problems. The consent form was intentionally written without the use of many of the terms I would use as a folklorist for the sake of clarity and readability.

I conducted my fieldwork through one-on-one interviews with the survivors. Although I did consider a group interview, none of the informants seemed eager to do so, probably due to their very different schedules. The preliminary meetings were done without any recording devices other than pen and paper. Although I did wish to record the sisters in future interviews, I found they talked more openly after the machine was shut off. This observation led me to the conclusion that I would receive better interviews without recording devices. None of the sisters seemed to mind when I took notes, so I decided to continue with this method of recording.

Most of the interviews were approximately one hour long, but I had interviews that lasted anywhere from a half hour to an hour and a half at one sitting. I performed multiple interviews with each of the sisters from November 2002 until June 2003. All interviews will take place on the grounds of the convent, normally in the private rooms of each sister.

When dealing with a topic that involves such a sensitive subject, I realize that confidentiality and traumatic memories are an issue. My consent form discussed the problem of confidentiality, letting the sisters know their information would be used for

the purpose of my thesis and may be stored in the Kentucky Museum afterwards. Since these tapes may be stored in a public place, I made sure that my informants were fully aware of the fact and agreed with these proceedings. Since the sisters do not have to worry about such things as job interviews or health insurance, I anticipated that they would be agreeable to these terms. This information should not be harmful for them in the same ways it may affect a member of the general public, so although confidentiality was an issue, it was a lesser one than it would be if I were interviewing the general public. In addition, some of the sisters have already asked if they can read my thesis before it is defended to make sure they are being accurately portrayed. I have agreed to this request and plan on giving my informants preliminary copies if they request them. I also will give a finished copy of the thesis to the convent or any of the informants if requested.

Although many people might find telling their story to be therapeutic, there are some that feel talking about a traumatic period in their life might cause mental anguish. I have informed the sisters of this possibility, both orally and in the consent form. All of the sisters I have talked to feel that telling their experiences can only help them and others. I made sure I asked what they would like me to do in case a traumatic memory does come up. All of the sisters were positive that would not happen, but told me they have a support system in place, both on the personal level with friends, family, and the other sisters, but also on the premises since two of the sisters are counselors and perform that function within the community. At this time, however, none of the sisters found any counseling necessary.



### The Ursuline Sisters:

As mentioned earlier, all of the sisters I interviewed lived at Mount Saint Joseph in Mount Maple, Kentucky. The order of the Ursuline Sisters was founded by St. Angela Merici in Brescia, Italy in 1535. St. Angela, instead of naming the order after herself, as is common with most orders, named the order after St. Ursula, who was a martyr and one of the patron saints of education. The first Ursulines lived with their families, ministering where they were needed. The order has a special concern for the education of women, and the majority of the sisters in this order have at least some college education themselves. There are also several members with Master's degrees or Ph.D.'s.

In 1874, five Ursulines came to what would become Mount Saint Joseph from Louisville, Kentucky, where sisters from Bavaria founded a community sixteen years before. The Ursulines established a school for young women and grew to become an independent community in 1912. The sisters at Mount Saint Joseph currently have women ministering throughout the United States and in Chile. They also teach and minister at Brescia University in Owensboro, Kentucky, and administer the Mount Saint Joseph Conference and Retreat Center. Their mission statement is as follows:

We, the Ursuline Sisters of Mount Saint Joseph, proclaim Jesus to all people through our ministry of education and Christian formation. We are energized by prayer and our life in the community. In the spirit of Angela Merici, our foundress, and responding to the values of our rural heritage, we commit ourselves to simplicity, hospitality, justice, and service.  
(Welcome to Mount Saint Joseph Pamphlet 2002)

I found that during my time there, everyone I met embodied these commitments. Each sister lived in a single room, often sharing bathroom facilities with everyone else on their floor in a dormitory style. Their meals were simple and nutritious and their lives were paced, but unhurried. Their chapel was also simply, but beautifully decorated. They dedicated themselves fully to their commitment of hospitality by offering to let me stay in their guest house, where I was welcomed with everything from mints on my pillow to stationary, and invited to share in meals and worship with them. I was given full use of the grounds, including the codes to most of the buildings, and welcomed everywhere I went.

### Introduction to the Informants:

I spoke to five different women at the convent, whom I will briefly introduce here. Even though the sisters all agreed to have their information used and their names published, I have decided to use pseudonyms because I feel their information is very personal.

Sr. Agatha was hospitalized for a hysterectomy when her family doctor came in and told her that they found a tiny speck on her lung and wanted to operate since she had a family history of cancer. Sr. Agatha agreed because she did not want it to get any bigger. She was then treated for twenty-eight days of radiation and has never had any problems since.

Sr. Elisabeth started to have pain when they took her to a doctor. She was diagnosed with breast cancer and had a mastectomy. She still has some problems with her condition, but continues to be in remission.

Sr. Angela was diagnosed with breast cancer in 1974 during a routine exam before surgery for kidney stones. She had a biopsy and surgery, followed by radiation. She was told she had a 50/50 chance to live three years at the time, but proved everyone wrong by going into remission and staying there until this day.

Sr. Catherine was also diagnosed with breast cancer. She was told she either had to have a radical mastectomy or thirty days of radiation. She chose not to do either and went to see another doctor, who prescribed taxomfin. A year later, there were no signs of cancer.

Sr. Theresa had pain in her ovaries since she was a teen, but her ovarian cancer was not found until eight years ago. She had six cycles of chemotherapy and was given blood and platelets during her treatment. She and her doctors both believed she was going to die. But after her treatment and a visit home for Christmas, she returned in perfect health.

## Chapter Three

### Interviews:

As previously described, all of the interviews took place at Mount St. Joseph's in the rooms of each of these women. The interviews were typically conducted with the two of us sitting in chairs across or next to one another. Although I had a list of questions that I wished to ask, I deviated from this list quite often and asked questions that went with the natural flow of conversation. I referred back to my list of questions only when there was a lull in the conversation or when asked if I had any more questions.

The first pattern I found in all of my informant interviews was the way this illness was described. All of my informants described their illness with the same formula. They typically begin with what happened leading up to their diagnosis using phrases like "Well, I hadn't been feeling good for some time." or "I had pain in that area for awhile." Then they discuss their first appointments, testing, and diagnosis. My informants often assumed I understood why they were given certain tests.

After discussing their diagnosis, all of my informants went on to describe their treatment. This subject was typically the area discussed in the greatest detail and depth. However, the detail and depth was mostly given to their reactions to the drugs. Often, I was just told the name of the treatment and nothing else about it. I was given an answer such as "I was given chemo." or "I was given radiation." Sometimes my informants would tell me exactly what type of chemotherapy they had, but not describe it in any way other than the name and the reaction that they had to it.

Lastly, my informants told me of their current experience with their past illness. I was told, "I've been in remission and I haven't had any problems since" or "I still have a

few problems, but they really don't bother me too much." Often if asked further about their current state of health, they compare themselves to their health before diagnosis with statements like "Well, I don't have the same amount of energy as I did before, but I am getting older." A statement similar to that one was very common, as if they were looking for another reason other than a cancer history as the cause of their current problems.

As I mentioned, the sisters spoke to me about their disease and treatment as if I knew all about cancer. At first I assumed they thought I was very knowledgeable about all types of cancer since I was writing my thesis on it, but I later realized I was wrong. It was after considering the structure of their stories that I realized why they did not fully explain their disease and treatment. Although logically it does make sense to tell a story in chronological order, it was their expansion on their symptoms that made me start to realize they were telling their story to me in the same way they would tell a doctor about their medical history. Anyone who has had any type of serious illness soon realizes how much information is wanted and needed, not only by doctors but also by others. These stories were designed to tell someone the minimum amount of information, but still tell him or her everything they want or need to know. Not only do these stories accomplish basic information without much detail they also give detail exactly where a doctor or other health professional would want it. They first mention how they knew something was wrong. This information would show doctors how self-aware they are, how likely they are to go to a doctor when something is wrong, and if they were at all symptomatic. In many cases of cancer, you can either be asymptomatic or symptomatic, often defined as A or B, respectively. This information is important in order to proceed because it can

define the amount and frequency of testing that will be needed in the future. Patients who tend to be symptomatic are tested less because they are considered to be more aware of their disease. Although doctors usually do not place judgment or value on whether or not a patient is symptomatic, it is an important piece of information to know.

This also explains why the type of testing done or types of treatment were not further explained. When patients are telling their story to a doctor, he or she is going to know exactly what this information means, so there is no need to explain it further. However, it would be necessary to further explain your reactions to that type of treatment. Information such as this would also be useful, not only to see how strongly one reacts to certain types of drugs but also how one reacted to treatment in general. If a person gets nauseous easily, then a physician will be more likely to administer better anti-nausea drugs in the future. By explaining their symptoms, they are letting their doctor know how to treat them and what type of treatment to use.

