

NARRATIVES TO LIVE BY: STORIES OF A CANCER SURVIVOR
AND HER CARE-TAKERS

A PERFORMANCE THESIS

by

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ABSTRACT

Storytelling is an essential part of life. Much of what humankind has known has been through storytelling. This performance thesis focuses on the narratives of a cancer survivor and her caretakers. In-depth interviews were conducted to determine how, through narrating their stories, participants could possibly develop awareness of the experience of healing. I gave my participants a voice through a public performance, which took place on April 1st, 2016 in the Hazel Kelly Wilson VIP Room of the Jack B. Kelly Student Center at West Texas A&M University. This performance thesis, presented five different narratives: The Worst Phone Call Ever, The Heavenly Call, The Battle for Life, A Message from God, and God's Existence—My Biggest Take-Away. Through these narratives, the participants shared their experience, and the process of how each coped with cancer. Three stages of the process of the illness were analyzed: The Genesis, The Fight, and Survival of the illness. Feelings of healing were observed, and mentioned from participants. The theory of Narrative Medicine by Rita Charon provided the theoretical basis for the study.

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CHAPTER I

INTRODUCTION

In our busy world, some of us go about our daily lives with limited surprises while others receive the most unexpected news of their lives. Waking up one morning to have a yearly checkup is something many of us do, but when the results of those tests send us down a different path, our lives change in an instant. This story is familiar to me because it happened to someone I love very much. The unexpected news of my mom having breast cancer was devastating, and left us unsure what to do next. Our story is one of many that happen every day.

Breast cancer has become world known and a common diagnosis discussed anywhere I go. When given the news, the only thing to say is how is that possible and what am I going to do? Who will help me with this? How will I cope with the news? Once diagnosed the questions and worry are never ending. One way to answer these questions is to take a look at how others have dealt with the illness and the story of their journeys. Understanding the narrative of others' journeys is important for the future, because hearing other peoples' stories, will shine a light on the process of living with breast cancer and expand awareness. Narratives offer a completely new perspective to

release information about oneself or others. Sharing experiences that could be used as powerful tools by others to learn how to deal with certain experiences, could be considered effective by people who have been exposed to narratives, as a way to learn how to manage certain experiences in life. Particularly, this project sought to use narratives of breast cancer experiences as a way to understand how survivors cope. Sharing these stories can bring a new way to experience the process of how others experience breast cancer in their family cluster. The aim of this research focused on how the narrative of other peoples' stories about breast cancer could serve as a path to healing.

Rationale

According to the Breast Cancer Treatment Centers of America (2015), "Breast cancer is the most common non-skin cancer among American women. One in eight women will develop invasive breast cancer during her lifetime" (Breast Cancer Treatment Centers of America, 2015, para.1). Narrating breast cancer stories of survivors and their caretakers, through a public storytelling performance was the focus of this research. The purpose of narrating these stories is to provide a voice for both breast cancer survivors and their caretakers. By telling people's stories, I could bring comfort, hope, and alternatives to other patients as they hear how these patients feel, what happens with their bodies, minds, and themselves, while they experience the illness, and how they coped with the experience of being ill. After reading the work of Rita Charon (2006), the enthusiastic and grateful responses of clinicians, students, literary scholars, writers, and patients has encouraged me to think that we are developing useful approaches to medicine, to literature, and to suffering (p. viii). Certainly, narrative medicine appears to be effective as previous research endorses it (Charon, 2006). "Performance is often

conceptualized as a creative act that occurs in specific times and places, and that promises to repeat, transform, contest, or transgress established cultural patterns" (Gencarella & Pezzullo, 2010, p. 2). Performance is the perfect tool to share these stories. Storytelling and performance are both powerful ways that allows the researcher to be more than a writer, but be a part of the story itself.

According to National Storytelling Network (2015), storytelling allows dual communication through the performer of the story and the audience. In a collaborated involvement of both audience and storyteller occurs when performing through storytelling. Walls do not exist, the storyteller has the opportunity to make an impact with the audience by using all kinds of verbal and non-verbal communication to captivate the audience, and create a meaningful story that can offer a delightful experience (National Storytelling Network, 2015). Indeed, the goal of this research was to combine the power of performance and storytelling by collecting and sharing the narratives in a public performance to give breast cancer survivors and their caretakers a voice for their unknown stories.

According to Melcrum (2015), the use of storytelling allows the researcher to deliver the stories that connect with the audience in a particular way creating a deep meaning that influences extensive areas of the brain than rational data would deliver through messages causing a deeper impact to the audience (para. 1). Jenny Nabben from Melcrum (2015) explains that facts and figures impact small areas of the brain, while stories engage different areas of the brain regions that work together to build colorful, rich three-dimensional images and emotional responses (para.14).

Literature Review

A brief review of the literature includes the stages that most breast cancer patients experience once they are diagnosed.

The Genesis

According to Health Alot Team (2015),

Breast cancer, like all cancers, is the uncontrollable multiplication or growth of cells within the body. Breast cancer, specifically, is the abnormal growth of cells located in breast tissue. This growth usually forms a large grouping known as a tumor that separates from cells growing at a more normal rate. This cancerous cell growth can then invade surrounding tissue or spread to other parts of the body, known as metastasizing. Cancer cells that metastasize can cause serious and fatal health complications when left untreated (para. 1).

Explaining what breast cancer is to the audience helps them understand what goes on within the body of the patient. The statistics show that "60,290 women will be diagnosed in 2015 and 231,840 will be diagnosed with invasive breast cancer in 2015" (Breast Cancer Treatment Centers of America, 2015). When talking about the percentages of women surviving breast cancer, statistics show that there has been an increase of survivors from "1960s with a 63% of survival vs. 89% of survival in 2015" (Breast Cancer Treatment Centers of America, 2015).

According to the Breast Cancer Treatment Centers of America (2015), risk factors involved that lead to the developing breast cancer could be due to being overweight, family illnesses, sex, and alcohol consumption. (para. 3). Although the diagnosis seems

negative, treatments are available and most people diagnosed with breast cancer survive. In the last several years, medicine has come up with standard treatments such as surgery, chemotherapy, radiation therapy, targeted therapy, and hormone therapy (What Every Women, para. 4). Indeed, the procedures to help breast cancer patients such as mastectomies are not needed as much, compared to the past. New techniques have been introduced such as the lumpectomy. These new treatments have introduced a less aggressive treatment with less side effects compared to chemotherapies and radiation treatments (Breast Cancer Treatment Centers of America, 2015).

The Fight

After diagnosis, many times breast cancer patients are introduced to the different options they have to treat cancer. During this time, patients have several things running through their minds. Other research found that women decided writing about anything or even about their own experience as a type of support for themselves. A patient wrote a "note to cancer, "You may have knocked me down today, but I will kick your butt in the end" (Bell, 2014, p. 27). As they are given the options to fight, some patients experience the following:

Everything seemed to be surreal. I thought I was having a bad dream, more like a nightmare. At that point, I lost physical strength and could barely sit up. A hundred different thoughts raced through my mind, but at the same time, I could not think straight. Among other things, I thought, "Am I going to die so young? I am not strong enough to live with cancer, nor do I have the courage to wait for a cure. Why Lord? Why me? Why

me? Why me! I wept and wailed. This was the worst day of my life.

(Johnson, P. 2014, pp.5-6)

Recent research says that some of those things are, "I'll never be the same again. I will always be different" (Boehmke & Dickerson, 2006, p. 1121). Another study conducted found that women have "the will to live" (Landmark & Wahl, 2002, p. 112). In addition, the attitude women have to confront the illness was "connected to the threatening challenge of death relative to the future, to life" (Landmark & Wahl, 2002, p. 115). Breast cancer patients manage illness in many different ways. Some women experience emotional reactions while fighting the disease as few have commented "I didn't have time to think about having cancer. The thing that was toughest for me was when the treatment was over, I was on my own, and I have to work through all this by myself" (Landmark & Wahl, 2002, p. 116).

Research found how women feel about losing a breast during surgery, "the breast is linked to femininity and sexuality, thus loss of a breast can result in loss of femininity and give rise to feelings of degradation in relation to the opposite sex" (Landmark & Wahl, 2002, p. 116). Women who are fighting breast cancer seem to experience different procedures within the process because every case is different, and "the need for social support was valued as either positive or negative" (Landmark & Wahl, 2002). During the fight, other women experienced a plethora of emotions as they prepared for surgery. A study found that contrasting feelings emerged; some women felt confusion over their health while trying to become familiar with the disease, while others expressed anxiety because there was nothing they could do about the situation. During chemotherapy some hear things such as "Everybody says chemo is the worst part, and you'll get that out of the

way first," the surgeon said, smiling. "The rest will seem easy after that" (Bell, 2014, p. 9). In addition, some patients express their feelings about losing their hair "Nothing prepared me for the cascade of loose locks that poured over my body in the shower after my second chemo treatment or for the fist-size clumps of brown that filled my brush each time I ran it across my head. Finally, I said, "Enough!" and made an appointment with my hairdresser" (Bell, 2014, pp. 16-17). Others felt positive about the process and saw this as an opportunity to cope with their experience and share it with family. They found the study applicable to help other women cope with the anticipation of breast cancer surgeries (Drageset, Lindstrom, Giske, & Underlid, 2010). Other studies found that besides the medical treatments, healing from breast cancer could be found through narratives.

