### **DISCOURSES OF A CANCER DIAGNOSIS:**

### NARRATIVES OF WOMEN

### IN ACADEMIA

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Submitted to the Faculty of the Graduate College of the Oklahoma State University in partial fulfillment of the requirements for the Degree of DOCTOR OF PHILOSOPHY December, 2014

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## **DEDICATION**

May these words serve as encouragement for other women to speak and to act out of our experiences with cancer and with other threats of death, for silence has never brought us anything of worth.

(Audre Lorde, 1980, p. 10)

#### **ACKNOWLEDGMENTS**

First and foremost, I owe a great deal of gratitude to the women who contributed their experiences to this study. I truly hope the stories you so graciously shared with me speak the voice of your experiences and help other women who have dealt with similar situations, and eventually help those who might face a cancer diagnosis. There are many women I have met along the way who I know have dealt with these circumstance but didn't contribute their experiences; I want to thank you as well for motivating me to continue the process and attempting to speak also on your behalf. This study would not have been possible had I not witnessed the unfortunate circumstance of several female faculty members while at Oklahoma State University. There is one woman who truly inspired, motivated, and encouraged me throughout this research project. I am forever indebted to you, Steph for being a mentor, a confidant, and constant fuel of aspiration. I would not be where I am had it not been for who you are.

The overwhelming support of my family, colleagues, and friends has truly been responsible for pushing me to completing this project. To my mother and brother, for not really knowing what I was doing but standing by me, always feeding me and providing love. Nourishment was always appreciated throughout this ordeal! To Breanna and Isaac, you both took a great deal of the brunt having to endure while I took classes, did homework and listened to my many lectures regarding education. I know it was challenging at times and even know you might not completely grasp why this degree became important for us all, but hopefully someday you will better understand the legacy Acknowledgements reflect the views of the author and are not endorsed by committee members or Oklahoma State University.

it will leave you. To my dear grandmother, the many times you asked if I am a doctor yet, I know this was your way of being encouraging. Thank you for being a strong, beautiful, passionate Latina that I am inspired to be because of your light.

Dr. Jerrid Freeman, Dr. Eric Grospitch, Dr. Tim Alvarez, Dr. Joel Perez, and Dr. Cornell Thomas, thank you for always being there during this process. Your mentorship truly helped me to know I was not alone in the dissertation journey. Dr. Anthony Walker, I thank you for always pushing me to think differently, to allowing me to vent, and being a level-headed voice of reason when I needed you to be. The beautiful Aaron T. Christensen, your expertise, direction, and treasured company you have provided me during this process are irreplaceable. Thank you to my many friends and colleagues at Oklahoma State University, specifically Ursula (U) O'Hara and Kay Porter, your shoulders were essential during this ordeal. To all my NASPA familia, thank you for your encouragement, being role-models, and making me so proud to be amongst you as my colleagues.

To my beloved three Ivans. Ivan Godinez, your music, your activism, your passion for love and beauty, you have always been there to refresh my spirit and help me to believe in the good of humanity. Ivan Ibarra, your friendship, your humor, and your companionship kept me grounded, kept me realistically cynical while allowing me to be me in raw form. And my Ivan Rochelle Riley, words cannot express my deepest gratitude for being the best friend I could have ever asked for. You have truly been a guiding star and my rock. To the moon and back times two wouldn't even come close to expressing how grateful I am to have you in my life. I truly love you all and please know I could not have done this without you.

Acknowledgements reflect the views of the author and are not endorsed by committee members or Oklahoma State University.

I dedicate this work to the many students I have advocated for along the way. I have been blessed to be inspired by your courage, strength and resiliency. My hope is to use my voice and my privilege to always advocate for those who are disadvantaged due to our broken immigration system so that someday our opportunities are the same.

To my dissertation committee, thank you for all your support throughout this process. May this study and my future career serve as a reminder how each of you contributed to my Ph.D. journey. Dr. Bailey, I hope to make a difference and be an example of passion and dedication as you have been for me.