Finally, their last mention of how they are doing now will tell a doctor why they are there. If they mention problems, then that might be the actual reason for their visit even if it is just a check up. Another interesting point is that patients are accustomed to blaming their current problems on other sources. Many doctors are still unsure or unwilling to accept the long-term side effects of cancer treatment. Although some doctors will take the time to explain why certain side effects occur, they are less likely to admit that cancer and the treatments associated with cancer caused such complaints as fatigue. Worse yet, some doctors feel their patients should just be grateful that they are alive! (Multiple interviews, Names withheld by author 2003). This attitude shows one of the major problems with medicine, which is a focus on the “magic bullet.” The idea of the

“magic bullet” came about in the 1800s when more and more drugs were being developed. At this time, doctors found that many of these new medicines could treat and cure many things that were untreatable in the past. It was then that the idea that there was a pill or a “magic bullet” that could fix anything was developed. Doctors started to believe that giving their patients a pill would cure anything they had. Side effects, both long and short term, were seen as minor and treatable with another pill. This tendency towards treating the symptoms and not the person is still seen today. However, medicine is starting to take a turn towards a more holistic approach, but our ideas of treating a symptom instead of a person still remain (Cockerham 2001).

As I mentioned in Chapter One, I wanted to see who was the perceived audience during the performance of these narratives. Specifically, I was wondering if cancer survivors in religious life perceive God to be a part of their audience. Although many of the Sisters told me they consider God to be a witness to all they do, I wanted to explore their conversations with God, not only in everyday life but also during prayers. Not only did I want to see how they prayed to God but I was also interested in what they had to say to God while in treatment and if they consider themselves a witness to God’s presence in their life.

I saw a variety of similarities and differences. One of the things they all had in common was their willingness to put their illness in God’s hands. The idea of putting something in God’s hands is a common one in most major religions. This idea, that one gives up an element of control or an attempt to control and places faith in God that He will take care of them, is found in the New Testament in two separate places. The first is in Matthew 6: 25-34:

Therefore I say to you, be not solicitous for your life, what you shall eat, nor for your body, what you shall put on. Is not the life more than the meat: and the body more than the raiment? Behold the birds of the air, for they neither sow, nor do they reap, nor gather into barns: and your heavenly Father feedeth them. Are not you of much more value than they? And which of you by taking thought, can add to his stature by one cubit? And for raiment why are you solicitous? Consider the lilies of the field, how they grow: they labour not, neither do they spin. But I say to you, that not even Solomon in all his glory was arrayed as one of these. And if the grass of the field, which is to day, and to morrow is cast into the oven, God doth so clothe: how much more you, O ye of little faith? Be not solicitous therefore, saying, What shall we eat: or what shall we drink, or wherewith shall we be clothed? For after all these things do the heathens seek. For your Father knoweth that you have need of all these things. Seek ye therefore first the kingdom of God, and his justice, and all these things shall be added unto you. Be not therefore solicitous for to morrow; for the morrow will be solicitous for itself. Sufficient for the day is the evil thereof. (Catholic Study Bible 1995)

And again in Luke 12 22-30:

And he said to his disciples: Therefore I say to you, be not solicitous for your life, what you shall eat; nor for your body, what you shall put on. The life is more than the meat, and the body is more than the raiment. Consider the ravens, for they sow not, neither do they reap, neither have they storehouse nor barn, and God feedeth them. How much are you more valuable than they? And which of you, by taking thought, can add to his stature one cubit? If then ye be not able to do so much as the least thing, why are you solicitous for the rest? Consider the lilies, how they grow: they labour not, neither do they spin. But I say to you, not even Solomon in all his glory was clothed like one of these. Now if God clothe in this manner the grass that is to day in the field, and to morrow is cast into the oven; how much more you, O ye of little faith? And seek not you what you shall eat, or what you shall drink: and be not lifted up on high. For all these things do the nations of the world seek. But your Father knoweth that you have need of these things. (Catholic Study Bible 1995)

All of the sisters I talked to seemed to be willing to place their life in God's hands. Although to some extent this practice is what they have done their entire lives, many people find it difficult to surrender to God. For many lay cancer survivors, surrendering to God is the hardest part of their experience. Surrendering to God becomes



something that most of them struggle with, something most of them question, and finally, something most of them come to accept. Within this struggle, the question of “Why me?” is always present. Even though many of the sisters had remarkable faith in their situation, that does not always mean they were not afraid. Sr. Catherine said, “I was scared to death! I thought, finally, something that can kill me. But I didn’t want to die” (Sr. Catherine 2002). Sr. Theresa stated, “A positive attitude is very important. It affects everyone differently because we are all different people. I thought ‘I’m not going to die. I’ve got two lungs and a good heart’” (Sr. Theresa 2002).

Some of the other sisters reported their acceptance of their diagnosis with a remarkable sense of calmness. Sr. Agatha mentioned her relationship with God and how she felt about having her illness several times throughout her interviews. She said, “Whatever God sends, I have to accept. I would never think that God is mean” (Sr. Agatha 2002). She also stated, “We have to see things the way they are meant to be seen and do the best we can” (Sr. Agatha 2002). She did admit things would have been a little different if she had been a mother. She stated, “Did I question my relationship with God? No. But if I would have been a mother, it would have been different. But I know I did nothing to bring this on, it’s just a part of life” (Sr. Agatha 2002). She also mentioned the passages in Luke and Matthew by saying “I had good doctors, good nurses, everything I needed, so what would I worry about?” (Sr. Agatha 2002). Sr. Elisabeth echoed these same thoughts saying, “God gave me strength. He still does” (Sr. Elisabeth 2002).

Another similarity I noticed among the sisters was the way they prayed to God. Although they all had the utmost respect for God, they prayed to him as though they were

talking to a life long friend. Most of their stories about their prayers made it sound as though they talked as casually to God as they talked to each other. Throughout my life I have noticed a trend in prayer that seems to span a lifetime. As people get older, they tend to do less kneeling and formal praying at home. Although many people still continue to say written prayers and rosaries, they also add in a conversational approach to their communication with God. Their speech becomes more casual, their tone less formal, and they just talk to God. I found the sisters to be no different. However, I was surprised to see their sense of humor and joke “bargaining” with God. Although many lay people tend to “bargain” with God, promising conversion, prayers, and other life changes in exchange for their prayers being answered, the Catholic Church discourages this tendency. I remember when I was growing up, my grandmother told me it was a sin to try to bribe God, especially with promises I knew I could not keep. Needless to say, I was shocked and amazed that many of these women had a joking relationship with God, which included joking about bargaining. The sisters, although still very respectful, laughed at some of their prayers, not only because they seem funny to them now, but also because some of their prayers were jokes with God. Sr. Theresa told me, “Once I said, ‘Lord, let me have five years,’ Now at eight, I say, ‘How about ten?’” (Sr. Theresa 2002).

Although many may consider talking with God to be an internal monologue and a form of unicultural expression, as you can see here, if the person thinks of God as a separate entity, then they perceive these discussions to be between two people, thereby being an example of a dyad instead of an example of a unicultural expression. These women, while praying or speaking to God, do not think of themselves as participating in an internal monologue but as participating in a conversation between two people, even to

the point where they are trying to entertain the other person. Therefore, engaging in a conversation with an entity perceived to be listening and participating in the dialogue in some way is an example of a dyad. This particular form of prayer or conversation is not the same as internal monologues or beliefs we tell ourselves without discussing them with others. These prayers and conversations are active dialogue with someone who is perceived to be listening, perhaps even laughing.

The problem that most people have with believing that a relationship with God is a dyad is due to their own relationship or lack of relationship with God. However this is not a problem for folklorists since we consider ourselves to be cultural relativists. It does not matter what we believe, but what our informants believe. When we consider dyads, we tend to think in terms of human relationships. In his article “‘Banana Cannon’ and Other Folk Traditions Between Human and Nonhuman Animals,” Jay Mechling stated, “In everything written by folklorists on larger folk groups and by Oring on dyad, the implication is that only human beings are members of these groups” (Mechling 1989: 313). Although Mechling’s article deals with relationships between people and their pets, he does make the point that we assume that folklore happens only between two humans. Just as Mechling showed that a dyad could exist between a person and their dog, I wish to show that a relationship can exist between a person and their God.

Elliot Oring’s definition of a dyad is “a more or less enduring interaction between two individuals who primarily relate to one another as persons rather than as occupants of social statuses” (Oring 1984: 19). In their prayers, these sisters show that although they pray to God, they are also talking to God as a friend or companion. Their prayers often act as an example of metaphorical code switching, which shows more than one

relationship with an individual. Although they do pray to God as a supreme being, they also speak to God as a friend, which would fall under Oring's definition of a dyad since they relate to God on a level other than as regards social status. They talk to God not because they have to or are expected to as followers of a religion, but because they want to.

Mechling also alerts us to some of the fallacies committed in the study of folklore. One of these, the "equality fallacy", shows that folklorists too often assume that participants in a dyad are equal in power and ability (Mechling 1989: 319). The dyad between humans and God is a perfect example of this assumption. Although some may argue that it would be impossible for this relationship to exist as a dyad since one of the participants in this dyad is a supreme being, a dyad can exist between two people who are not equal in power and ability, for example the dyad between a parent and their child.

Lastly, it may be argued that a dyad between a human and God cannot exist since there is no interaction. This debate, of course, depends on one's idea of interaction. Although few people feel God personally speaks to them, many feel that God speaks to them through other people or events. So, as long as a person considers God to be communicating to them in some way, then their relationship can be considered a dyad.