Telling a story is the best way I can say what goes on in situations where people find themselves on a cutting moral edge, spiritual vertigo their main reality, while they yet try to make sense of loss, grief, illness, crippling injury, or the ravages of genetic or social circumstances, and are then placed in institutions in the hands of physicians and other health professionals. (Zaner, 2009, p. 174)

Other studies explain how storytelling is a powerful tool that creates bridges of communication to others as well as ourselves. The relevance of "stories convey meaning and open us to the deep mystery of compassion. Stories are methodological tools in the aesthetic domain of nursing, paratelic ways of knowing that carry us beyond logic to a higher order of understanding" (Repede, 2008, p. 226). It is interesting that medicine comes in different forms other than medical drugs. Combining the power of stories with medical attention can be powerful. "The power of the mind is so much more than we

know. However, what we do know is that just as the mind can make us sick, it can make us better. The mind, body and spirit works together and when ones is diseased, it effects all three" (Repede, 2008, p. 230). This research has established the effectiveness of narrating stories that heal not only the bodies, but also the minds of ill people.

Rita Charon (2006) explains how teachers of literature, novelists, storytellers, and patients have written about their illnesses and have become collaborators at medical centers. They now teach others how to develop skills that enable them to learn from other's experiences. (p. 3). the skills are necessary to understand the meanings of narratives and the skills that "enable one person to receive and understand the stories told by another" (Charon, 2006, p. 3). According to Rita Charon (2006) "A scientifically competent medicine alone cannot help a patient grapple with the loss of health and find meaning in illness and dying" (p. 3). "Narrative medicine is a very practical undertaking. It arises from the day-in, day-out events of the doctor's or nurses' office—right there off the crowded waiting room, the desk drawers filled with prescription blanks and rubber hammer, the gauze and the scalpels and the needles and the betadine, the telephones ringing and the computer screens filled with lab test results" (Charon, 2006, p. 17).

Rita Charon (2006) gathered various research information and added them into her work, she shared that narrative shift has taken place across these many fields of human learning, challenging scholars and practitioners from religious studies to psychoanalysis to police work to concentrate on not just the facts but the situations in which these facts are told (p. 11). Charon (2006) stated that narrative is a magnet and a bridge, attracting and uniting diverse fields of human learning (p. 11).

As other researchers read Rita Charon's work, it inspired their research into narrative medicine, such as Bochner, Zaner, Langellier, Sharf, Harter and Frank, "By adopting narrative sensibilities, authors reveal processes through which the creation of a sense of the natural, necessary, and appropriate takes shape and gains traction" (Harter & Bochner, 2009, p. 115). Narrating stories with deep meaning creates awareness in not only breast cancer patients, but also other illnesses in which patients feel the need to express what happens inside them. Giving these patients a voice, allows them to heal their bodies from deep inside, creating healing through a combination of methods.

The Survival

The exhausting process of fighting breast cancer seems to bring a light of hope for many patients who desperately battled against all odds to heal physically, but the question is what comes after treatment? What is the experience of recovering and surviving the struggles? One study focused on creating a film to represent the experiences of women who were recovering from breast cancer diagnosis, treatments, anxiety, and many other prolonged symptoms. "After the Cure" gives voice to a community of women who have been stifled by the need of health care communities to fix problems and to treat conditions" (Strickland, 2009, p. 646).

The use of storytelling in the field of communication has contributed to prosperous advances in the way the medical community handles illnesses. "Narratives produce stronger cognitive and affective responses immediately, which, in turn, influenced message processing and behavioral correlates. Narratives reduced counter arguing and increased cognitive rehearsal, which may increase acceptance and motivation to act on health information in populations most adversely affected by cancer disparities"

(McQueen, Kreuter, Kalesan, & Alcaraz, 2011, p. 674). Indeed, narrative is in fact useful as it raises awareness of many different issues that need to be addressed as demonstrated through research. In this case, breast cancer patients have received the benefits of narrative medicine as performance.

Certainly, the narrative of survivors has become very popular in society. One study focused on how narratives influence breast cancer survivors to adopt a healthy life style by including physical activities and concluded that "both narrative and informational communications hold promise as effective tools to improve intention and positive beliefs about physical activity in sedentary women with breast cancer" (Falzon, Radel, Cantor, & Longueville, 2015, p. 767).

Research suggests that medicine itself cures the illness, but that there is an importance to narrative in the process of healing breast cancer. Many of those studies sustain the relevance of sharing stories, through narrative or performance, and is consider a great step to help women cope with breast cancer experience. (Langellier, 2009).

Women's survival experiences were presented in several studies, and showed the power of narratives in the process of healing the body, mind, and soul. Undeniably, research has supported that " Narrative medicine has come to understand that patients and caregivers enter whole—with their bodies, lives, families, beliefs, values, histories, hopes for the future—into sickness and healing, and their efforts to get better or to help others get better cannot be fragmented away from the deepest parts of their lives" (Charon, 2006, pp. 12-13). In addition, Rita Charon (2006) states that "narrative medicine" came to her as a unifying designation to signify a clinical practice informed by the theory and practice of reading, writing, telling, and receiving of stories (p. viii). The literature

review provides a strong framework to support the idea of my research on the healing narrative.

Theoretical Approach

Through exploring the importance of narrative performance in the healing process of breast cancer survivors and their caretakers, narrative medicine offered the anchoring theoretical support to my study. Narrative Medicine by Rita Charon (2006), explains how "medicine practiced with these narrative skills of recognizing, absorbing, interpreting, and being moved by the stories of illness. As a new frame for health care, narrative medicine offers the hope that our health care system can become more effective in treating diseases by recognizing and respecting those afflicted with it and nourishing those who care for the sick" (p. 4). She also explains how "narrative is a magnet and a bridge, attracting and uniting diverse fields of human learning" (p. 11).

Narrative medicine emerges from a deep understanding Rita Charon had when she was practicing medicine. She became aware of the needs of patients to explain what was going on beyond their illnesses. It was more about realizing that they needed to narrate the way they felt and what was happening to their bodies; something they did not find through regular medical practice. She concluded her study by developing a new way to help her patients who needed to be heard. Rita Charon (2009) explains:

Narrative medicine reminds us that illness unfolds in stories, that our bodies, being more than machines on wheels, live through our lives with us, perform our lives, carry our scars, our bliss, and our memories, simultaneously both limiting and expanding our lives. Narrative medicine recognizes that the central events of health care are the giving and receiving of accounts of self. (p. 119)

In addition, narrative medicine helped support my study through a collaborative effort of performance, which allowed survivor stories to be heard. "Narrative medicine as performance is to recognize the texts and bodies, the stories and selves, which participate in its practice-patients' and physicians' embodied stories as well as the body of medical discourse itself" (Langellier, *Performing narrative medicine*, 2009, p. 151). Scholars such as Langellier have used Rita Charon's work of narrative medicine and have become aware of the efficiency of narrative medicine. She undertook research where she fused narrative medicine and performance to call the narrative medicine a performance (p.151). Langellier also considers that "performing narrative medicine reminds us that somebody has been hurt and that somebody speaks and gestures, touches and is touched, feels fear and pain, hope and despair. The story identifies the bodies and selves that participate in performance by highlighting the increasing frustration with a health issue, years of resistance to a surgery, and a long and uncomfortable recovery" (p. 151).

Langellier (2009) also refers to narrative medicine as imbedded and alive in performance acts, which encloses the meanings of both clinicians and patients' experiences. The aim of narrative medicine as performance is directed to create the stories, the characters, and the senses (p. 152). Narrative medicine is communitive because it focuses on performance to display or represents the non-verbal cues of a person, the tones that voices take while performing, and body skills required when speaking and listening to enable the performer to either disclose, or disguise, to create responsiveness or to elude, to become near or simply keep a distance. The whole focus of having the whole body involved in the performance is to create a connection and have an effective response of the audience. Here the performer seems to take advantage of all the

skills to communicate the stories to the public (Langellier, *Performing narrative medicine*, 2009). The importance of performing is valuable, as it allows the performer to reach out to the audience profoundly.