Name: Sara A. Mata

Date of Degree: DECEMBER, 2014

Title of Study: DISCOURSES OF A CANCER DIAGNOSIS: NARRATIVES OF

WOMEN IN ACADEMIA

Major Field: SOCIAL FOUNDATIONS

ABSTRACT: The purpose of this study was to explore experiences of female faculty members diagnosed with breast cancer and how they navigated their roles in the gendered institutional structure of higher education to provide both voice and visibility for women in these circumstances, contributing to the broader understanding for others. This qualitative study used online journaling and photovoice to narrate five women's experiences with a life-threatening diagnosis in a challenging professional role. Feminist theory was used to guide the study, and thematic narrative analysis (Reissman, 2008) was used to analyze the data. Although literature explores the experiences of female faculty members in academia as well as women's experiences dealing with breast cancer in other contexts, there is a gap in research investigating women's experiences with cancer while in a tenure track position. This study contributes to broader understanding of the ways women in these circumstances navigated the responsibilities and requirements associated with a tenure-track role and the ways gender shapes both their experiences and the institution of higher education. The four themes that emerged from this study were: (a) finding agency and supportive spaces: managing, adjusting, and responding; (b) connections for preservation: negotiation, comfort, and reassessing; (c) expressing cancer: laughter, fears, and sharing; and (d) embodying changes: impact, expectations and consequences. This study concludes with recommendations for institutions of higher education to promote in both small and more substantial ways a more positive environment for those having to deal with illness while working in institutions of higher education.

## TABLE OF CONTENTS

DEDICA'	ΓΙΟΝiii
ACKNOV	VLEDGMENTSiv
ABSTRA	CTvii
Chapter	Page
I.	INTRODUCTION
	Background of Study2Contribution of the Study6Epistemological and Theoretical Perspective9Theoretical Framework12Methodology14Research Questions16Summary17
II.	LITERATURE REVIEW
	History of Women in Higher Education20Roles and Performances in Academia22Tenure Process and Procedures23Tenure and Female Faculty27Female Faculty Experiences29Family Formation30Gendering Embodiment31Women and Breast Cancer32History of Breast Cancer34Feminism and Health36Summary37
III.	METHODOLOGY
	Research Questions40Online Narrative/Autopathographies41Photovoice45Participants and Recruitment49Data Collection51Data Analysis54

	Researcher Reflection on Positionality	56
	Quality Criteria	58
	Summary	59
IV.	PARTICIPANT PROFILES.	60
	Gloria	62
	Carolyn	
	Audre	
	Susan	68
	Barbara	70
	Discovery of Diagnosis	
	Gloria	72
	Carolyn	75
	Audre	76
	Susan	77
	Barbara	78
	Summary	79
		0.4
V.	FINDINGS	81
	Theme 1: Finding Agency & Supportive Spaces:	
	Managing, Adjusting, & Responding	84
	Maneuvering the Structure:	0.4
	"Professional Expectations Remained the Same"	
	Figure 1	
	Figure 2	
	Student Responses: Empowering to Hurtful	
	"Focused Mode"	
	"Uncancer Spaces": "Something Other Than Cancer"	
	Figure 3	104
	Theme 2: Connections for Preservations:	
	Support, Comfort, and Reassessing	
	"The Little Things"	109
	Negotiating Relationships:	111
	"Some Became Strained, Others Flourished"	
	Figure 4  Cancer Culture	
	Comfort in the Treatment Room.	
	Living For Others & For the Future	
	Figure 5  Control & Boundaries	
	Reassessing & Prioritizing	
	Theme 3: Expressing Cancer: Laughter, Fears, and Sharing	
	Voicing With Humor	
	Renaming	
	iviidiiiig	104

Figure 7Voicing Gratitude	138 141
	138 141
	141
Visibility: "Hard Diseaseto See"	
Fears and Worries	143
Waiting: "It Isn't Cancer That Kills You"	
Telling: "Sharing What I Had To or When Asked"	
Theme 4: Embodying Changes:	
Impact, Expectations, & Consequences	152
VI. DISCUSSIONS, IMPLICATIONS, RECOMMENDATIONS, AND	
PERSONAL REFLECTIONS	157
Occasions of the Findings	150
Overview of the Findings	
Figure 8	
Figure 9	
Figure 10	
Figure 11	
Recommendations for Chairs	
Personal Reflections	170
Recommendations for Future Research	171
BIBLOGRAPHY	174
APPENDIXES	
APPENDIAES	104
APPENDIX A - INVITATION LETTER	186
APPENDIX B - SOCIAL MEDIA RECRUITMENT INVITATION.	188
APPENDIX C - HOMEPAGE IMAGE OF WEBSITE	190
APPENDIX D - IRB APPROVAL	