Many people other than cancer survivors and Catholic nuns experience dyads with God. One does not need to be in religious life or have a life threatening illness to experience this sort of relationship with God. However, as Katherine Russell Rich wrote in her autobiography, cancer acts as an intensifier, speeding up processes and relationships. Many cancer survivors quickly develop a sense of God during their treatment because they find they have a need for him. Although this need to talk to God

can happen at any time in a person's life, it happens more frequently in the difficult times (Rich 1999: 31).

A striking characteristic of the religious cancer survivors I spoke with was the levels of acceptance experienced by the sisters. Although all of them grew to the point of acceptance, for some of them it was easier than others. This variation was not only because of their different personalities but also because of their different life experiences. A few of the women experienced loss of loved ones from cancer, family histories of cancer, and other experiences with illness. It seemed that these women who had experiences like these before were more able to give themselves and their problems to God. At first I thought it would be the opposite, that these women would have a harder time since it seemed that bad things kept happening to them. However, it almost appears that once you learn to give yourself up to God, it becomes easier the next time once you get past the initial shock. However, some experiences are still hard to remember and hurt even though you have grown to accept them. One of the sisters lost four members of her family in one year from cancer. At the time, she was at school in the convent and could not go because they believed in keeping the novices away from the outside world when they were considering entering the order. Since all sisters take a vow of obedience, she stayed in Saint Louis and did not leave. The hardest part for her was that from her room in Saint Louis, she could see the hospital where her sister was dying. She says, "It's harder now than it was then. Then I was being obedient. But I am the person I am today for having gone through that" (Name withheld by author 2002).

Upon comparing the literature and autobiographies of lay cancer survivors with the interviews of the sisters, I noticed one important theme was missing from the sisters'

interviews. Most lay cancer survivors feel a sense of loss when it comes to their appearance and a crisis of identity, not only as regards identity as a person but also to purpose in life. Many lay cancer survivors mention in their autobiographies their sense of loss at losing hair or seeing changes in their body. These changes in appearance are often mentioned even in their initial storytelling as symptoms. However, I noticed none of the sisters I interviewed even mentioned if they lost their hair or if they noticed any physical changes in their body, other than weight loss, which was always seen as a negative thing. The first reason that would automatically come to mind is, since the sisters are not concerned with appearing attractive the opposite sex, they were not as concerned with these problems. However, I feel the reason is much deeper than that. The reason why most people feel a sense of loss when their appearance changes is because their sense of identity is often tied into their looks. Although that is common for most people, when this sense of identity changes, it sets off a chain reaction of questioning. Questions such as “Who am I?”, “What am I doing with my life?”, and “What is my purpose?” are often asked. However, the sisters do not seem to have this problem. Perhaps it is due to the nature of their vocation. When persons wish to enter Catholic religious life, he or she expected to go through a period of discernment. This discernment process can last several years and is structured to help each person as an individual learn if religious life is right for him or her. Since this process is based on self-reflection and other’s opinions on whether or not a person is ready to continue onto the next step in the process, most people “find themselves” and are typically sure of their feelings toward the commitment they are about to make. Although I would not dare to suggest that none of them has ever had any doubts about their lifestyles, it seems that the majority of them are very sure about the

choices they have made in their lives. Perhaps we would see the same certainty in lay cancer survivors who also felt they had made the right choices. Although self-doubt would certainly happen to any person at any time, those people who are more certain about their life choices seem to be comfortable with their new label as cancer survivor.

## Chapter Four

### Sick Role Theory

Sick Role Theory was a concept first discussed by Talcott Parsons in his 1951 book *The Social System*. This theory was one of the most significant for the field of American medical sociology since it reoriented the field in a theoretical direction. This theory, which was the first that showed the function of medicine in the view of society, describes a patterned set of expectations defining the norms and values appropriate to being, both for the sick person and others who interact with that person. Parsons' sick role theory defines sickness as deviance from the norm, thus giving doctors a role in social control as the person who corrects this deviance.

Parsons' sick role theory is based on the concept that sickness is not a deliberate and knowing choice of the sick person and that the person wishes to return to health. He places the specific aspects of sick role theory into four basic categories, according to Cockerham:

1. *The sick person is exempt from "normal" social roles.* An individual's illness is grounds for his or her exemption from normal role performance and social responsibilities. This exemption, however, is relative to the nature and severity of the illness. The more severe the illness, the greater the exemption. Exemption requires legitimation by the physician as the authority on what constitutes sickness. Legitimation serves the social function of protecting society against malingering.
2. *The sick person is not responsible for his or her condition.* An individual's illness is usually thought to be beyond his or her own control. A morbid condition of the body needs to be changed and some curative process apart from personal will power or motivation is needed to get well.
3. *The sick person should try to get well.* The first two aspects of the sick role are conditional on the third aspect, which is recognition by the sick person that being sick is undesirable. Exemption from normal responsibilities is



temporary and conditional upon the desire to regain normal health. Thus, the sick person has an obligation to get well.

4. *The sick person should seek technically competent help and cooperate with the physician.* The obligation to get well involves a further obligation on the part of the sick person to seek technically competent help, usually from a physician. The sick person is also expected to cooperate with the physician in the process of trying to get well. (Cockerham 2001: 161)

By taking each of these aspects apart, I will show how this sick role theory, which defines the way western medicine sees people who have an illness, relates to and affects cancer survivors. The first aspect, the sick person is exempt from “normal” social roles, is typically true. Not only is cancer seen as a good reason to take time off from work or other responsibilities, it is seen as the ultimate reason to do so. However, due to the duration of the illness and treatment, most people undergoing cancer treatment find they either cannot take this much time off or they do not want to. Most forms of chemotherapy can last anywhere from four months to years and most forms of radiation are done every day for anywhere from two weeks to two months. Although some patients with cancer often find they cannot take that much time off from work, most would rather try to keep their schedules the same and often succeed providing they make the necessary adjustments to facilitate their healing. In his book *Wrestling with the Angel*, writer Max Lerner continued his work, even during his hospital stay. He wrote, “My writing and journals were signals I sent myself that under it all the major current of my life was still flowing. It was the best therapy I could muster” (Lerner 1990: 33).

Lance Armstrong wrote:

Why did I ride when I had cancer? Cycling is so hard, the suffering is so intense, that it’s absolutely cleansing. You can go out there with the weight of the world on your shoulders, and after a six hour ride at the high pain threshold, you feel at peace. The pain is so deep and so strong that a curtain descends over your brain. At least for awhile you have a kind of

hall pass, and don't have to brood on your problems; you can shut everything else out, because the effort and subsequent fatigue are absolute. (Armstrong 2000: 85)

The second aspect, the sick person is not responsible for his or her condition, only works in some instances of cancer. Many lung cancer patients and survivors have found they are frequently blamed for their cancer, even if they never smoked. People also feel cancer is somehow "brought on" through improper diet, lack of exercise, and high-risk behaviors, such as smoking and drinking alcohol. Although participating in high risk behaviors can increase your chances of contracting certain types of cancer, no one really knows for sure why some people get cancer and other who participate in the same behaviors do not. Cancer, like most other diseases, should not be seen as someone's fault. Parsons' sick role theory is accurate in its perception that a person is not responsible for his or her condition, but unfortunately this perception is not always the way others perceive cancer survivors. People like to believe cancer is caused so that they can believe it will not happen to them (Sontag 1978: 47-49). Everyday we see people who are healthy and live a healthy lifestyle develop cancer. Medicine has yet to find any one reason why certain people are prone to cancer while others are not. One of the specific ways that folklorists may be able to help is by increasing the awareness of the cultural aspects of attribution of responsibility.

The third aspect, the sick person should try to get well, almost seems ridiculous to mention. Why would anyone want to stay sick? Parsons mentions some people like to pretend they are sick longer than they actually are because of the secondary gains associated with illness. Some people find they like not being responsible or expected to take care of themselves. Although this behavior varies from individual to individual, the

majority of people who have any type of sickness, from a cold to cancer, want to get better or at least recognize that they should want to get better. Although we cannot know anyone's motivation to stay sick or become well, we can recognize that people who are sick do know that others expect them to try to return to health, regardless of whether or not they actually try to get better.

The last aspect of Parsons' sick role theory, the sick person should seek technically competent help and cooperate with the physician, is one that is currently being debated. Although most people will seek help when they are sick, what is considered to be "technically competent" by one person is not considered to be competent at all by others. This is especially true for people who decided to take control of their treatment or seek alternative therapies. Hufford also focuses on how patients who refuse treatment according to outside factors are perceived. He states: "When patients resist aspects of medical care that they find offensive, or when poverty or other factors outside their control prevent them from conforming to those aspects of the classic sick role that they would like to, they tend to be blamed" (Hufford 1997b: 119). Doctors learn what has been the most helpful in the past and prescribe that for their future patients. Doctors often refer to this concept as "protocol." Protocol does not work for all patients, and it can even be detrimental to some; however, both medical professionals and their patients treat protocol as the answer. It is only after protocol fails that many decided to seek alternative forms of treatment.