According to Langellier (2009) narrative medicine as performance highlights participation in storytelling as embodied reading and listening out loud. Charon's tool teaches clinicians the writing of narrative medicine, which produces texts that complete and complement their reading (p. 155). Other scholars have recognized Rita Charon's work, and no doubt Langellier, has been wise to pair her work with Charon's. Langellier (2004) states that performing narrative requires bodily participation: hearing and voicing, gesturing, seeing and being seen, feeling and being touched by the storytelling (p. 8). Performing stories can be challenging not only for the storyteller, but also for the audience, there is a delicate process involved. According to Langellier (2004) performing narrative is not a discrete event—somehow external to the body—of processing and recounting prior events. The body of the storyteller does not function as a kind of organic video camera or tape recorder. Rather, the storyteller takes up some part of bodily activity (such as the performance of a story) (p. 9).

Methodology

My study used a qualitative approach, focusing on narratives. According to Creswell (2013), a narrative study researcher gathers data, works with a dual participation of both participant and researcher by telling stories. The narrative study can be examined in various ways. Frequently, it will contain turning points and it will occur in unambiguous places or circumstances. This particular study fitted into a biographical approach in which the experiences of others are narrated. This allowed the researcher to

seek in depth details of the stories being narrated in the performance. This study collected the stories of a breast cancer survivor, and four caretakers, and the collection of data was done through in-depth interviews. Two separate questionnaires were presented to gather the data. The structure of the interview questions gave the participants the opportunity to expand, and contribute details about themselves and their survival stories.

Summary

Chapter 1 discussed the research question my performance thesis addresses: How can a performance about experiences of breast cancer survivors contribute to the healing process? Additionally, I provided a rationale for my research, a brief review of the literature and a discussion of my theoretical framework, which relies on the concept of narrative medicine developed by Rita Charon and the qualitative approach I used.

CHAPTER II

INTERVIEWS AND DATA ANALYSIS

My approach in this performance thesis is qualitative in nature. The present study relied on in-depth interviews of a breast cancer survivor, and four of her caretakers. Chapter 2 explains my qualitative approach, the participants, and the themes that emerged from analyzing their responses.

Interviews

The interview questions were shaped separately. One had the purpose to find relevant data about the breast cancer survivor's experience, and the second set of interview questions, sought for the caregivers' experiences. The questions had the purpose to find as much detail as possible, and because of that reason many of the questions were restated many times to give the participants the freedom to provide extensive details. A copy of my interview protocol can be found in Appendix A and B.

All the interviews offered substantial data about how breast cancer is experienced by each one of the participants. Through the interviews, the researcher was able to find the different perspectives, emotions, thoughts, and processes that occurred during the time participants experienced breast cancer directly, and for others indirectly. Two

different views presented two dissimilar ways to experience breast cancer. The breast cancer survivor's standpoint and the caregivers' perception. The information was gathered after receiving full approval from West Texas A&M University's Institutional Review Board. A copy of the approval letter from the IRB is located in Appendix C

Participants

The participants were specifically chosen to participate through a convenience sampling, because all five of them meet the requirements of the study's purpose. One of the participants is a stage four-breast cancer survivor, and the other four are her caregivers. Their participation was voluntary. The interviews took place in a residential setting with the purpose to create a cozy intimate environment to encourage the participants' responses. The interviews were conducted in person. Two sets of questions were used, one for the cancer survivor and the other for her caregivers. The interviews continued until saturation was reached. All five interviews presented significant and similar information, enough to map the results, and find the emerging themes. The researcher identified an important event throughout the five stories that had not been shared with others. This was relevant to the study, because the researcher was experiencing deep information that participants had not disclosed for over twelve years. They recalled saying that their experience was placed under a lock in their hearts. Only one of the participants did not mention-this issue.

Emerging Themes

The emerging themes drawn from the in-depth interviews showed that during the stage of "the genesis," "shocking emotions", was a similar response of all participants including the breast cancer patient. Participants described in depth details of their

emotions. They were asked about the experience of knowing the diagnosis of the stage-four breast cancer, and they all confirmed that it was "shocking" experience. All of them agreed on how impacting the news were for all of them. For the breast cancer patient the feeling was similar to "a bucket of ice falling on top of your head, paralyzing your whole body, mind and soul." She recalled the uncertainty, of not believing it was happening to her for a third time especially knowing that the diagnosis brought with it a 25 % of survival. She said she was told, "there is nothing to do for you Mrs. Vargas". Although, she replied saying "you will not determine when I am going to die." "I will look for a second opinion" As for the caregivers, the same theme emerged; they all said it was a shocking, impacting news to hear about the breast cancer diagnosis. They also agreed on how unexpected this news was for all of them. One participant recalls being disappointed to hear his mother was diagnosed with cancer for a third time, adding that it was disappointing, because not only was it the third time, but also because they were told, there was a low survival possibility, and that was devastating. The breast cancer survivor's husband was with her when she received the news about the diagnosis by a phone call. She cited "this was the most unethical experience" she had ever had with a doctor.

The second emerging theme during the stage of "the genesis" was "fear". The breast cancer survivor remembered thinking how painful it was for her to imagine her death, and the fact of not seeing her children, and husband. That terrified her as she said, just having to think about not being there scared her, mainly thinking about not seeing her children "poked her heart with sharp needles" she said. The process of death was just inconceivable for her. Her son said that he was afraid of losing his mother. Her husband

also agreed about being afraid of her dying. Her mother who was also a caregiver, expressed fear of losing her daughter. Only one participant did not recognize being afraid of her dying, she expressed that from moment one, she was shocked, but not afraid of losing her. She said "My faith is greater than anything else". Thirdly, they all agreed about having "faith", they treasured faith every second of their lives. They all agreed on this theme. In addition, to being "shocked and fearful" "faith" came along to take away the fear out of their hearts. These three major themes happened during "the genesis".

Moving on to the second stage "the fight," participants gave similar responses from two different points of view. On one side, the breast cancer survivor expressed negative and positive effects of fighting for survival. She recalls feeling "pain, sorrow, uncertainty, sadness, sourness, weakness, and anger for not being able to be independent." As for the caregivers, they remembered feeling "pain, sadness, disappointment, uncertainty, anger for not being able to help her". The responses here are similar, but the breast cancer survivor experienced them physically and emotionally. She recalled "the fight" as the most painful, and difficult of all the stages she went through. She remembers how she felt pain all over her body; she was directly affected by the treatment's reactions. Her hair fell out her skin became irritated, her immune system was weakened and she was sad because she could not do anything on her own. In the case of the caregivers, the emerging themes are similar from another point of view. They did not experience the direct effects of the treatment, but for all of them it was difficult to see her suffer, and care for her without being able to take away all of her pain. They expressed feeling sad, disappointed, angry, and heart broken, because there was nothing they could do to take away her suffering. "It was very painful to see her with no hair, throwing up

her own flesh, and feeling restless and weak," they all said. Not being able to help her take away all that physical and emotional distress was the difficult part for all of them. On one side you have the breast cancer patient being affected and experiencing all the painful reactions of the treatments, and on the other side you see the husband, the children, and her mother suffering to see her in such distress.

Finally, moving to the stage of "the survival" the common themes emerging within all participants were "love, strength, courage, passion for life, God's influence, and faith once again". The breast cancer survivor showed through her responses, how brave, strong, passionate, faithful and blessed she felt by God's presence in her life. She attributed her survival to God and the love for her family. Certainly, the caregivers confirmed that love, strength, God, passion for life, faith and family were the major motives she had to survive. The caregivers also described that the love, the faith in God, the passion she had for life and the love for family were the motives to come through this hardest moment of their lives. When they were asked about the negative and positive take-away experiences, they all had similar responses, referring to God's existence in their lives.

The survivor said God kept her strong and faithful. Her husband said that his faith in God and the love he feels for his wife, and his children helped him overcome this experience. Margarita, the breast cancer survivor, shared a beautiful story she had with God. She shared how God manifested his love to her through the wiggles of a white butterfly. This was a sacred story she had not disclosed for over twelve years. She described during her interview how the white butterfly became an essential physical manifestation of God to her. She recognized how brave and strong her daughter was, and

she as a gift to her decided to share a never told story of her experience with God. Her son said, "My Biggest Take Away is that God Exists" when I see my mother alive, even though she still struggles with the after effects of the treatment. Her mother said that her prayers to God and to her Lady of Guadalupe were her biggest strength to overcome this experience, and the love for her daughter and family. Finally, her daughter expressed that God provided the biggest strength she had to help her mother and herself overcome this painful experience.