#### CHAPTER I

#### INTRODUCTION

During my years in higher education, I have witnessed several female faculty members who have faced the challenges of a breast cancer diagnosis and have realized the importance of increasing awareness of such experiences. There is little research on this topic. The purpose of this study is to explore the experiences of female faculty members diagnosed with breast cancer to provide voice and visibility to women in these circumstances and to understand how they maneuvered the gendered institutional structure of higher education. In this qualitative study, I collected women's narratives through online journaling and photovoice to examine women's reflections on their experiences with a life-threatening diagnosis in a tenure track role. I used thematic narrative analysis (Reissman, 2008) to analyze the women's online narrative journaling and their captions from their photovoice submissions to speak to how the women approached their roles and responsibilities personally and professionally as well as how the gendered spaces of academia played into their experiences.

Feminist scholars have explored how gender and power dynamics shape the landscape of academia and situate women in particular ways. As a result, their experiences are often silenced and therefore unheard (Armenti 2000). Studies that focus on women's experiences contribute to their voice and visibility as well as broader collective understanding for others. Ultimately, the findings from this study are intended to raise awareness of women's experiences and inform university administration policies

and procedures to better assist those dealing with a cancer diagnosis in higher education. Chapter I provides an overview of this research project focused on women faculty who have experienced breast cancer during their career in a tenure track position. It consists of the background to the study, significance of the study, research questions, and the theoretical framework informing the study.

#### Background of the Study

Maneuvering the ranks of academia can be a challenging process. Historical discrimination and underrepresentation of tenured female faculty members (West & Curtis, 2006) can contribute to the complications of a career in higher education for women. Historical studies reveal that academia was founded in a patriarchal paradigm. As feminist scholars have argued, gender can have a strong influence on female faculty's roles and performances as they navigate through the ranks of reappointment, promotion, and tenure processes (Jackson, 2002; Knight & Richards, 2003). Female faculty members occupy many roles and challenges external to the institution, within the institutions, and also within their own gender identity (Lester, 2008). Stereotypical perceptions of women in academia can often negatively impact the experiences of a female faculty member and inevitably reinforce gender inequity (Nilsson & Nocon, 2005). Nilsson and Nocon suggest that men in academia often do not view women as their colleagues but rather as irrelevant. Men also view the work of women in academia as insignificant and invisible (Nilsson and Nocon, 2005). The university system historically has not been a supportive environment for female faculty members who have family commitments (Mason & Goulden, 2004) or become pregnant (Silbergleid, 2009).

Balancing a demanding career of teaching, research, and publishing, while also maintaining personal commitments to family and friends, can be challenging.

Facing an unexpected and often devastating diagnosis of breast cancer can evoke a range of reactions and responses on both personal and professional levels making a faculty position even more challenging. Discussing the issue with family, friends, colleagues, and students as well as deciding when to tell them, how to tell them, or whether to tell them at all, are all decisions each woman must make. These decisions can also be influenced by current institutional policies, teaching schedules, committee obligations, and the overall demands of the position. The intertwined personal circumstances and professional obligations involved in a faculty position play into the many ways women must negotiate a cancer diagnosis and its implications. Responding and reacting to a cancer diagnosis can often have a deleterious effect upon personal and professional relationships.

It is often very difficult to keep a cancer diagnosis and the resulting emotions confidential or private in the university setting. When faced with a life threatening disease such as cancer, a professional woman must reveal certain parts of her life despite efforts to protect her privacy and potential desire to preserve from public knowledge a very personal struggle (DiPalma, 2003). Being diagnosed with cancer can thrust a person's personal life into the forefront. Despite all the measures an individual might take to keep information private, dealing with cancer becomes public and exposing on many levels.

The treatments associated with cancer and side effects of chemotherapy and mastectomy provide women little choice but to have their diagnosis be outwardly

revealed. Physical effects of treatment can take a toll on the body in various forms. Fatigue and loss of concentration, often called "chemo brain," can impact productivity. Changes in physical appearance are often most noticeable. The loss of hair can cause emotional and psychological distress given the ways it can embody both individuality and femininity for women. The loss of a breast can lead to questioning and uncertainty, both internally as well as externally. The pain of a mastectomy is both physical and emotional. Kasper (1994) describes how the socialization in American culture puts a high regard on breasts as symbolic of idealized womanhood. Because women are socialized into these norms, losing a breast not only can threaten the physical integrity of women's bodies but also a woman's sense of self and feminine identity. The destruction breast cancer can cause to the breast often requires women to decide whether they want to pursue reconstructive surgery and/or breast augmentation, or wear a prostheses, among other decisions (Lorde, 1980). Ultimately, not only are the women dealing with compromised health and feelings of being betrayed by their own body, additionally they are dealing with the demands and stress of a faculty role.