Doctors often look at people who take an active approach to their medical care with suspicion. Some doctors feel their patients either do not trust them or do not want to get well. Adler states: "Popular interest in these various healing systems seems to have

increased with the development of patient empowerment and medical consumerism” (Adler 2001: 115). Adler goes on to say that with patient empowerment, the use of CAM (Complementary and Alternative Medicine) has increased. The real problem with CAM is that patients are not reporting them to their doctors when often times these therapies can have negative interactions with drugs that are already being used. Patients are the ones that see their doctors as the problem, feeling that the doctors either do not care or do not believe that CAM works. Doctors, however, see the patients as the problem stating that the patients have unrealistic expectations of their physicians, are unable to tolerate reality, are hostile or in denial in the face of bad news, and are disorganized in seeking information (Adler 2001: 123). Patients are no longer taking a passive role in their health care. Lance Armstrong wrote, “It’s another fact of cancer that the more informed and empowered patient has a better chance of long-term survival” (Armstrong 2000: 267).

In O’Connor’s book, she addresses the issue of patient-doctor relationships. She restates the idea that the patient is ultimately in control of their his or her health care and discusses the idea that conventional medicine does not provide everything a patient needs to cope with all aspects of their illness (O’Connor 1995: 161-62). It is typically the place of alternative and complementary medicine to answer the “Why me?” and “Why now?” questions that western medicine cannot answer.

O’Connor also addresses the issue of compliance and how it is assumed that it is ultimately the doctor’s and not the patient’s decision as to what should be done with the disease (1995: 173-76). It is both the doctor and the patient who feel this way. It is usually once the doctor’s advice has failed that patients seek alternative treatments.

Max Lerner had a great deal to say on the patient/doctor relationship from his own cancer experience, which articulately shows a common universal theme in survivorship narratives. He states:

In our traditional perception of illness, the doctor has been central, the authority figure who notes the symptoms, maps out the test procedures, diagnoses what is wrong, decides on the treatment, superintends the healing. From time to time he may touch base with the patient but usually pro forms. The whole model is drenched with authority.

The patient suffers the illness, pain, disruption, and disorder of life. He suffers what is done to him, not as the subject of his own destiny but as the too passive object of the sometimes mistaken diagnosis, the endless testings, the medications and therapies, the minor and major “interventions,” from catheters and biopsies to exploratory surgeries, radiation, bypasses, and transplants. He moves through technologies and ministrations alien to him, to a destiny he has little role in shaping. (Lerner 1990: 66)

Lerner looked into himself and even the etymology of the word “patient” stating:

I had to fight the essentially passive role assigned to me, while all the artistry was left to the experts, the doctors and technicians. The very word “patient” (Latin root, *patior*, “to suffer”) is a giveaway. Patients suffer things to be done to them, becoming thereby the acted upon, the diminished. We ignore the fact that patients have an intelligence, experience, and will of their own and can themselves be a resource in restoring the equilibrium we call health. (Lerner 1990: 63)

In yet another example of a common theme, Lerner later states:

In conversations with fellow patients, as we waited in the anteroom of doctors’ offices, huddled together on wheelchairs outside the testing room, or walked and talked with each other in the hospital corridor, I was overwhelmed by their idolatry of authority. I saw their anxiety-ridden faces and watched their body language that conveyed the surrender of their sovereignty as persons. Among them were lawyers, teachers, executives, heads of families, community leaders. I wondered about their failure to assert their life experience and knowledge of themselves. My instinct was to distance myself from this mind-set. (Lerner 1990: 67)

This example is a perfect illustration not only of the “idolatry of authority” but also the tendency to discount one’s own narratives and experiences. Hufford states

“Physicians imagine what they would feel and do in the patient’s place. The problem, of course, is that this tells them little or nothing about what the patient feels or why they do what they do. Each person’s reaction to sickness or anything else is heavily conditioned by their history”(Hufford 1997b: 120). Hufford feels by teaching doctors ethnographic methods, folklorists can make a huge contribution to the medical field by enabling doctors to better understand their patients.

### Alternative Therapies:

I found it interesting that none of the sisters I talked to admitted to using alternative therapies, when in fact, they were using one of the most well-known and common alternative therapies -- prayer. Although the sisters did not consider it to be a form of treatment, probably because prayer is a constant part of their lives, prayer not only helps patients gain control of a situation, it helps them to feel as if they are doing something about their situation. Prayer can be a form of patient empowerment. By praying and asking others to pray for you, you are doing something at a time in your life when you are expected to just get better. Sr. Angela said, “They kept telling me to relax and just get better. Well, I didn’t want to relax. I wanted to do something! But I couldn’t. So, I prayed” (Sr. Angela 2003).

Some of the sisters also used visualization. Sr. Rosario stated, “I just tried to imagine myself better instead of worse” (Sr. Rosario 2003). Lerner also used this form of alternative therapy saying:

I had read just enough of the work of Carl and Stephanie Simonton, about the Houston cancer clinic, to be caught by their visualization idea. Their patients visualized the battle between the killer

cells, who had taken possession of the field, and the benign cells who chemotherapy was rallying to the defense of the organism.

Why not try it? Essentially it was cops-and-robbers stuff, a grim kind of play. I was playing at war, much as I had seen Michael and his younger brothers over the years, arranging their battlelines with their toy soldiers. I now made myself a four-star general in a map room, deploying the forces in both camps.

Yet amid the make-believe it was a real war I was playing at. I had a smoldering conviction of the reality of what I was doing as I ranged the battalions of cells against each other, then focused in turn upon each pair of combatants, and finally managed to make the forces of light smite the forces of darkness (Lerner 1990: 61-62).

Not only is this a good example of visualization, but it also shows the dominance of war-related terminology in the literature and in my interviews. In *Illness as Metaphor*, Susan Sontag writes:

The controlling metaphors in descriptions of cancer are, in fact, drawn not from economics, but the language of warfare: every physician and every attentive patient is familiar with, if perhaps inured to, this military terminology. Thus, cancer cells do not simply multiply; they are “invasive”. (“Malignant tumors invade even when they grow very slowly,” as one textbook puts it.) Cancer cells “colonize” from the original tumor to far sites in the body, first setting up tiny outposts (“micrometastases”) whose presence is assumed, though they cannot be detected. Rarely are the body’s “defenses” vigorous enough to obliterate a tumor that has established its own blood supply and consists of billions of destructive cells. However “radical” the surgical intervention, however many “scans” are taken of the body landscape, most remissions are temporary; the prospects are that “tumor invasion” will continue, or that rogue cells will eventually regroup and mount a new assault on the organism.

Treatment also has a military flavor.... There is everything but the body count.

The military metaphor in medicine first came into wide use in the 1880s, with the identification of bacteria as agents of disease. Bacteria were said to “invade” or “infiltrate.” But talk of siege and war to describe disease not has, with cancer, a striking literalness and authority. Not only is the clinical course of the disease and its medical treatment thus described, but the disease itself is conceived as the enemy on which society wages war (Sontag 1978: 64-65).

Throughout all of the secondary resources and my interviews with the sisters, this military terminology was used. The sisters used words such as “fight,” “win,” “war,” and “invasion” in their descriptions of their disease and their reaction to it. Every one of the sisters mentioned their need to fight this disease and win, showing that they were used to this military terminology as well.

### Stigmatization:

Erving Goffman stated that the word stigma first came from the Greeks, who used the term to “refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier” (1963: 1). Goffman himself later defines a stigma as “an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed. An attribute that stigmatizes one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself” (1963: 3). In this way, Goffman is trying to show that in some cases stigmas are looked at differently. He uses the example of how a person without a degree will try to hide that fact when trying to get a job. However, if a person with a degree is a failure and does not want anyone to know, that person might hide the fact that he or she has an education when trying to get a job. The same thing can apply as regards cancer survivors. Although some people may laud survivors for their strength and fortitude, others will blame survivors for their disease or be unwilling to offer them a job based on their medical history.

Goffman also states, “The term stigma and its synonyms conceal a double perspective: does the stigmatized individual assume his differentness is known about



already or is evident on the spot, or does he assume it is neither known about by those present nor immediately perceivable by them?" (1963: 4). For many cancer survivors, their stigma is not noticeable. They may have scars, but they may also be able to conceal them. At first glance, it is difficult, if not impossible, to determine who is a cancer survivor and who is not. Although to some extent, that concealment does make the survivors' lives easier since their stigma is easily concealed, but it does make some aspects of their life even more difficult since their virtual social identities and actual social identities do not match.

Goffman discusses social identities by saying:

“Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories. Social settings establish the categories of persons likely to be encountered there. The routines of social intercourse in established settings allow us to deal with anticipated others without special attention or thought. When a stranger comes into our presence, then, first appearances are likely to enable us to anticipate his category and attributes, his “social identity” – to use a term that is better than “social status” because personal attributes such as “honesty” are involved, as well as structural ones, like “occupation.”

We lean on these anticipation that we have, transforming them into normative expectation, into righteously presented demands. Typically, we do not become aware that we have made these demand or aware of what they are until an active question arises as to whether or not they will be fulfilled. It is then that we are likely to realize that all along we had been making certain assumptions as to what the individual before us ought to be. Thus, the demands we make might better be called demands made “in effect,” and the character we impute to the individual might better be seen as an imputation made in potential retrospect – a characterization “in effect,” a *virtual social identity*. The category and attributes he could in fact be proved to possess will be called his *actual social identity* (Goffman 1963: 2 original emphasis).

Goffman brings up the issue of honesty in this discussion, which I feel is the real reason why people become upset when they find out their assumptions are wrong. When one makes an assumption about a person, they tend to treat their assumption as truth.