As Margarita's daughter, I noted that God spoke to me over the mountains. This experience helped me overcome seeing my mother's distress, and pain. God is my rock and the air I breathe. He gave me the strength to help my mother and myself. He showed me his grace, and I am forever thankful to God for giving my mother the gift of life. Every day I wake up is a new day, a new beginning, and new opportunity God is giving me. I count each day as a beautiful gift from God.

Finally, all participants answered that it was beneficial to share their experiences with others. Margarita said, "Yes, my heart feels less heavy, I let go some of the pain I held constantly, because even after twelve years, the struggles I have as consequence of the treatments, keep reminding me how grateful I am to be alive, but there are times it hurts to remember". "I think that by sharing my story, I can let go off some of the pain. I also think sharing my story could serve as reference to others as a way to learn about how to deal with terminal breast cancer, if you find yourself in that position sometime of your life".

Jesus Sr., her husband said that he thought sharing was a way to let go some of the sorrow kept inside for years, and the pain that this still causes every day as he see her

struggle. Nevertheless, he also said, it could, perhaps, help somebody relate to his story, and maybe help somebody overcome similar situations. Jesus, Jr., her son said, "yes I believe that sharing my story after twelve years, has helped me, and maybe I could help others who are going through similar experiences with their loved ones. I can say, that by sharing any story or any learning you might have from life experience, is a way to learn more over how to deal with certain experiences and painful pathways we face in life. This was such a relief for me", and I truly hope it is for others as well". Margarita's mother, Fermina, said, "Is a relief, to let go some of this pain I keep inside. Seeing my daughter suffering has been one of the most painful moments of my life, along with the suffering of my other daughters, and son who experience different illnesses. I know that I feel better by sharing my story; I feel my heart less heavy"—as she smiles.

The Theory of Narrative Medicine, by Rita Charon, along with the information gathered during the interviews, supported the idea of how narrating stories and sharing them with others is a helpful tool to help oneself and others overcome different experiences and situations. My findings support the idea of healing through stories, as stated by the work and research of Rita Charon.

Summary

This chapter has offered a detailed overview of the data collected from in-depth interviews, relevant information about the participants and a descriptive analysis of the entire collection process and findings.

CHAPTER III
PRODUCTION CONCEPT

My interest in pursuing a performance thesis springs from my love for my family and the family stories that we share. As I thought about my own experiences, particularly those tied to my mother's battle with cancer, I wanted to explore, not only my own reaction to my mother's diagnosis and recovery, but I also wanted to explore her feelings and those of other family members. Chapter 3 describes my production concept for the performance of my family's personal narratives about dealing with cancer.

The Setting

Figure 1: Family Photos on Table



The Hazel Kelly Wilson Room at the Jack B. Kelly Student Center was the perfect setting to perform the stories since it is an inviting place, which makes you feel at home. The room has a mock fireplace, which provides a setting, homelike in nature. I displayed family pictures over fireplace, and a floral arrangement, which served as a prop that honored those who gave care and love during the battle of the treatment. These pictures served as props to honor those who gave Margarita love and care during this process. (See Figures 1 and 2).

The chairs in the room were arranged in a reception style to bring the audience into the cozy home environment. Three readers' theatre blocks covered with a white, tablecloths decorated with a white butterfly were placed downstage left from the fireplace.

Figure 2: Family Photos on Table



Figure 3: Block 1



Figure 4: Block 2



Figure 5: Block 3



The first readers' theatre block had a coffee pot, two small coffee cups, two small plates, a fork, two spoons, and a plate with pancakes, red lipstick, a small mirror, Kleenex, and a red phone. This first prop represented the Genesis, it is here were Margarita received "The Worst Phone Call Ever" story as she is informed about her breast cancer diagnosis. (See Figure Block 1). The second readers' theatre block had a mini laptop, an apple, water, a pink lipstick and a picture of myself. This prop served to represent "A Heavenly Call" story, which was my personal story about my connection with God. (See Figure Block 2). The third block had a picture of Margarita and Jesus, when she had lost her hair, a hair turban, an inspirational book, a rosary, a silicon breast prosthesis, and an angel. The third prop represented the Fight Margarita experienced during the battle of cancer. (See Figure Block 3). Down to the left of the readers' theatre blocks a cardboard wall simulated the sky with butterflies flying, on the side over the table there was a floral arrangement with a white butterfly on top to simulate it was flying over the flowers. On front of the floral arrangement, a sign that said "Love" with a butterfly was placed, and a picture of Jesus, Margarita's son was down left of the table. On the back of the simulated cardboard blue sky there was a coat stand, where I hung

Margarita's red sweater used in the story of "A Message from God", which I put on as I narrated the story.

Figure 6: Butterfly Cakes



Right by the entrance door, was a table decorated with a black tablecloth. On this table was a floral arrangement, a recent picture of Margarita, bottles of water, small plates, napkins, and small white butterfly cakes with

white and pink butterflies on top as decoration. (See Figure 5 Butterfly Cakes). By the door, beautiful antique table held the presentation programs for guests.

During the time Margarita the survivor, stated that her story of the white butterfly was a never told before. The story itself brings her joy, hope, and the greatest proof of God's existence in her life every time she remembered it. It is a sacred story disclosed after twelve years. Finally, I placed family pictures, a small black binder with a quote by Rita Charon, and pictures of the family.

Use of Color

I used white throughout the performance, because, white represents the faith and hope the breast cancer survivor projected, and the purity of her family's love for her. The white butterflies everywhere represented the essence of all the stories combined, which characterizes her inner spirituality. The story of the butterfly turned her painful story into a story of graceful survival, which she appreciates with all her heart, mind and soul. The flowers, the objects, and the pictures all represent an important role in this performance, as well as illustrating the major themes of the stories. I wore black to contrast with the

story of the butterfly. Black represented the darkest, painful, bitter moments, the sorrow, and the obstacles in my mother's recovery. The white butterflies embraced the significance of God's existence, the hope, and the faith. I considered this story the most special moment of all.

Stage Blocking

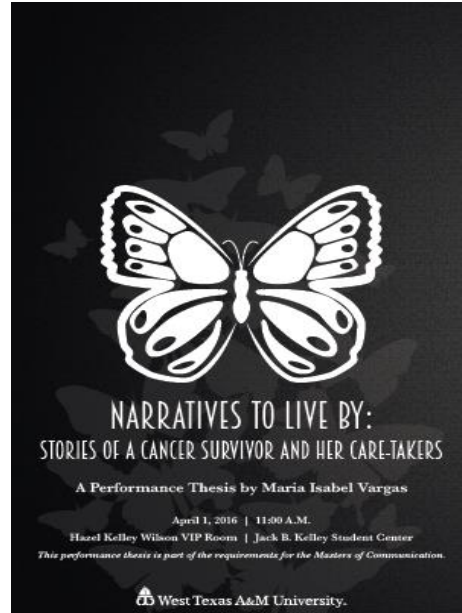
The performance began at 11:00 a.m., at The Hazel Kelly Wilson room in the Jack B. Kelly Student Center on April 1st, 2016. Dr. Hanson, as my committee chairperson, welcomed audience members to my presentation. She gave a brief explanation of the significance of performing stories, and the expectations the audience could have. I welcomed my audience, into the heart of these stories by saying—"It has been twelve years since my mother's life was forever changed by a phone call, I will now share with all of you some of the thoughts she had that day. The starting point was that in a beautiful morning Margarita starts by thinking, and asking herself about breakfast. As she debates about breakfast that morning, it all started unfolding. This is the moment where I moved to the first cube, where there is a red telephone, which represented the moment, when the breast cancer survivor received the devastating news about her diagnosis. Next, I moved farther down left, to the prop that had a laptop, an apple, a phone, and a picture of the breast cancer survivor's daughter. This prop represented her daughter's story. I then moved down farther left to next prop were objects placed were representing the story were the cancer survivor narrates her cancer battle. A red sweater, an inspirational book, a rosary, a silicon breast, a picture of her and her husband, when she lost her hair and a turban were placed and used in the third prop. I then moved down left to a prop that had a floral arrangement, with butterflies flying, and one white butterfly

that was used to support the survivor's most sacred story. Finally, I moved down center to the fireplace, as I grabbed the breast cancer survivor's daughter picture to present the experience of her mother's breast cancer odyssey as she was facing breast cancer, and that she was giving no hope for survival. Then, I picked up the cancer survivor's son picture and narrated his story, and placed her daughter's picture down. Following, I opened a black notebook as I stated one of Rita Charon's quotes. Then, I placed the book down and I finished presentation with a short reflection and a thankful message to the audience.