The vulnerability of becoming more visible with the effects of cancer can potentially lead to the clash of personal responsibilities and care for one's self with professional expectations. Not only are responses to cancer physically revealing and exhausting, the emotional responses are also immense. Emotional reactions are not customarily accepted in patriarchal workplace systems in which social expectations require repression of feelings (Kearney & Bailey, 2012). Crying can cause conflicting feelings among professional women in academia. According to Hoover-Dempsey, Plas and Wallston, (1986) women face a dilemma to "integrate personal emotional style with

expected professional behavior" in an environment governed by masculine expectations (p. 20). The authors suggest professional norms require women to be tough and in control of their emotional states. Such expectations can produce an internal battle whereby a woman feels the demand to contain her emotional responses in the workplace but also a need to express the emotions she feels as she copes with the realities of a diagnosis and treatment. The challenges of work demands and expectations alone produce stressors; dealing with an illness can further complicate the situation and intensify emotional distress.

The stress of performance expectations and demands placed on a faculty member during the tenure track process can influence how much personal information and experience an individual will allow into the professional setting. As Maunsell, Drolet, Brisson, Brisson, Masse, & Deschenes, (2004) suggest, the work environment is not conducive to a person struggling with cancer or any serious illness. Problems can range from job loss, change in work duties, demotion or change in pay, as well as problems with supervisors and colleagues (Maunsell et al., 2004). Yet, for someone who has experienced cancer, maintaining and/or returning to a position of employment is often paramount to recovery and stability (Anderson, 1995). Not only does the return to work provide a return to a sense of normalcy, it also can be symbolic to recovering from cancer and moving forward (Kagawa-Singer, 1993). Regardless of the profession, no career or position is immune to a cancer diagnosis. Standardizing policies and procedures related to how the university accommodates, responds, and assists in these situations is essential to protecting the careers of those afflicted.

This study examines the experiences of female faculty members who have dealt with the effects of a cancer diagnosis while working in academia and the multidimensional effects of the gendered conditions on their professional and personal roles. The purpose of this study is to explore experiences of female faculty members diagnosed with breast cancer and how they navigated their roles on the gendered institutional structure of higher education to provide both voice and visibility for women in these circumstances and to contribute to broader understanding for others. Using a feminist theoretical perspective and framework (Crotty, 1998), this study assumes that institutions of higher education are gendered and hierarchical, and that women's experiences are a valid and important source of knowledge. This study contributes to broader understanding of the ways women in these circumstances navigated the responsibilities and requirements associated with a tenure-track role and the ways gender shapes both their experiences and the institution of higher education.

### Contribution of the Study

Scant research examines the experiences of female faculty members diagnosed with breast cancer (DiPalma, 2003). However, reports indicate that 1 in 4 women will receive a diagnosis of breast cancer during her lifetime (American Cancer Society, 2009). Of women diagnosed with breast cancer, 10.2% are between 35 and 44; 22.6% are between 45 and 54; and 24.4% are between 55 and 64 years of age (Howlader, Noone, Krapcho, Neyman, Aminou, Waldron, Altekruse, Kosary, Ruhl, Tatalovich, Cho, Mariotto, Eisner, Lewis, Chen, Feuer, Cronin, & Edwards, 2010). Cook (2011) states women faculty members typically attain tenure at the age of 40 or beyond. When taking into consideration the ages at which rates of cancer diagnosis are higher and the age

female faculty commonly obtain tenure, it would be likely that anyone working in higher education would, at some point in their careers, have a colleague affected by the disease.