“Normals” as Goffman calls them, feel that the stigmatized person should somehow make the stigma known if it is not immediately apparent (Goffman 1963: 74). Goffman calls this “covering” showing that most stigmatized people know that they either should not or do not have to explain their conditions to others. In the case of cancer survivors, having one’s stigma discovered can cause a dramatic effect, leading people to fire or even cease to speak to cancer survivors. This attitude may lead back to the old assumption that cancer equals death. Somehow people feel if a cancer survivor is not honest with them from the beginning, they have been misled and have let themselves get too close. Since they perceive the survivor to not only have lied to them, but also to have let them get close to someone who is or was ill, they will have a tendency to feel betrayed (Goffman 1963: 5, 35, 42, 50, 74, 95, 102-4).

However, one also sees examples showing honesty does not always make things better. Lerner discussed his experience with honesty saying:

Everyone stricken with some “dread” disease must at some point confront the question of how much to talk about it, and how much to reveal.

Understandably there is the smell of taboo around life-threatening maladies, since a society tribally tries to protect its integrity and sees a stricken person as a threat to the well-being of all. Very early, and throughout my illness, I tried to be honest about my cancer, with myself and others. I paid a price for my openness. As word spread, my lecture requests and magazine assignments melted away. Max Lerner healthy in his late seventies presented quite a different image from Max Lerner with cancer – and God knows what else – on his way out of life’s arena. We immure our sick in hospitals but we also invent ingenious ways of moving them offstage, banishing them from life’s center, making their healing and self-healing more difficult. (Lerner 1990: 38-39)

It seems cancer survivors are in a no win situation. If they do not tell the truth, they will seem dishonest. If they tell the truth, they make their own lives and healing processes more difficult. Armstrong wrote:

When I was 25, I got testicular cancer and nearly died. I was given less than a forty percent chance of surviving, and frankly, some of my doctors were just being kind when they gave me those odds. Death is not exactly cocktail-party conversation, I know, and neither is cancer, or brain surgery or matters below the waist. But I'm not here to make polite conversation. I'm here to tell the truth. (Armstrong 2000: 2-3)

However, after speaking with the sisters, I found stigmatization was not as much an issue for them. To begin with, they did not have to worry about losing their jobs or losing their insurance, two main concerns of lay cancer survivors. When asked if they felt they had been treated differently by the other sisters in the convent, most of them replied with a simple "No." Some went on to say that some of the other sisters were a little worried about them since they were sick, but they never felt that anyone withdrew from them. If anything, they felt more drawn into the group. They often had the same experiences with their own families. Some of the sisters preferred to stay with their biological families when undergoing treatment and found them to be a source of comfort and hope to them. Sr. Angela even said, "My little niece was my savior. I spent so much time playing with her I didn't have time to think about all of my problems" (Sr. Angela 2002).

Lay cancer survivors often find comfort in close friends and family as well. Max Lerner constantly writes about his relationship with his wife, while Lance Armstrong tells of the care provided by his mother and other close friends. It seems that it is the world outside of these close-knit groups that causes problems. Those people who are close, but not that close, and the strangers we meet tend to be the ones that are the least accepting of illness. Lerner states, "Except in recent work on family systems therapy, the medical model tends to scant the role of the family in illness and healing. Yet nothing is more

critical to the human ecology of a dangerous illness” (Lerner 1990: 40). Later he says, “It was conversations with my family and intimate friends that counted most for me. A dangerous illness can destroy family relationship if they are already crumbling, but it strengthens the valid ones. Illness has a way of sloughing off the inessential and causing us to focus on what comes first. Every major illness is combined tornado and earthquake, shaking our values. You discover what was jerry-built in your life and what can stand the storm” (Lerner 1990: 53-54).

Cancer survivors, regardless of their experiences and feelings during treatment, often find that in the end they have discovered what is really important in their lives. They learn whom they can trust, who will be there for them, and most importantly what they are capable of.

### Labeling and the Sick Role Theory:

When one considers sickness one tends to think of it in absolutes. A person is either sick or healthy. However, in cases of serious or chronic illness, this label of sick or healthy does not fit. The idea that sickness is deviance from the norm also does not work in the case of chronic illness. Many illnesses and injuries can last a lifetime, becoming the new “norm” for the person who has them. Folklorists are in the unique position to consider the culture that is behind the analytic logic of the sick role. Folklorists are training to look at society’s reaction and interactions with these people as well as consider the role of the person who is chronically ill. One idea that might help society better understand chronic illness would be to increase the awareness of chronic conditions, from cancer to back injuries, through the use of narratives and ethnographies.

A folklorist could offer others another perspective to help them realize that people do live with pain, fatigue, and other symptoms of chronic illness on an everyday basis and are often not depressed or unhappy about their circumstances. As Sr. Angela said, “Sure I’m tired, but if I wasn’t tired what else would I be? It’s either tired or dead” (Sr. Angela 2003).

Folklorists can help others to understand that there are levels of illness by drawing attention to the socially constructed nature of labels. It is not always black or white, healthy or sick. Some people can function normally even though undergoing treatment for cancer. In that case, are they sick? Are they following Parsons’ sick role theory? Not really. There are levels of illness from functional to nonfunctional.

The real problem with labeling and stigmatization is that it confuses the illness with the quality of one’s character. Cancer is not a punishment for people who are evil. Andrew Weil discusses how our self-help books and New Age philosophies have fostered a sense of personal responsibility for an illness. He states:

People who promote these ideas are well intentioned. They want us to be more responsible for our own well-being and to recognize that we can use our minds to help the healing process, all of which is fine. But an unintended result of their message is to create a great deal of guilt “I gave myself cancer.” “If I don’t get better, I must be a bad person. Guilt about illness is destructive; it cannot possibly help the healing system. (Weil 1995: 112)

Further relating to the social process of labeling is the lack of social mechanisms for de-labeling. Once one has been labeled as sick, that label will never go away, no matter how far removed one is from the situation. The patient will always be remembered as that person with cancer. Not that person who survived cancer or that person who beat cancer, but that person *with* cancer. Although many cancer survivors will mention they

are who they are today because of their illness, many cancer survivors become upset when everything they do is because they had cancer. Sr. Catherine mentioned, "I'm not a nice person because I had cancer. I was a nice person before. Cancer did not make me any nicer, smarter, or more able. It didn't make me any less, either" (Sr. Catherine 2003).

### Effect of Community Living:

When I first started the research for this thesis, I thought living in a community would have an effect on survivors. At a number of levels some of the effects were obvious. The sisters did not have to worry about insurance, job security, or making enough money to pay for their necessities. Since all of these things can affect a cancer survivor's well being and therefore, their overall health, by living in a community, the sisters did not have these everyday stressors that often affect cancer survivors. They were released from the everyday worries of life, causing them less stress and giving them one less thing to worry about.

In Katherine Russell Rich's book *The Red Devil*, she discusses how she had to wait for months to get the lump in her breast checked because she was in-between jobs and did not want to be rejected for her new insurance. Lance Armstrong devotes quite a few pages to sponsors who did not work out because of his diagnosis and his problems with insurance, including a brief, but frightening period when he did not have insurance at all. These kinds of stressors do not facilitate healing; in fact, they may even hinder the healing process. By living in a community, the sisters did not have to deal with problems such as these.

As Rich remarks,

In Cancerland, I was just beginning to learn, people are forced to live in two time zones at once. We exist on cancer's time and real-world time simultaneously. We continue to care about our love lives and careers and vacations and retirement plans – about the big and the small – but with a particular urgency, since the clock is racing double time. This double time magnifies all of our emotions; Compassion and sorrow. Fear and relief. Irritation and joy – the first because each day has to be redemption; the second, because each day is. (Rich 1999: 37)

As the beginning of this passage shows, lay cancer survivors have to live in “two time zones” and have little opportunity to really focus on their own healing process. For the most part cancer has to fit into their lives and their lives have to fit into cancer. However, for the sisters, even though they are very entrenched in the real world, they still do not have to worry about any of the things that Rich mentions. They have more freedom to spend active time on their healing. However, they can understand and sympathize with the second part of Rich's quote: the idea that their clock is racing double time. Sr. Agatha said, “I always felt in such a rush when I was sick. There was so much to do and so little time! And I had so many things to think about!” (Sr. Agatha 2003).

I also expected the sisters would not have the same issues of stigmatization. Although, for the most part, they did not, they still had some experiences with doctors and other health professionals stigmatizing them. I originally thought that by living in a community they would be living day-to-day in a more supportive environment. Although that assumption was true, the majority of them chose to spend time with their families during their illness. I had also assumed that lay cancer survivors felt a lack of support. This idea was not true at all, according to my sources. The accounts of most cancer survivors include the description of the formation of their own communities, whether it was family and friends or other survivors and patients. It was very rare that anyone was completely alone in his or her cancer experience. I had originally thought since the sisters

lived in a community setting that they would have more support. However, I found I was wrong in assuming lay cancer survivors felt a lack of support. Lerner, Armstrong, and Rich all mention those people around them that made a difference in their lives and helped them to not feel alone. These people typically consisted of their family and close friends, but often also involved other patients and survivors and the occasional health professional.