Advertisement

Brittney Thoene designed a poster, and the theme was a black background with a big white butterfly in the center, and other white butterflies on the background to symbolize the essence of the stories, which were stories that left a light on and hope. The black color represented the darkest, painful and sorrowful moments, while hope, faith, and love was represented through a white butterfly. The posters were placed in strategic places at the Fine Arts Complex Building, in the Jack B. Kelly Student Center, the Library, the Graduate School Building, and the Nursing School Building. The poster design was also used for the program cover to maintain the same color scheme. Dr. Hanson, my chairperson, invited the whole Communication Department through sending the poster via email to advertise the presentation as well.

Figure 7: Poster Design



Summary

Chapter 3 includes a discussion of the production concept for the performance. I discussed the details of the setting, use of color, stage blocking, and advertisement designed and distribution. I explained the staging of the performance, as well as the significance of the items I chose to include to support this personal narrative.

CHAPTER IV

THE PERFORMANCE

The performance took place on April 1st, 2016 at 11:00 a.m. in the Hazel Kelly Wilson Room in the Jack B. Kelley Student Center at West Texas A&M University. The performance lasted approximately an hour, followed by audience questions and discussion. Those attending included peers, faculty members, family members, friends, students, and my thesis committee: Dr. Trudy Hanson, Professor Paula Schlegel. There was a video camera videotaping the performance, to be used to evaluate myself, after the performance. The video also served as a great way to present my performance to the guests who were invited, but were not able to attend the presentation for various reasons..

The following performance script was designed and created for presentation. Storytelling does not require the storyteller to memorize the exact script of the stories. Instead, it gives the storyteller the opportunity to connect with and approach the audience, in a warm and casual way. It is the storyteller's responsibility to respect the audience at all times, and to maintain the focus of the audience as well.

Performance Script: Narratives to Live By

The Worst Phone Call Ever!

It has been more than twelve years since my mother's life was forever changed by a phone call. Let me share her thoughts about that day.

(Isabel moves DR to the red phone prop, and applies red lipstick to her lips. Red lipstick is something unique about her mother's personality. Her mother told her that the Red lipstick makes her feel alive, joyful, and strong).

It was a beautiful and cool fall morning, an ordinary day unfolding. At this point, I was thinking, and asking myself, what should I cook for breakfast? As I wondered in my head, I thought to myself, we love pancakes, it is a great cool morning for pancakes and coffee, so why not! I cooked pancakes for breakfast, for my husband and me. I brewed a fresh pot of coffee and said my morning prayer as I was preparing breakfast. I have always believed a great attitude is essential to start my days, feeling positive in God's presence. We enjoyed our breakfast, and as I was chatting with my husband, I recall telling him, *Vargas I will have a busy day, many brides will come out throughout the day to have alterations done.* Well, he said, you will do great as always, you are so talented. *Thank you honey, I think it will be a great day. Oh Vargas, they might call to set an appointment to give me my yearly checkup results.* Results? He asked, I said *yes remember I had my fun squeezing moment few days back! Oh yeah, I forgot. Are you going back for a doctors' visit? I think so; I am just waiting for their phone call, to schedule an appointment to go over my results from my yearly screenings, Pap smear, Mammogram and all that fun squeezing and smashing fun stuff you know.* We both smile and soon the phone rings.

Honey, I'll take the call! As we remained seated, I said—Hello! Mrs. Vargas? *Yes, this is she!* We are calling to talk about your results, as I said, *oh are you scheduling an appointment for me to come in?* No not quite that, I would like to know if you are with somebody beside you, and if you are sitting down. I said *yes, my husband is with me and we are having breakfast!* So whatever you have to say ma'am just please do. Oh, yes, Mrs. Vargas, your results are in, and they are positive for a very aggressive type of breast cancer! We would like you to come and see the doctor. Oh, my body froze for a moment; I didn't know what to say, I stayed quiet for few seconds, because I could not believe they were giving me results over the phone! I thought really, they are telling me about an aggressive breast cancer over the phone! I got so upset, but I kept listening. At that moment, I did not think of anything, I was shocked, and I thought; Wow! You call me over the phone to tell me I have breast cancer! Yep! Que bien bola de insensibles! Wow you people have no feelings for people whatsoever, I thought. That is how you give people news about their health issues, I kept thinking! As the receptionist-continued, Estaba muy enojada! I was so upset, but I was listening—Mrs. Vargas, you need to come over tomorrow for an appointment with the doctor, at 9 am. I said, *okay I will be there,* and hung up! My husband said—mija que pasa? What is going on, honey? *I said oh well, it was a phone call from the doctor's office to tell me I have a very aggressive breast cancer! Por telefono, puedes creerlo Viejo? Over the phone! Can you believe that, honey?* At that moment, my whole day just turned gray, and that is how the new journey of my life started. It was not a great day after all, I thought! My husband asked: Que quieres hacer mija? What do you want to do, sweetie? I know that you will be fine; we are a family who believes in God, and have faith! I was quiet, thinking; I was in shock! I

keep thinking how a phone call had changed the way I felt before and after. My attitude and vision of the day had had a dramatic turn. My husband gave me few minutes without asking anything. Minutes later, he asked me again—what I wanted to do and I said, *take me to work! To work? Si llevame al trabajo! Taking me to work!* I sarcastically smiled and said I didn't know what these people were thinking by giving me results over the phone! I remember telling my husband, I didn't believe what I just heard, so just take me to work. I could not believe that the staff at the doctor's office were acting in a very unprofessional, unethical, and insensitive way, I said. My husband drove me to work, as I kept thinking; that cannot be true. I will just go to-work, and I will see what tomorrow brings. Okay mija! Just know that whatever your decision might be, I am here to support you, you just tell me how, okay. We arrived at work, and before I left the car, I said—you know what, *if this is true, I will fight this! We will go to the doctor and talk about things I can do to fight this!* He said, yes! I love you! We will make it! We will make it!

(Isabel moves down center and honors her father)

It is essential to say that it was a blessing to know that my mother was not alone, my father stood tall in every step of the way. He encouraged her, supported her, admired her, and most of all loved her as she is, a wonderful women inside and out, as he stated many times. My father has been the rock that supports her every day, no matter how hard, how tough or how wonderful the circumstances might be, he truly loves her with all his heart.

A Heavenly Call

(Isabel moves down center to the laptop, phone and apple prop)

I am Isabel and I lived in Acapulco, Mexico, and I talked to my mother almost every day through Skype. I will share my story when my mother gave me the news about her breast cancer, and what I experienced after the video chat with my mother.

While in Acapulco, I was awaiting my mother's video phone call, as usual. It was something we did often, or communication via Skype, but that day my mother called me to share some news. I greeted her as always, *hola mami!* Joyful and happy as I could be, I couldn't help it, I have a strong, and joyful spirit! That is something unique about me. I heard and felt the phone call was full of heavy, sad emotions through her voice. My heart felt as if I had been running fast, and I said *Mami que pasa? Como estas? What is going on, mami? How are you, my sweet mom?* What I was about to hear, I had not been expecting at all! I stayed quiet, and I listened to my mother. What my ears were hearing was unbelievable, and unexpected. At that moment, my head, my thoughts, my mind, my soul, all of me, seemed to be gone from this world for seconds. A million things were running through my mind, and my heart was falling to pieces again. My body felt paralyzed, as I heard her say—I have breast cancer, and it is in a very advanced stage. They are not giving me much time, but I want to fight, I think I can fight, what do you think mija? For a moment, I just listened to her, I could not think, but deep inside I knew, I have to be calm and strong. As my soul came back to life, I realized, I have to say something to cheer my mother up. *Mami cual es el plan a seguir? What is the plan Mami? Estoy contigo! I am with you, as you know. This rock over the road—we will kick it out of the way, as we have done before. Lo vamos a lograr otra vez Mami! We will defeat this 'thing' again, you will see.* My mother immediately changed her tone of voice,

and as I heard her sorrow, and her painful tone of voice, I kept building strength, a strength I could not explain, to maintain a strong front, about the comments I was about to say.

I remember telling her: *Mami, I will get things ready to fly up there as soon as possible. I will soon be there to help you fight this, you know that, right? You have defeated this beast over, and over again! What do you say Mom? Si mija! Voy a pelear!* Yes mija! I will fight this, I want to live, and I will live! Si Mama, asi sera! *Yes Mom, you will, we will fight this again. God is with us!* I teared up, as I made sure she did not notice I was crying, but I calmed myself down, and I did my best to empower my mother as I kept telling her, *this is not the first time, it is not easy, but we have no other choice, we have to fight again!* My mother and I told each other Te Amo! I love you as we hung up! Soon, I was working as always, with a strong and joyful spirit as always, or at least that is what I made myself believe. It was a tough day, because my job was to sing and make people happy, through reflecting my happiness and joy. The night came for me. It had been a long, hard day at work. My heart was loaded with heavy, heavy pain. Part of my job during the day consisted of bringing other people joy, which I did not have at the moment. I felt restless and hopeless. I finally let my feelings flow, and cried for minutes, until through my prayers I noticed I found a moment of peace. I do remember that I was not afraid of her dying; I just questioned why she had to fight again, and why we had to see her go through the same process for a third time. I was peacefully praying, praying.