Female faculty members also face gendered challenges and barriers in the reappointment, promotion and tenure processes. Gender inequities have long existed in tenure and promotion (Caplan, 1997; Unger & Crawford, 1992), family formation (Gerald, 2003), and policy and procedures (Wolf-Wendel & Ward, 2003) in institutions of higher education. The history of gender inequity has manifested itself in many different ways in higher education (Pasque & Nicholson, 2012). Despite the blatant examples of gender inequality still present in the workforce in terms of resources, power, privilege, and salaries, the university environment is progressively evolving (Acker & Webber, 2006; Cotterill, Jackson & Letherby, 2007; Pasque & Nicholson, 2012). Providing a vehicle to give voice to women's experiences is crucial to supporting and advancing their careers in the face of complex embodied life course events.

It is unfathomable for an outsider or a person without cancer to grasp fully the unexpected and tragic occurrence of dealing with cancer. Essential to the needs of employees facing such circumstances are supportive institutional policies and procedures. When unanticipated situations such as cancer occur, colleagues may be unprepared or uncertain how to respond appropriately and supportively. Accordingly, the current study aims to give voice to women's experiences, provide a better understanding of the complexities of women's embodied experiences within academia, and to help inform departmental, college, and institutional policies that will support the overall well-being of tenure track faculty dealing with a cancer diagnosis. In particular, it is important to convey how women negotiate the vulnerability they may face in a tenure-track role, and

the responsibilities of that position, at the same time that they find themselves vulnerable to a disease. Ultimately, this study's findings aim to help institutions accommodate women encountering the difficulties of a diagnosis.

Using participants' narratives, this study provides a unique perspective in both professional and personal experiences of how female faculty manage their cancer. Hilda Raz (1999) in her book *Living on the Margins*, a text composed of women writers' stories of breast cancer, stated women writing about their experiences "could articulate both the substance of their experiences and also a reparative response to inadequate stories about the body, illness in general, cancer, and especially breast cancer" (p. ix). Raz suggests through expressive writings, women provide an artistic expression of insight as well as a repair through the difficult situation of breast cancer.

Reverby (2002) provides, in essence, the fundamental purpose of this study when she states: [we must ask] "...women more about what they have experienced, how it affected them, what they remembered, what changed or did not change their choices and lives, and which choices they thought possible and which ones they did not have" (p. 9). These questions are also relevant to academic women's experiences. Breast cancer can be an isolating and lonely experience. The role of a faculty member is often focused on individual experiences and labor; preparing for classes, grading, and conducting research can often be quite solitary and secluded activities. Mentorship is often needed to learn the norms and structures of the institutions of higher education for faculty. The spaces of academia often do not allow for these mentorship opportunities to flourish particularly with the demands of the role. The occurrence of breast cancer can further segregate female faculty members from their peers. It is the researcher's hopes that this study will

contribute to promoting commonality and sharing dialogue with other women dealing with similar vulnerable situations.

Richardson (2001) suggests writing provides an outlet of "nurturing our own individuality" and an ownership of our lives and its meaning. Writing narratives, according to Herndl (2006), can provide a method of reclaiming the feelings of agency after an experience of breast cancer not necessarily for just the women themselves but for others. Herndl states narratives "rebuild a sense of self by building that self into community" (p. 228). In essence, giving voice to womens' experiences not only informs others who may remain gravely unaware of the circumstances women encounter but also speaks for many women who have lived similar situations but have not been heard. Richardson (1997) describes the concept of "collective story" which tells the experiences "of a socially constructed category of people in the context of larger sociocultural and historical forces" (p. 14). In this study, I consider the collective stories that the personal narratives represent through the lens of feminist theory. These embodied experiences with illness are situated in an environment historically influenced by gender inequality and patriarchal practices. By providing insight into this private and personal experience, that becomes public in the work environment this research will assist in increasing awareness of women's experiences. In addition, this research hopes to inform changes to current policies and practices that may not be conducive to supporting women attempting to balance their career while recovering from cancer.

#### Epistemological and Theoretical Perspective

Constructionism is the epistemology that shapes this study. Shadish (1995) states constructionism reflects an orientation toward knowledge in which a researcher

"construct[s] *knowledge about* reality" but is not "constructing reality itself" (p. 67). Crotty (1998) provides a similar definition by stating constructionism is "the collective generation [and transmission] of meaning" (p. 58). Constructionism meanings "are constructed by human beings as they engaged with the world they are interpreting" (p. 43). This means that, unlike the epistemology of objectivism, the researcher proceeds with the understanding that individuals interpret and construct their worlds, based on their historical and social perspectives, and through social interaction with others (Crotty, 1998). Crotty also states in constructing knowledge, people's meanings are varied and different even when they may be experiencing the exact same situation (p. 6). In Constructionism, according to Crotty, no understanding of the world is objective, absolute, or truly generalizable to other circumstances or understandings (p. 16). As the researcher, I consider the women in the study as actively interpreting their realities through their experiences with a cancer diagnosis and revealing those interpretations within their personal narratives. In turn, I approach the investigation as an act of interpreting and constructing what the women in the study reveal about their realities. Using online journals and photovoice methods, I collect narratives to share women's recollections of having breast cancer and provide insights into women's experiences in their academic positions and environment.