The hospital setting itself can be detrimental to a patient's well-being. As Yanna Lambrinidou states:

Severe illness threatens lives and relationships and personal identities. But when it is taken under the auspices of the hospital, it also threatens the very histories, values, and traditions that give meaning to people's lives. The contradiction here is that the hospital becomes life-threatening in the sense in which histories, values, and traditions not only give meaning to people's lives, but are their lives. (Lambrinidou 1997: 94)

As one can see, the maintenance of relationships can be very important to a person who is receiving treatment for a serious illness. Those who knew the patient before their illness can help the patient to maintain identity. Within the context of the convent, there is an excellent example of a way that people can help a patient to maintain identity. Whenever anyone needs to leave the convent for any medical reason, the convent makes sure that someone stays with the patient at all times. Not only is this a good idea for the safety of the patient since there will always be someone there in case anything goes wrong or if they are unable to make decisions they also have someone there to help them maintain their pre-illness identity and join them in conversations (both with God and without) that reaffirm their relationships and identity.



Narratives themselves can also help persons reaffirm their identity and help them to construct a new identity. Linda Hunt discusses this point in her article “Strategic Suffering: Illness Narratives as Social Empowerment among Mexican Cancer Patients” by stating:

.... the disruption introduced by chronic illness may appear in purely negative terms; something has been lost, and the loss is something to be coped with and endured. However, examination of people’s long-term adaptations to chronic illness reveal that the initial phase of disruption is often followed by a period of reorganization and reconstruction of the self and one’s place in the world. Becker (1997) has shown that people confronted by major disruptions to their lives, such as chronic illness, use narratives to restructure their sense of self and social location, telling stories that both articulate and mediate disruption. (Hunt 2000: 88-89)

We can see from this statement that people can regain their sense of self and why this illness happened to them through the use of narrative. By telling their stories to others, including themselves, they can reorganize and reconstruct their own lives and their place in this world. Always having someone with them, not only to reaffirm their identity pre-illness but also to listen to their narratives both during and after illness, may contribute to the sisters’ acceptance and understanding of their illness.

However, even the act of telling a story to oneself about oneself can also be therapeutic. In her article “Relating Intrapersonal Storytelling (Idionarrating) and Interpersonal Communicating” Marjorie Bard defines intrapersonal narrating as “narrating in which stories are generated in solitary reflection and developed through silent feedback and response between self-as-teller and self-as-audience” (Bard 1992: 61). She later shows how people practice telling stories by telling them to themselves. One can act as both listener and teller and one “has a reserve of untold story material which it retains for any purpose and may be brought forth in interpersonal

communication *after* intrapersonal narrating” (Bard 1992: 64). Bard also shows the importance of telling one’s stories by stating:

We hear often enough from Holocaust victims that they “survived” solely for the purpose and opportunity of telling their stories. We know that before such opportunity occurred, those survivors told the same stories to themselves; *they acknowledge the cathartic and therapeutic value of validation of existence through self-narrating.* (Myerhoff 1980: 22-43 as stated by Bard 1993: 65-66 emphasis mine)

This statement shows that even though some cancer survivors do not tell their stories to others, the act of telling their stories to themselves can also be therapeutic. This repetition of traumatic event stories can also foster a sense of self-acceptance within a person and help that person to later tell the story to others to also help with their self-acceptance and recovery (Bard 1992: 68).

## Chapter Five

### Conclusion:

Overall, I have found that cancer survivors I have looked at experienced many of the same things. They all felt they had been stigmatized at some point; however they had felt stigmatization in varying degrees. It seems the lay cancer survivors in the accounts that I have read felt the most stigmatization, perhaps because they dealt with more people in work and other environments. However, in my research I have yet to find a single cancer survivor who does not feel some sort of stigmatization. As discussed earlier, the education of others may be a way to help reduce stigmatization. Unfortunately it seems experience is the best education and many people may not understand what it means to be stigmatized unless they experience it themselves or have someone close to them experience it. Often, stigmatizing is not actually recognized for what it truly is. Many people are put off by doctors and told not to worry because of their age, race, or gender or because they are not believed due to stereotypes. Hufford observes, “Some disparities documented by gender are even greater than those for race” (Hufford 1997b: 116). Some forms of cancer, such as lung cancer, is more common in men in their late 50’s who are smokers than in any other group; therefore, many doctors feel if you do not fit the typical profile of a lung cancer patient (if you are a different gender, age, or a non-smoker) then there is no reason to check you for that disease, even if you display all of the symptoms of the disease. Although at first being told “not to worry” about cancer because you do not fit the typical profile may seem like a good assumption, it can prove to be wrong. My sources suggest patients are the best judges of their disease and have a clearer understanding of what is wrong. This form of stereotyping is very common for many

minority groups and people who are “too young” to have a disease. Rich describes being stigmatized for reasons of both gender and age in this passage of her book:

I was surprised to receive the one letter I did get, from a former coworker named Bob, who confided that he'd had testicular cancer but was fine now and hoped that I would be, too.

Not knowing Bob well, I didn't call and ask if he'd had to strong-arm his doctors into action when he'd found his lump. Anyway, my guess was he hadn't.

“What I usually tell women with these is just to go home and not worry.” Victor was saying, with a shake of his head and a little chuckle. *Those jittery girls!* “But if you really want me to, if you need it for your peace of mind, I can biopsy it.”

Biopsy it, I said in a low, hard voice, and his smile flattened. All right, he said, leaning back. All right, if I wanted him to. In later years, I've reflected on what would have become of me if I'd been more like one of those squeamish women in the stories. But I don't have to wonder about this for very long. The answer's clear. I would be dead. (Rich 1999: 28-29 original emphasis)

Doctors often assume some people are more or less able to handle a disease based on their preliminary experiences with the disease. One of the sisters told me that she once read her chart and her doctor had written, “Did not take news of illness well.” She was very upset at this comment and said, “Well, what did he want me to do? Wouldn't any normal person be scared, cry, and worry?” Her doctor went on to write he felt that she would be a problem because of this initial reaction. She stated, “I was a model patient. I saw some people get really upset in the chemo room. I didn't. I kept it all inside after reading that. And I didn't tell him anything else, either. I was too afraid he would think I was being a problem again” (Name withheld by author 2003). Obviously in this case, not only was the patient/doctor relationship damaged, but it was damaged to the point of no return, to the point that the patient would not even talk about her symptoms to her doctor for fear he would consider her a problem. As we can see in this case, stigmatization can be damaging and has the potential to even be fatal.

We also see both lay cancer survivors and those in religious life both fall under Parson's Sick Role Theory in the same way, with one exception. Both groups of people I researched knew they should want to return to their normal health, sought competent medical care, and did not see themselves as responsible for their illness, in spite of what others thought. However, they split when it came to being exempt to normal roles. Although some of the sisters chose to keep doing what they had done while healthy, the majority of them still switched their focus to becoming healthy. Most lay cancer survivors either do not have that luxury or do not wish to leave their current roles. Armstrong mentions, "Who would I be if I wasn't Lance Armstrong, world-class cyclist? A sick person" (Armstrong 2000: 14). The idea of being a "sick person" seems to bother the lay cancer survivors I looked at more than it did any of the sisters. All of the sisters seem to think cancer was just a part of their life or what they were supposed to do at that moment. They were much more accepting of the entrance of cancer in their lives, whereas the lay cancer survivors fought more with the idea of cancer in their lives. I feel this reaction goes along with the ability to "give up to God" and their own certainty about their identity which was discussed in Chapter Three. These sisters were able to accept their illness and transcend it in a much different way than the lay cancer survivors, who often struggled with this idea to a greater extent.

Prayer or some form of belief was reported by all of the survivors, even if God was not mentioned. Many of the lay survivors spoke out loud in a similar way to the sisters. Although they did not always consider this dialogue to be praying, they were talking to someone or something.

Armstrong writes:

I decided that I was an essentially good person, although I could have been better – but at the same time I understood that cancer didn't care.

I asked myself what I believed. I had never prayed a lot. I hoped hard, I wished hard, but I didn't pray. (Armstrong 2000: 112-113)

He later writes:

Beyond that, I had not idea where to draw the line between spiritual belief and science. But I knew this much: I believed in belief, for its own shining sake. To believe in the face of utter hopelessness, every article of evidence to the contrary, to ignore apparent catastrophe – what other choice was there? (Armstrong 2000: 113)

Although many may feel he is directly talking about God in some indistinct form, I will not put words in his mouth, but instead offer up his own words as testimony and let the readers draw their own conclusions.

Some of the other accounts had a great deal to say about their prayers and talking to God. Max Lerner writes in his journal dated October 18, 1985:

From this it was only a logical stem to welcome the Great Intervener into the battle. It took some doing at the time. My gang had all but ousted God, saying "No anthropomorphism! You can't be foolish enough to think of God as a venerable old man with a beard. If you want to bring him back, bring him as a 'Principle...'" That's what I had done for some time. I had a sense of awe and reverence for a cosmos those mystery baffles our comprehension. I even tried to think of God as an energy field.... But when I got sick it didn't work. It was too distant....

Curiously I began bootlegging the personal figure of God. It was a carryover from my visualizing of the battles, and from the human imagery that haunts and infests the night – asleep, awake, and in between.