Suddenly, after I had peace of mind, I thought—well I have to be strong and get ready for the next battle. I said to myself—Isabel, you are a strong, joyful soul and you will find your way to help your mama again! I have to say that even though I had calmed

myself down, my mind was spinning with thoughts, and I knew that God was taking over. I directed myself into the kitchen to grab some fruit, because after a long day I felt a little hungry. I stopped by the door, and I looked up to the sky, and I recall crying, but, I looked at the mountain in front of our home, and a flash of light went across my eyes! It was like lightning striking my sight. I told myself, Isabel you are dreaming! It has been a long day! Indeed, I stood by the door as I witnessed the most beautiful message in front of my eyes. God had spoken to me, I thought! I prayed and I prayed! The only thing God was doing at that moment was showing me His grace. The bright flash of light turned gold, it looked like a fire. Soon up in the middle of the mountain, I saw a message being written: "Confia en mi", "Trust in Me", and beside the message, a rose was drawn with the same golden fire light. I realized my eyes had tears, but my heart felt relief as I was witnessing what I have considered "A Message from Heaven". I just thought, God had answered my prayers—I knew at that moment, that it was me wanting to see a miracle, but I believe indeed God had talked to me, and I just knew that my mother was going to be fine.

The Battle for Life

(Isabel moves down to the left, to the red sweater prop)

Back in Amarillo, TX, my mother was expecting her doctor's appointment to have more explanations and details about the breast cancer illness. I will now share her experience during the time she decided to fight fourth-stage breast cancer.

The appointment to see the doctor was here, and I was not prepared to hear what they were about to say. Mrs. Vargas, well you know that we told you over the phone! What the results have showed. You have unfortunately developed an aggressive stage

four-breast cancer. You are in a terminal stage, which makes it complicated. *Oh! What does that mean?* I said. Well you are in a very advanced stage, you are rapidly showing Stage IV symptoms, I think there is nothing we can do to help you—I paused, and I thought how angry I felt, upset, and maybe not because I had cancer, but because of how I was treated by the physician. For him, I was just another patient. A dying patient, with no hope! He was emotionless, cold blooded, and insensitive. I said *you are not going to tell me that, I will visit another doctor, and I will have a second opinion. You will not tell me I am going to die; it will not be you, who decides, when or how I am going to die!* I hold a rosary in my hand, and I was holding on to it, like a fish to water! I went on and thought—I have passion for life; I will do whatever it takes to fight and live. I knew that even knowing the illness was in a complicated stage to fight it, I had no doubt, I could fight it, because I wanted to be able to see my children succeed, I wanted to see their children grow. I wanted my life as it was before this news! I was so glad my sister and daughter-in-law were with me.

Nevertheless, the chemotherapies started, and so did the reactions to them. All the symptoms that you could not even imagine happened to me, from weak immune system, to sore feet, to sensitive skin problems. The smell of food as family was cooking bothered me, the taste of the silverware in my mouth was awful, and just to top off my ice cream with a cherry on top, my throat was burned, and I was constantly throwing up. The fatigue and weakness had become my best friends, and the overall rollercoaster was just a terrifying sensation, as other chemotherapies were awaiting me. My hair fell out; my nails were black and sensitive. My body was always cold and sore. At least I had my other cozy friend—my warm sweater! My red sweater followed me every way I went. I

prepared myself for some of the reactions, but my nails being black was shocking for me. In addition to my suffering, it was quite hard to forget that the biopsy had been the most painful experience I had ever felt in my entire life. I didn't even feel that when I had my children, because even knowing I had childbirth labor pains, I was rewarded with my beautiful children. It was something that I do not think, I will forget! Ever! Finally, I had one more thing to deal with every day, and for the rest of my life—my beautiful silicon breast, that has become part of my body, and my best friend for the rest of my existence. I do not care if I don't have a breast. That does not make me less of a woman. I, until this moment, never felt incomplete! I love myself as I am, and I feel just so graceful to be here—to be alive! The third chemotherapy was getting closer and closer, but, fortunately, my daughter was with me. She flew from Mexico to care for me, to love me, and to help me get through this bitter, painful moment of my life, and I assume, of their lives! The last two chemotherapies, I consider the hardest ones for me, and for her, I think. I was having painful reactions, and there was a moment, where I felt I was giving up. My daughter was my rock! She stood strong and said Mami ya vamos ganando, sigamos no te rindas porfavor! Mom we are winning, let's keep going, please do not give, you have come so far in this process! I love you mom! We all love you, and we are here for you, keep going strong.

(Isabel moves down center to honor her Grandmother, her nieces and her sister-in-law)

The process of treatments and its reactions have been hard, painful and tough. My Grandmother was essential in the battle my mother was experiencing. She was, is and will always be the strong woman we know. The one that would do anything for her loving children. My Grandmother cared for my mother in every

unimaginable way, she lifted her up every time, spiritually, emotionally, physically, but most of all loving her truly. My nieces – Genesis, Abigail, and Trinity Faith were the air my mother breathed every day, they were the magic medicine for her, and Genesis helped my mother take the hardest moments as bittersweet moments, making my mother see life from her magical point of view, simple and innocent during the fight. Trinity kept her alert, kept her sane, she helped us keep her up and going, by forcing her to watch over her. My mother knew that she was responsible to watch over the girls, without knowing we were backing her up. Esmeralda was a lovable supporter, and caregiver, she even offered my mother skin from her own breast, so that my mother could have hers reconstructed. Family was with no doubt the pure air my mother was breathing, and keeps being the most important thing in her life.

The Message from God

(Isabel walks DL to white butterflies prop)

During the process of the fight against breast cancer, my mother had a few quiet, and peaceful moments where she said she had deep chats with God. I will now share one of those special moments. This is a never before told story, for me and for everyone around her, this will be the first time she shares this with her family and now with all of you.

A shiny day touches my face through my bedroom window, and I know I am defeating death! I feel so full of grace. Thank God, I think the worst has passed. The last chemotherapy reactions were fewer as the days passed, and I was feeling God in every breath I took. I knew that at some point, I was going to be okay. I kept telling myself,

how fortunate I have been, to have the love and care of my husband, my children, my mother, my sisters and brother, and the love of my whole family and friends. Every day, my baby sister came over to visit. Not only has she visited me because she loved me, but I knew she was giving my daughter and my mother relief. They spend all day taking care of me, and I knew she was trying to help, as well. I thought, I raised my baby sister, and now she is taking care of me. Wintertime was the scenario, but it was amazing that my daughter-in-law had a beautiful bed of roses that I had planted for her years before. The flowers were still blooming! I knew, because I had seen them every time I had the opportunity to be out for my treatments in the hospital. One afternoon, that I was feeling stronger and better, my baby sister said to me—Margarita! Would you like to go outside, to take a little bit of what is left from the sun today Manita! Sister! I responded rapidly—*yes! I do want to go out for a moment.*

My sister took me outside, and we spent a wonderful time talking, gossiping, joking, and laughing. The minutes passed and I felt thirsty. I remember I told her—*Alma! Would you bring me some water please! Si manita!* She replied—yes! I will! She went inside the house, and I remained seated, on a comfortable chair. I felt happy, peaceful. I was outside, contemplating God's Wonders! The bed of roses caught my attention once more, and soon on my hand, a beautiful white butterfly stopped, and wiggled her wings, like saying hello Margarita! I talked to the butterfly, as I always talked to my plants. It was there, just peacefully wiggling over my hand. I kept observing it for a moment, it would not go away, and a breeze touched my face and my heart started beating faster and faster! I soon was crying gently, tears were coming out of my eyes, as I thought God, Thank You! Thank you for being here to love me through this butterfly, thank you for

listening to my heart, for answering my prayers. I was just so happy, my heart rejoiced! I knew God was there in the butterfly, loving me tenderly. That was a moment I have never shared, because I treasured it with all my heart and soul. I kept the secret to myself for twelve years. It was not long ago that my daughter had the courage to share my story, and their stories. It was not until now that I have spoken about this experience with God. At this point, I accepted that my daughter wants to share these stories with others. She says she has a purpose, and I believe she does. I think I was ready to share that with her, and with others. Indeed, this was one of the best things I have experienced, out of all those dark moments! God was truly present through a wiggling white butterfly over my hand; well—that is what I believe!

God's Existence-My Biggest Take Away!