The theoretical perspective of this constructionist study is feminist, which holds that gender shapes institutions, processes, and practices in ways that shape women's experiences and often perpetuate inequities based on gender. In this perspective, gender along with other subject positions such as race, class, and sexuality are lenses that matter in how researchers construct knowledge and how both men and women experience their

lives. This perspective is appropriate for this study due to its focus on women's experiences in a hierarchical and gendered institution and being diagnosed with the very gendered disease of breast cancer. Feminist assumptions guide the logic about the way one can collect information and create knowledge. The feminist theoretical perspective provides insight into what have been historically, "culturally imposed stereotypes, lifestyles, roles and relationships" for women and ultimately advocates "for equity and liberation" in reducing, if not eliminating, "the injustices and unfreedom that women experience" (Crotty, 1998, p. 182). It is a perspective that provides the opportunity to analyze experiences through the lens of gender and how they play out in various institutions and social processes and structures. Crotty states feminism speaks to the experiences of "a patriarchal world and the culture it inherits as a masculine culture" (p. 161). Given academic women's position in a still-patriarchal world, it is important to give voice to the unique experiences in ways that relate to how these environments contribute to and influences their circumstances.

There is an array of different types of feminist theory, however, according to Ropers-Huilman (Pasqual & Nicholson, 2012) there are three main principles shared among feminist theories. The first principle suggests in all aspects of society, women are valuable contributors. The second principle is that the oppression of women historically has resulted in the lack of achieving full potential in society. The third principle holds that feminist research should work towards social transformation (p. 11). Research guided by a feminist perspective provides insight into the patriarchal world and how it is shaped inherently by power and by gender (Crotty, 1998). In this perspective, women's power and agency are enhanced through sharing their experiences. Without this

knowledge, certain gendered silences persist.

#### Theoretical Framework

Feminism Standpoint Theory

Feminism, in general, is a movement and commitment to support equal rights and treatment regardless of sex. The quest for equity on the basis of sex is the overarching purpose of feminism. Feminists bring to the forefront issues of laws, culture, and societal expectations, on all levels influencing women's experiences. Feminist theory provides a framework to examine not only gender inequities that permeate social structures and institutions such as higher education but also gender differences among colleagues and family as they shape the roles and responsibilities of the female (and male) faculty. Feminist perspectives provide a way of looking at experiences and injustices in various contexts. More specifically in the field of education, feminists have examined diverse areas that include gender in the classroom, women's experiences as teachers, the gendered nature of teaching and learning, the importance of the curriculum pertaining to feminist perspectives and the importance of women's programs in higher education (Leathwood & Read, 2009).

The specific feminist theory in which this study is positioned is feminist standpoint theory. Critical to feminist standpoint theory is using women's voices to challenge the universal workings of social structures and the power relations that contribute to its functioning (Wood, 2009). Feminist standpoint theory is founded in the ideology that society is structured by the unfair nature of male domination over the subordination and oppression of women. Men, coming from a position of power, differ in their activities due in part to often having greater social and institutional rights and opportunities than women. Early versions of feminist standpoint theory (Woods, 2009)

criticize the imbalance of power between men and women and the inequality this produces. Women's lived experiences, which differ from men's, influence and shape their positions (Wood, 2005).

A premise of feminist theory is that the experiences and conditions common to women are not 'natural' but shaped by social and political forces. For example, Ruddick (1989) suggests social expectations of women's roles determine why women are assigned certain activities and the reason such activities are valued less than those assigned to men. Understanding the position of marginalization, women develop and share perspectives of their own group from their specific circumstances and standpoints that can provide insight to that of dominant groups and the workings of power that contribute to the creation and reproduction of inequality.