So there I was talking with God in the old Jewish pattern, from Job to Herzog, and finding him vividly an Old Testament figure indeed. It was the Buber I-Thou dialogue, but with a dash of Kierkegaardian "fear and trembling" thrown in. God knows I had *tsores* (troubles) enough to have played Job. But I didn't relish carrying on his argument with God... My role was that of a respectful, affectionate subject of a King who watches over humans as well as ruling them. I started talking to Him each time I had to undergo some critical test that medical science had contrived for me. When I came through it I started thanking Him: "Thank you, dear

God” – not that I had actually asked Him for anything. I figured He knew my thinking.

That was the start of the one-way conversation I have carried on since with God, broadening them into almost daily and nightly occurrences. I began to talk with Him during the wondrous brief ritual pause before I fall asleep, when I survey the day as a general might survey the field after the battle is over.

This may strike some as my form of prayer, but I didn’t see it that way....  
(Lerner 1990: 182-83)

He later states:

Are my conversations with God one-sided? Of course – expect that if God listens it is not so much to me but through me. It would follow that he also talks through me, even though he doesn’t to me.

After all I don’t expect Him to appear before me in a pillar of cloud or fire. He has better things to do with His theatrics. But my premise is that He is there because he has to be omnipresent, and that he listens, because how else can he be omniscient? As for what he says, I have only tacit knowledge of it....

If anyone were to say I am talking to myself I wouldn’t dissent strongly. But since there is God in each of us I can talk with Him only by “talking to myself”.... After these years of talking, I see God as my wiser comrade, knowing friend, shrewd and tolerant listener – however amused. He must be by some of the things I bring up in our colloquies.... Yet with it all, His abiding mystery remains. (Lerner 1990: 187-88)

Although the lay cancer survivors’ opinions of God, whatever that entity may be, vary from the beliefs held by the sisters, they share in some of the same ideas that still make them a dyad. Although Lerner admits to some extent he would not “dissent strongly” he still sees himself as having conversations with another being, even if that other being is a part of him. He also sees that being as greater than himself. Although Armstrong does not refer to his conversations as a form of prayer, he still participates in bargaining as shown in this passage of his book:

I tried negotiating with it. *If the deal is that I never cycle again, but I get to live, I'll take it, I thought. Show me the dotted line, and I'll sign. I'll do something else, I'll go back to school, I'll be a trash man, do anything. Just let me live.* (Armstrong 2000: 97-98)

Curiously enough, he never states what “it” is. Is he bargaining with God or with cancer? And what is the difference to him?

As we can see here, it seems common for cancer survivors to talk to someone or something, whether or not they call this entity “God” This shows their need to discuss their illness with others (perhaps not human others, however) and their need to feel a power greater than themselves, regardless of how they perceive it.

In some ways, this form of bargaining may also reflect one of Elisabeth Kubler-Ross’ stages towards acceptance. Her fourth stage, bargaining, discusses the patient’s attempt to enter an agreement (usually with God) to postpone the inevitable (Kubler-Ross 1969: 72). She mentions that often times, patients will not only bargain for their life but will also bargain to do some thing “one last time.” Even when they are able to perform their task, they often are not satisfied and try to extend or make other bargain even though this bargaining often includes a promise that they will never ask for anything else again (Kubler-Ross 1969: 73). She also mentions, “Most bargains are made with God and are usually kept a secret or mentioned between the lines or in a chaplain’s private office” (Kubler-Ross 1969: 74). In my research, however, I have found that almost everyone I talked to not only bargained with God but also made mention of it to me. This willingness could perhaps be because all of these people survived their illness or had their bargains fulfilled. One of my informants noted that when a bargain is fulfilled it is often called a “miracle” and when it is not it may be called “God’s will” (Name withheld by author 2003).



As regards community, I have found that concept to be very important. It seems that even if a survivor is not already a part of a community, they will create a community for themselves, by surrounding themselves with close friends, family, and other patients and survivors. This community is very important for the overall well-being and ultimate survival since it helps the survivors deal with any and all issues that many surface in the course of their treatment and years following. One may, in some cases, even consider God to be a part of this community that each survivor forms, since all of the survivors considered here included some sort of “other” in conversation, regardless of what name or lack of name they gave the other entity.

### The Role of Folklore:

As quoted before, David Hufford wrote “the ultimate goal of folklore applied to health care . . . is to help official medicine to recognize its cultural location within the community and to discover the means for interacting as effectively as possible with those additional resources with which it coexists”(Hufford 1994: 128). I offered some suggestions for folklorists throughout this thesis, including their role in developing educational programs, acting as cultural liaisons, and the development of more research. The very act of writing a thesis such as this one can also be a contribution to several fields for this reason: even if it does not offer all of the answers, it does bring certain problems to light. The majority of these problems deal with survivorship issues and helping survivors find their place in their own lives and in the world again. Armstrong writes,

But how to you survive cancer? That’s the part no one gives you any advice on. What does it mean? Once you finish your treatment, the doctors

say, *You're cured, so go off and live. Happy trails.* But there is no support system in place to help you deal with the emotional ramifications of trying to return to the world after being in a battle for your existence.

You don't just wake up one morning and say, "Okay, I'm done with cancer, and now it's time to go right back to the normal life I had".... I was physically recovered, but my soul was still healing. I was entering a phase called survivorship." (Armstrong 2000: 181)

It is in this phase of survivorship that folklorists can offer some perspectives on the support system that is lacking. Although some organizations, such as the American Cancer Society, are currently offering more and more programs for people who are survivors, including a section on their website for survivors, there is still much to be done. Folklorists can contribute through the use of their unique perspective. They can perform ethnographic research on support groups, continue researching and publishing their findings, look at organizations for survivors from an ethnographic standpoint, and help survivors to find their own voice and audience through ethnographic techniques so that they can share their experience with others both affected and unaffected by cancer.

Of course, we do have to be aware of our own biases and how we speak for people. This thesis makes extensive use of quotes and these quotes were used to give people another arena to speak for themselves. It is the words of the survivors themselves I wish to preserve, not my own.

In "Ventriloquist Folklore" Susan Richie discusses the idea of representation. She states that as folklorists we believe the material we collect from our informants somehow still belongs to them and our articles and books help to empower our informants although they still use their own voice. In medicine, the issue of advocacy is important. Large organizations feel they can speak for everyone who has had experience with cancer, not only patients and survivors, but also caregivers and medical professionals. Often through

the use of informants' words, these organizations and individuals try to plead a case for their own causes and what they feel is "right" for the people they are trying to help. As Richie shows, what we as folklorist think is right is not always what is right for our informants. Often, people misrepresent their informants to suit their own purposes or goals for what they feel the group wants or needs. Richie states "Representation operates on the very logic of fraud" (Richie 1993: 375). If the medical community could use the perceived and expressed experiences of patients in order to show others what they have already learned, they might become more conscious of the way in which they are using others to reach their own goals and listen more to what the patients want instead of what they think that the patients want. Here, I have tried my best to communicate what I feel these survivors were trying to communicate.

In "Applied Belief Study and AIDS", O'Connor states:

Folklorists and other social scientist specializing in healing traditions and the ethnographic study of belief are trained to identify and interpret the issues which culture and belief bring to the healing encounter. In both clinical and educational settings (and this applies equally to remote or isolated rural areas and to ethnically diverse urban centers), we may – among other roles – function as mediators who demonstrate to both patients and health care professionals that each group has significant and well-considered mandates to which its members must be responsive. Though such work will never eliminate conflicts between belief systems, it can lead to the possibility of negotiated settlements in terms which – though perhaps not nearly idea to either patients or physicians – are nevertheless acceptable to and productive for both. (O'Connor 1991: 93)

Although there are social workers in place in many hospitals that serve as a patient/doctor liaison, many of the patients feel these social workers are on the doctor's side and not their own. Folklorists may be able to help this situation, either directly as liaisons or indirectly, by teaching social workers as well as doctors how to apply

ethnographic methods to their interviews and discussion with patients. As O'Connor mentions, we might not be able to eliminate conflicts, but we may be able to improve patient/doctor relationships in a way that is agreeable to both the patient and the doctor.

Armstrong writes:

What you learn in survivorship is that after all the shouting is done, after the desperation and crisis is over, after you have accepted the fact of your illness and celebrated the return of your health, the old routines and habits, like shaving in the morning with a purpose, a job to go to, and a wife to love and a child to raise, these are the threads that tie your days together and that give them the pattern deserving of the term 'a life.'" (Armstrong 2000: 203)

How we help survivors to find their life again is up to us and up to them. By letting them speak for themselves and offering them a place to do so, we as folklorists can make a difference in the life, health, and well being of an ever present and growing folk group.

I would like to leave you with a final quote by Max Lerner. He writes: "I came to know from my experience that the source of my illness was my entire life. But as it turned out, so was the source of my healing" (Lerner 1990: 43).

# Appendix One: Informant Data Sheet

## PROGRAMS IN FOLK STUDIES INFORMED CONSENT AND DONATION FORM

Project title Narrative and Belief Among Cancer Survivors in Religious Life

Collector Andrea Kitta Phone: 270-842-3926  
(include name and phone of contact person, project director, or instructor)

### To the participant:

Your special knowledge, skill or expertise represents a potential contribution to the study of folklife at Western Kentucky University. In order to preserve your knowledge for future students and researchers, the University asks that you give your signed agreement to participate in this project and to permit use of the materials that come out of this participation as part of the University's Kentucky Folklife Archive.