(Isabel moves down to the fireplace prop)

Cancer touched our mother for a third time, but I was not alone in this process. My brother had become my story, and the story of all of us, because for the first time he dared himself to open up and shared the pain he experienced with my mother's breast cancer. I will share another part of my story and my brother's story of how my mother's faith and strength taught us a lesson for life.

Isabel's Story

(I will grab my picture to let the audience know it is me who is speaking).

Family is like a piece of gold! I treasure my family. My family is the rock that stands through the strongest storms. It is the maple tree, which offers fresh air in the mornings. It is my source of energy, which governs my days. My family is the courage I need to cross through the hard moments of life. They lifted me up, when I thought I was

restless and weak! They cheered me up when I was sad; my family loves me tenderly. My family has fought the unexpected, and defended me from the darkest moments furiously. What I value most is my family! The family that God gave me to fight the adversities, and the family that God gave to me, just so I know he exists! Life is not an easy path, and the experiences we live are many times the inconceivable things you think will never happen, just because you are never prepared to confront them. Nevertheless, God sustains us forever! Each one of us, although we sometimes do not see him, or feel him, he is there, waiting for us to run into his arms to wrap us with his love, and to comfort us.

My mother's experience, her story of the butterfly, has strengthened my own faith. I want to say that it is the first time; I dare myself and others to talk about what each one of us felt, and how, seeing our mother as a strong and faithful woman, made us be strong and faithful as her. It is not the first time she defeated cancer, and it is not the first time I felt the fear of losing her. It is not the first time I saw her cry and suffer. My mother is a remarkable, brave, and outstanding woman I truly admire and love with all my heart, as does my brother.

Jesus's Story

(I will put his hat on and grab his picture to indicate he will be sharing his story)

She is my rock, and my shelter, the one I look up to follow in the dark, because she always knows how to take my fear away. My mother is a piece of heaven, and I know that battling cancer for the third time was, indeed, another take-away experience for me. The sorrow she felt, was like sharp knives going through my heart. Seeing her tears felt like salt in a wound. I could not imagine, the things she felt for a third time, because each

episode has been different, but painful at the end. No one can take away the struggles she faced, or the uncertainty she might have felt. The fear we do not know she might have had to leave us. All I know is that life is always a new opportunity to learn, to experience, to achieve, to accomplish. If there is anything in this world I could have done to spare my mother her pain, I would have done it!

Somehow, inside my heart, the fear of losing my mother became an opportunity to find the only thing that kept me safe and strong always! God! God is my biggest take away! My mother's suffering is just a bad dream; because I think, God has shown me, that through the vilest storm, the sun shines again, and again, to remind us of His greatness! I feel a calmness in my heart from the sorrow her cancer caused in our lives. However, more relieved, I feel to know that for a third time, God knocks at my heart, mind, soul, and says—"I exist, I am, and I love you! Do not fear my child; your Father will never leave you! The experience of having to see my mother struggle with cancer for the third time, just reminds me once again that God exists, and that He is my greatest take-away from my mother's darkest painful moments.

(Isabel moves DC to address the audience directly holding the picture to let the audience know the following words are mine).

It was wonderful to share my story. In my research about narrative medicine I came across the work of Rita Charon, who wrote the following in her book, *Narrative Medicine: Honoring the Stories of the Illness* "By telling stories to ourselves and others—in dreams, in diaries, in friendships, in marriages, in therapy sessions—we grow slowly not only to know who we are, but also to become who we are. A medicine practice with narrative competence will recognize patients and diseases, convey

knowledge and regard, join humbly with colleagues, and accompany patients and their families through the ordeals of illness". Margarita, who battled breast cancer, is our warrior. I feel grateful to say, thank you Lord for blessing my family. Twelve years have passed, and she stands strong like the maple tree that gives us the air we breathe. The trace that cancer has left in her is nothing compared to the love she has for each one of us.

As Rita Charon said, "Narrative medicine has come to understand that patients and caregivers enter whole—with their bodies, lives, families, beliefs, values, histories, hopes for the future—into sickness and healing, and their efforts to get better or to help others get better cannot be fragmented away from the deepest parts of their lives".

For twelve years, my mother has been teaching us to fight, no matter how hard, or how impossible, the path might seem. God exists, and He is my strength. I love this woman with all my heart. Thank you, God! Thank you, Mom! Thank you all for sharing your stories, which are truly narratives to live by.

Summary

This chapter has provided the detailed script for the performance with an adapted version of all the stories compiled from interviews.

CHAPTER V

EVALUATION

The performance took place on Friday April 1st, 2016 in The Hazel Kelly Wilson VIP Room at the Jack B. Kelly Student Center of West Texas A& M University. The performance began at 11:00 a.m., and lasted 59:50 minutes. The question session lasted around 10 to 15 more minutes. The audience was composed of family members, faculty, students and committee members. There were 16 guests, including committee members. The committee members were seated in the back of the room, and they took notes as performance was taking place. A meeting to follow up performance, and choices made was scheduled for April 15, 2016 at 9:00 a.m. with all committee members and the official signatures of approval took place.

In my opinion, I think the performance went well. I am aware that some of the choices I made could have been done differently to avoid confusion to the audience. First, the wrapping paper on the pancakes' prop should have been removed before the performance. I was very nervous and I forgot some of the things I had planned for the

performance. I agree with Dr. Hanson, I should have kept the phone over my ear and change voices to differentiate **who** was speaking as I talked. At times, the voice of the characters of stories' was a bit confusing to the audience. I also think that indeed, music should had been utilized in all my stories, to connect the stories even more. The music played in the story of the butterfly was a beautiful moment, it helped me deal with my emotions, and continue with the performance. I think, I could had spoken a little faster, I noticed, the pace of my stories was slow, although I perceived the audience acceptance and feedback; I would have changed the pace. I think the props were carefully designed to fit into each of the stories. I should have placed another phone on the block were I shared my story about God's message in Acapulco. I think the decision of color used was effective, because everything matched the poster design. My clothing selection was appropriate, the pictures, and all the props utilized, help make greater emphasis towards each of the stories. I think I should have included a different song for each of the stories. I noticed, I did not say the closing frame planned for the performance, right when I needed to say—I thank God, thank my Mom, and I thank you all, for allowing me to shared truly Narratives to Live By. I did not memorize the script; I thought it would be better to let the stories unfold as I was recalling them from my analysis section, and, from what I remembered from the interviews with the participants. The spontaneous additions I made to my script, I perceived as effective. Overall, I think the performance was strong. Finally, I think the theory of the Narrative Medicine of Rita Charon was illustrated in my performance of this study, which accomplished the aim of the research. Healing was observed, and confirmed by each one of the participants. This demonstrated the true connection between the stories and the spirit of the Narrative Medicine theory.

My thesis committee evaluated the performance. Dr. Trudy L. Hanson and Professor Paula Schlegel were present in the presentation. The performance was video recorded, and served for Professor Kim Bruce to give an evaluation as well. The notes they took, gave a detailed evaluation included in this written assessment.

Evaluation of *Narratives to Live By*

By Trudy L. Hanson

Isabel Vargas performed for friends and family members on Friday, April 1, 2016, in the Hazel Kelley Wilson VIP Room of the Jack B. Kelley Student Center. This intimate setting for her performance was a good choice. Isabel arranged three readers theatre blocks down right from the fireplace. Each block was covered with a white cloth that had an embroidered butterfly attached. On each of the blocks she placed props that reinforced and supported her stories. On the nearby mantle, Isabel arranged family photographs. Behind a butterfly screen that Isabel had made, she placed a coat stand on which she hung her mom's red sweater. Isabel was dressed in black slacks, a white shirt, and a black jacket which complimented her black and white color scheme. Isabel had carefully blocked her performance and used the items placed on each block to move the stories along.

Isabel divided her performance into five main stories:

- The Worst Phone Call Ever
- The Heavenly Call
- The Battle for Life
- A Message from God
- God's Existence—My Biggest Take-Away

After sharing the story of the butterfly (A Message from God), a recording of Isabel singing “How Great Thou Art” was played as she moved to the final section of her performance. I think this addition of music was most effective. Perhaps, other songs could have been used during the transitions (moving from block to block) for the other stories, too.

The overall pace of the performance was a bit slow, but that may have had more to do with the emotional content of each of the stories. There were some transitions that I think could have been made clearer for the audience, specifying **who** was speaking. At times, the dialogue was moving forward for a bit before the audience understood that the “voice” they were hearing was not Isabel’s. I loved Isabel’s bilingual approach to telling her stories. The sound and rhythm of the Spanish sections added impact. Isabel was able to convey her own emotional struggle effectively in “The Heavenly Call.” Isabel’s approach in telling the butterfly story worked well. I think it might have been more effective if the butterfly had been held in the palm of her hand rather than attaching it to her finger. Some performance choices that I think should be changed have to do with using the red phone as a prop. I think it would be better to keep the phone to your ear, rather than extending it away from your body and use a slightly different vocal tone to indicate when the receptionist was speaking and when Margarita was speaking. The pancake should have been unwrapped and placed on the plate rather than unwrapping the foil as the performance unfolded. In the story where Margarita talks with the doctor, I think a deeper tone for the doctor’s voice was needed. I thought the use of Isabel’s and Jesus’ photos for the ending stories was effective. Jesus, Isabel’s brother, was wiping away tears as she spoke.