By the very nature of feminist standpoint theory, its purpose is for marginalized/subordinate groups to politically position themselves to challenge and identify the established social hierarchy and the power relations contributing to uneven consequences (Wood, 2009). In order to contest the powers, individuals or groups must recognize and analyze cultural values that contribute to the subordination of women.

Feminist research is at the very core of the feminist movement and feminist theorizing such as standpoint theory because it focuses on the need to change gendered oppression. Feminist research strives for equality and justice. By examining the experiences of female faculty members diagnosed with cancer through a feminist standpoint theory lens, this research provides an analysis of a gendered experience in higher education while also exploring how women experience their embodiment, roles, and relationships from their own "standpoint."

#### Methodology

This study used qualitative research methods to examine the experiences of female faculty members diagnosed with breast cancer in a tenure track role. The qualitative research methods that were used for this study include narrative inquiry and photovoice. A feminist theoretical perspective guides and shapes the methodologies of this study, which provide varied avenues to give voice to women, and insight into understanding their experiences from their viewpoint. The logic of a feminist theoretical perspective connects to the methodology of narrative inquiry by promoting different ways of knowing, to include subjective aspects such as listening and intuitive perspectives. Although interviewing is a tool often used in feminist research, for this study it was of utmost importance to preserve a sense of confidentiality and allow the participants an opportunity to share in their own time frame and on their own terms. Therefore I chose anonymous online journaling as the method of collecting data. This choice also allowed people across the country to participate by logging on to a web portal to access the questions and share their narratives in written form.

Some scholars argue there is a great deal of agency in writing. Providing the women an opportunity to process narratively through reconstructing and reflection of their experiences can potentially help them make sense of their situations. Writing can be a cathartic method contributing to emotional and psychological well-being (Pennebaker, 2000). By using online journaling, I believe the method provided women a way of sharing knowledge that other research methods such as surveys or interviewing might not have been able to encompass as fully.

Narratives are the product of an individual's voice of experiences, memories, and life stories in various forms. According to Riessman (2008), narrative inquiry "offers disciplines and professions that want to see how knowledge is constructed in the everyday world through an extraordinary communication act—storytelling" (p. 14). Riessman (1987) suggests "narratives link our experience of the world and our efforts to describe that experience or make meaning of it" (p. 172). Narrating personal experiences can provide an individual an opportunity to make sense, put order to his/her life, and in the process, provide connections to others who share similar experiences. Using personal narratives as data, the researcher's role of analysis is interpreting the stories that emerge from the data.

Depending on the type of narrative analysis a researcher uses, Riessman (2003) argues that the analysis process results in themes developed through the investigation, which have been influenced by prior and emergent theory, the purpose of the research, political purposes that speak from the data, as well as a variety of other factors. For this particular study, I chose the approach Reissman (2003) terms 'thematic analysis' in which the researcher's focus is primarily reliant on content of "intact" stories with the focus drawn on what is being said rather than "how," "to whom," or "for what purposes" (Riessman, 2003, p. 53). Narrative inquiry was used for the purpose of this study, providing an opportunity for women to write about their experiences through online and anonymous journaling via a web portal. As the researcher, I analyzed the narratives from the journals extracting themes speaking to how the participants revealed gendered experiences, both professionally and personally, with breast cancer in higher education.

Photovoice provides an additional outlet for participants to articulate their stories and express their experiences in a form different from the spoken or written word. Photovoice has been used in research in a variety of ways and is not merely a tool that is used to create images; participants also interpret the images they have produced and discuss their meaning. Whether by researchers or participants, photovoice is a potentially empowering tool utilizing photographs to communicate a critical reflection by giving meaning and understanding to the human experience. The actual subject matter or composition of the photographs submitted by the women in this study were not visually analyzed. The significance of the photos lies in the meaning and description given by those who captured the images so I focused on analyzing the captions of the photos the women provided. Photographs can contribute to the emotional interactions of an experience in different ways in which the translation of words might not always effectively portray. The narratives from the online journals, as well as the descriptions of the photographs, provided an opportunity for the participants to express themselves while also bringing meaning of experiences in dealing with cancer.