The collector will explain to you in detail the purpose of the project, the procedures to be used, and the potential benefits and drawbacks of participation. You may ask the collector any questions you have to help you understand the project. On the back of this form is a basic explanation of the project, which is yours to keep with a copy of this form.

**Informed consent:** I have read the summary of this project, and offer my cooperation freely and voluntarily. I understand that refusal to participate in this project will have no effect on any future services I may be entitled to from the University. Anyone who agrees to participate in this project is free to withdraw from it at any time. I understand that it is not possible to identify all possible drawbacks or problems in a project, and I believe that reasonable efforts have been made to minimize both known and potential but unknown risks.

**Donation of materials:** In consideration of the work Programs in Folk Studies and the Kentucky Folklife Archive is doing to collect and preserve material of value for the study of ways of life past and present in the upper South, I would like to deposit with them the following items:

- ◆ Tapes of recorded interviews
- ◆ Pictures
- ◆ Other various materials obtained by the research

to be used by researchers as part of the Archives' historic collections, exhibitions, and reference materials. Scholars, faculty, students, and others may use these materials for classroom demonstrations, comparative studies, and non-profit radio and television

programs produced at Western Kentucky University. They may also be commented on, quoted, or paraphrased in publications and in dissertation and thesis research.

Stipulations:

---

Signature of Participant

---

Date

---

Signature of Collector

---

Date

### **PROJECT SUMMARY**

The purpose of this project is to examine the accounts of cancer survivors concerning their experiences. Anyone who wishes to be involved with the project will be given a consent form and have the consent form explained to them. If you wish to participate, you will be asked to sign the consent form. The interviews will be recorded and approximately one hour long. The interviews will be conducted alone, unless you wish others to be present or in groups as appropriate. I will be asking you questions about your experience as a cancer survivor. If any of the questions make you feel uncomfortable, you can choose not to answer them. If at any time during the interviews you wish to quit, please let me know and we will stop the interview immediately.

Many cancer survivors feel the need to tell their story. It may help survivors to move on and to pass their knowledge of their experience on as well. The information from these interviews may help other survivors to know that others have gone through the same circumstances, which may be a source of comfort to them. With

describing any traumatic experience, there is a chance that painful memories will be brought up. I will provide the name and number of a psychologist and/or psychiatrist in the case that it is needed or alert someone else within the community of your choosing that can help. If any trauma happens in the course of an interview, I will immediately stop the interview and proceed with the course of action that was previously agreed to.

The material that I will collect (pictures, tapes, etc.) may be used by researchers as part of the Western Kentucky Folklife Archives' historic collections, exhibitions, and reference materials. Scholars, faculty, students, and others may use these materials for classroom demonstrations, comparative studies, and non-profit radio and television programs produced at Western Kentucky University. They may also be commented on, quoted, or paraphrased in publications and in dissertation and thesis research.

If you no longer wish to continue with this project, please let me know at any time, including in the midst of an interview. We can immediately stop and I will destroy or give you the material that I have collected from you. This in no way will change any institutional relationships that you may have or services you may receive from Western Kentucky University.

**CONTRIBUTOR INFORMATION**

\_\_\_\_\_  
NAME (include fullest possible name, including first, middle and/or maiden, and last)

\_\_\_\_\_  
ADDRESS

**COLLECTOR INFORMATION**

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\_\_\_\_\_  
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RELATIONSHIP TO CONTRIBUTOR: \_\_\_\_\_  
(cousin, friend, employer, acquaintance, etc.)



## **Appendix Two**

### **List of Possible Questions**

#### Questions for Narrative and Belief Among Cancer Survivors in Religious Life

1. How first learn that you had cancer?
2. What was your immediate reaction to the news?
3. How did you feel about your doctor?
4. How did you feel about the news after you went home? After a few days?
5. Did treatment begin immediately?
6. Did you do any additional testing or surgery?
7. Did you get a second opinion?
8. What were your treatment options?
9. Did you tell anyone about your diagnosis?
10. Did you take other people with you when you went for your first treatment?
11. How long did your treatments last?
12. How did your treatments make you feel?
13. What was it like when you finished treatment?
14. Did your doctor make you feel more or less positive about your prognosis?
15. Did others make you feel more or less positive about your prognosis?
16. Did you have any friends or family in treatment at the same time?
17. Did you know any other cancer survivors?
18. Did people act differently around you when you had cancer? How did that make you feel?
19. Did people act differently around you after you were in remission? How did that make you feel?
20. Did you feel differently about yourself during treatment? After treatment? As a survivor?
21. How do you feel about the term “cancer survivor”?
22. How do you define “cancer survivor”?
23. Did your relationship with God change after your diagnosis? During treatment? After?
24. Did your relationships with others change after your diagnosis? During treatment? After?
25. What did you do when things got tough? How did you cope?

## Bibliography

- Adler, Shelley R. 2001 Integrating Personal Health Belief Systems: Patient-Practitioner Communication. In *Healing Logics*, ed. Erika Brady, pp.115-28. Logan: Utah State University Press
- Allen, Gaynel. 1998. *"It's Not a Cold": From Cancer Person to Cancer Survivor. The Process of Living With Cancer*. Atlanta: Georgia State University.
- Altman, Roberta. 2000. *The Cancer Dictionary*. New York, New York: Facts on File
- American Cancer Society. 2003. *Cancer Facts and Figures 2003*. Atlanta, Georgia: American Cancer Society.
- Armstrong, Lance with Sally Jenkins. 2000. *It's Not About the Bike: My Journey Back to Life*. New York: Berkley Books.
- Brady, Erika. 1987. "'The Beau Geste' Shaping Private Rituals of Grief." *Folklife Annual*. 24-33.
- \_\_\_\_\_, ed. 2001. *Healing Logics: Culture and Medicine in Modern Health Belief Systems*. Logan: Utah State University Press.
- Cockerham, William C. 2001. *Medical Sociology*. New Jersey: Prentice Hall.
- Dreifuss-Kattan, Esther. 1990. *Cancer Stories: Creativity and Self-Repair*. Hillsdale, New Jersey: Analytic Press.
- Fletcher, Katherine. 1996. *A Methodological Study of Felt Stigma in Cancer Survivors*. Kansas: University of Kansas.
- Germain, Carol P. Hanley. 1979. *The Cancer Unit: an Ethnography*. Wakefield, Massachusetts: Nursing Resources.
- Goffman, Erving. 1959. *Presentation of Self in Everyday Life*. New York: Doubleday.
- \_\_\_\_\_. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster Trade Paperbacks.
- Goldstein, Diane, ed. 1991. *Talking AIDS: Interdisciplinary Perspectives on Acquired Immune Deficiency Syndrome*. St. John's Newfoundland: ISER Research and Policy Papers 12.
- Hufford, David. 1982. "Traditions of Disbelief" *New York Folklore* 8, 47-56.

- \_\_\_\_\_. 1997. "Introduction" *Southern Folklore* 54: 61-66
- \_\_\_\_\_. 1997b "Gender Culture, and Experience: A Painful Case" *Southern Folklore*: 114-23.
- Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Perseus Books
- \_\_\_\_\_. 1997. *Writing at the Margin*. Berkeley: University of California Press.
- Kubler-Ross, Elisabeth. 1969. *On Death and Dying*. New York: Macmillan Company.
- Lambrinidou, Yanna. 1997. "'No Whining': Visitation Restriction in American Hospitals and Their Impact on Health Care." *Southern Folklore* 54: 78-100.
- Lerner, Max. 1990. *Wrestling with the Angel: a Memoir of My Triumph Over Illness*. New York: Norton.
- Mattingly, Cheryl and Linda C. Garro. 2000. *Narrative and the Cultural Construction of Illness and Healing*. Berkeley: University of California Press.
- Mechling, Jay. 1989. "'Banana Cannon' and Other Folk Traditions Between Human and Nonhuman Animals." *Western Folklore* 48:312-23.
- O'Connor, Bonnie Blair. 1991. "Applied Belief Studies and AIDS" In *Talking AIDS: Interdisciplinary Perspectives on Acquired Immune Deficiency Syndrome*, ed. Diane Goldstein. pp. 83-93. St. John's Newfoundland: ISER Research and Policy Papers 12.
- \_\_\_\_\_. 1995. *Healing Traditions*. Philadelphia: University of Pennsylvania Press.
- \_\_\_\_\_. 1997. "Applying Folklore in Medical Education." *Southern Folklore* 54: 67-77
- Oring, Elliot. 1984. Dyadic Traditions. *Journals of Folklore Research* 21: 19-26
- Primiano, Leonard. 1995. "Vernacular Religion and the Search for Method in Religious Folklore." *Western Folklore* 54:37-56
- Rich, Katherine Russell. 1999. *The Red Devil: A Memoir About Beating the Odds*. New York: Three Rivers Press.
- Ritchie, Susan. 1993. "Ventriloquist Folklore: Who Speaks for Representation?" *Western Folklore* 52:365-78.

Sontag, Susan. 1978. *Illness as Metaphor*. New York: Farrar, Straus and Giroux

Weil, Andrew. 1995. *Spontaneous Healing*. New York: Ballantine Books.

Zeitlin, Steve and Ilana Harlow. 2001. *Giving a Voice to Sorrow: Personal Responses to Death and Mourning*. New York: The Berkley Publishing Group.