Isabel's performance was a thoughtful tribute to the members of her family. Her honesty and sincerity and the deep emotion she felt for each story was apparent to all listeners. The use of the black notebook at the end for citing Rita Charon was a good performance choice. I think the text that was read for this section could have flowed more smoothly and have been a bit more polished—meaning that when Isabel read from the scholarly text, the delivery needed to be more formal than the conversational style used for the majority of the performance. That said, there were certain phrases that needed to have greater vocal emphasis and some pauses needed to be inserted.

The overall performance was most effective and lasted for almost an hour (59:50). In the question and answer session that followed the performance, Isabel explained the impact that her research had on her family. She mentioned several times that her family had never talked about her mother's battle with breast cancer until she began conducting the interviews for her performance thesis. Rita Charon (2009) wrote: "Narrative medicine recognizes that the central events of health care are the giving and receiving of accounts of self" (p. 120). "Like all narrating situations," Charon continues, "these instances of storytelling unite the teller and the listener in a shared world either recalled or imagined." Isabel Vargas achieved that unity of spirit as she shared personal narratives of courage, of overcoming cancer, of hope.

Evaluation Narratives to Live By

By Paula Schlegel

This program provided a beautiful glimpse into private moments experienced during the crisis that comes with a cancer diagnosis. The glimpse wasn't just revealed to those outside the family circle, but those within as well. This revelation of moments

created an emotional event that will most likely be revisited by family members in attendance, and, retold to family members that were absent. Isabel divided her performance into five family stories discovered during her interviews. She was challenged with selecting the stories that would represent her mom's strength, determination, and love for her family. Like all public performances, Isabel's narrative selections required practice. I had the opportunity to watch two practice sessions in my office. The first session was minimally blocked with confusing transitions. The second session was more organized with some props and story location identified. Character voices were a challenge at times and possible solutions were discussed. Timing was discussed as well. Each telling became longer as more details were told. This was a concern that was addressed during the second practice session, when she had told for 45 minutes.

I coached on movement, and how, to word transitions that would help her audience understand the voice behind each story. It was discussed that one transition would be completed with a recorded sound track of her voice singing "How Great Thou Art". I was unable to hear that until the performance. That song transition was wonderful. I wish it had been used between each story. It would have allowed Isabel an opportunity to recollect herself after each emotional narrative. The stories were performed in the Hazel Kelley Wilson VIP room in the Jack B. Kelley Student Center. This room has a feeling of "home" to it because of the sofa and chair groupings. Isabel made the space her "home" by establishing three reader's theatre blocks complete with props needed for each story. Family pictures helped create a connection to the props and the story. Isabel's dress of a white blouse, black jacket and

pants matched publicity posters, and the somber subject of her selected stories. Although I had heard the stories several times, and knew the person behind the stories, there was at times confusion over whose narrative was being told. I wasn't always sure whose voice I was hearing until the story was well underway. Perhaps, additional practices with complete props and blocking space could have identified and prevented this problem.

The narrative selections were emotion filled. The stories were being heard for the first time by family members and their emotions were visible. While this emotional challenge was anticipated, it did result in a slow-paced production. Isabel concluded her performance with a quote from Rita Charon (2009) that stated the important role that “narrative medicine” can play in creating a shared experience. Although, this program was slower than anticipated, I believe in this instance, for this audience it was okay. The slow pace, in my opinion, this was due to the emotional challenge of not just telling personal stories and the reality that these were “new” stories for all involved. Each family member learned something new and important that can lead to full emotional healing and not just full physical healing. Overall, I believe that Isabel met her goal of sharing experiences of a cancer diagnosis to promote healing.

Evaluation of *Narratives to Live By*

By Kim Bruce

Isabel Vargas' live performance of *Narratives to Live By* on Friday, April 1 was recorded, and uploaded for this evaluation. Isabel carefully prepared the performance space, the VIP Room at Jack B. Kelley Student Center for her performance with family pieces, pictures and keepsakes. Together these pieces served as a setting for each story and as tools to the narrative transitions. Her simplistic attire in a black suit with a white

blouse looked professional, yet neutral in nature giving her more leeway between characters.

The specific five stories she told about her mother's cancer battle were The Worst Phone Call Ever; The Heavenly Call; The Battle for Life; A Message from God; and God's Existence —My Biggest Take-Away were told in great detail using at times Spanish phrases with tight English translations. These gave a lovely and talented context to the culture and closeness her family shares. The physical movement between blocks was helpful to each transition and obviously rehearsed. The music, "How Great Thou Art," played between the fourth and last story. After her introduction and the portion of her story that talked about being in a band, I anticipated a musical performance, so the music created a nice and slightly expected addition.

At times the stories slowed under the emotional and complex transitions between male/female characters and the different generational characters. Adherence to more standard tones and/or positions for the different characters in each story would help the audience stay more attentive and understand the thematic nature of the narrative sooner. Overall, her performance was a kind and considerate tribute to her entire family. Her honest emotional connection to the story and her audience was evident.

Rita Charon's narrative medicine (2006) was the origination of Isabel's research and the foundation to these beautiful stories of family and faith. In the question-and-answer segment at the end of the performance, Isabel explained the research preparation for her performance included the family interviews and was the first time they talked openly about the experience of caring for their mother and with her about the suffering

she endured. As her research journey proved, the therapy in narrative medicine lasts far beyond the battle and penetrates the heart in shared meaning.

CONCLUSION

Using the lens of Narrative Medicine, as explained by Rita Charon, provided the theoretical framework for my performance. The aim of this research was achieved by giving the participants a voice, thorough narrating their stories through a public performance. During the process of the research, it was clear that participants found themselves healing as they narrated their stories to the researcher. In addition, the day of the performance, the participants' reactions were positive, emotional, and they demonstrated once more how sharing their stories helped them deal with the pain all of them felt because of my mother's battle with breast cancer.

Figure 8: Isabel (with flowers) pictured with her aunt, her mother and her grandmother



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APPENDIX A
INTERVIEW GUIDE FOR THE CANCER SURVIVOR

Interview Questions for Breast Cancer Survivor

1. What were your first thoughts and reactions when you were diagnosed with breast cancer?
2. How did you deal with the news as you received it?
3. Who was the first person you informed about diagnosis, if you did? Otherwise, what was the first thing you did right after diagnosis, if you can remember?
4. What was the next step you took after you received the news?
5. How did you deal with your feelings, and emotions at this point? What were your inner thoughts or fears?
6. Were you able to talk about the news with your family, or did you decided to keep the information to yourself, and if you did explain why?
7. Can you describe the experience with the doctor as you were receiving the news? How do you think the physician handle the information with you?
8. How was the overall experience of dealing with breast cancer?
9. When you share the information with your family what were the reactions you received from them?
 - a. What comments upset you the most?
 - b. What are some comments or things you can remember about your family that were helpful or comforting to you?
10. Think of the people who provided support for you during your illness. Was there someone who you relied on?
11. What kinds of counseling were provided for you after your diagnosis?
12. How was the experience during the time of treatment?
 - a. What is the worst part you remember of it? What can you possibly takeaway from all this experience? What did you learned from all this?
 - b. Describe the way you communicated with others about your illness.
13. What part, if any, does sharing your story have with the way you have managed this illness?

14. How do you feel as you share your story?

15. What are your final thoughts you about the importance of narrative?

a. How can this help yourself, and others deal with the experience of breast cancer?

b. How do you think narrating your story can help others who are dealing with the experience of breast cancer?

APPENDIX B
INTERVIEW GUIDE FOR CARE-TAKERS

Interview Questions for Care-takers Affected by Breast Cancer Experience

1. What were your first thoughts when you were informed a family member was dealing with breast cancer?
2. How did you handle the news, how did you feel, and what did you feel?
3. How did you support your family member affected with breast cancer? What was the first thing you told them?
4. What did you observe from your point of view about your family member who was affected with breast cancer?
5. Describe your experience as caretaker and a family member of a breast cancer patient? (Emotions, feelings, thoughts, or anything you can remember from moment one?)
6. Describe how you have communicated with others about the topic of your family member's diagnosis with breast cancer.
7. What, if any, are the benefits of sharing such narratives with others?