#### **Research Questions**

The purpose of this study was to explore experiences of female faculty members diagnosed with breast cancer to provide voice for individual women and to give group visibility for women in these circumstances and to also explore how they maneuvered within the gendered institutional structure of higher education. This information is intended to help others better understand women's experiences in these circumstances and to inform policy and practice. The following research questions were developed to attain the goals of the study:

- 1. What are female faculty members' experiences with a breast cancer diagnosis during their tenure track role in academia?
  - i. How do tenure tracked women in academia maneuver professional expectations after a cancer diagnosis?
  - ii. How do tenure track women express voice and provide visibility to their experiences after a cancer diagnosis?
  - iii. How did the institutional structures of academia contribute to the gendered power relations the women experienced with breast cancer?
- 2. What are the implication of the findings that can inform policies and procedures regarding academia and the tenure track processes for those impacted by a cancer diagnosis?

### **Summary**

Employing feminist theory and qualitative methodology in this study is appropriate to understanding the lived experiences of women in tenure track faculty positions who have been diagnosed with cancer. Feminist researchers have contributed vital scholarship, poetry, and writing on women's experiences with cancer that have raised awareness of the powerful implications of living with cancer (DiPalma, 2003; Lorde, 1980; Raz, 1999). However, the voices of female faculty diagnosed with cancer and their experiences in spaces of academia have not previously been explored. Their experiences might offer particular insights into the ways certain kinds of working contexts shape women's embodied experiences with cancer as well as the ways women in these circumstances navigate this type of context. Utilizing a feminist lens, I examine the experiences of female faculty members diagnosed with breast cancer during the gendered institutional structured process of tenure track position.

The study strives to bring visibility to the experiences of individual women who often prefer to protect their privacy in the context of their working lives but whose experiences individually and collectively can inform others. The findings might benefit

other women with breast cancer, others who need to understand their experiences more fully, as well as educational policy and practice. Ultimately, the study findings can promote advocacy against cancer-based work discrimination and help in creating supportive climates. The experiences women narrate demonstrate the complexity of dealing with the disease and its side effects publicly and outwardly personally (loss of hair, etc.) while working for tenure. Women in this study share directly the sources of support that work for them. Positioned in the epistemology of constructionism, theoretical perspectives of feminist standpoint theory guided the thematic analysis of narratives and photovoice of women in tenure track positions who have been diagnosed with cancer.

The current chapter has provided the background of the study, the theoretical framework, the study's significance, and the research questions. Chapter 2 provides the literature review for this study. Chapter 3 provides the methodology, methods for data collection, and methods of analysis. Chapter 4 provides an introduction to the women of this study featuring participant profiles as well as a personal description of how a cancer diagnosis entered their life. Chapter 5 provides the thematic finding of how the women negotiated their personal and professional roles in higher education, and the challenges, as well as the sources of support they received after their diagnosis, and presents narrative data to share how women expressed themselves. Finally, Chapter 6 will conclude this dissertation with recommendations, study limitations, future direction for the research findings, and inspired art work that I created to represent and promote the themes and the significance of this study.

#### CHAPTER II

#### LITERATURE REVIEW

### History of Women in Higher Education

Throughout history, women have had to overcome adversity in almost all roles within society, notably within education. Dating back to 300 B.C., Aristotle stated that women's brains were smaller than men's. He suggested women were less intelligent, the 'less noble sex', therefore naturally inferior to men (McKeon, 1941). Eileen Byrne (1993) points to Paul Broca, a French surgeon in the 1860s, who also claimed brain size was proof women were inferior to men. Because of such claims, many have argued across the centuries that women were incapable of benefitting from education. In fact, this type of research gave way to such literature as Edward C. Clarke's book Sex in Education; or a fair chance for the girls published in 1873 (as appears in Bagihole, 2007). Clarke (1873) believed that allowing women to obtain a college degree would make their brains heavy and their wombs shrivel. According to Clarke, his research offered evidence for why college educated women tended to have fewer children than non-college educated women (Kimmel, 2000). Philosophers such as Aristotle and Broca laid a foundation which bred a wide array of negative beliefs of women's biological capacity for intellectual and educational achievements.

As academia opened the doors for women, resistance to their presence and learning persisted. The Progressive Era brought with it criticism regarding coeducation feminizing the institution and contributing to making male students soft and less

masculine (Gordon, 1990). The rhetoric continued negative perceptions of women in higher education. Rich (1993) stated in higher education, outside of women's studies, "...we live with textbooks, research studies, scholarly sources and lectures that treat women as a subspecies, mentioned only as a peripheral to the history of man" (p.123). Feminist researchers argue that women have spent a great deal of time overcoming the challenges of such ideologies and, to some extent, still suffer the repercussions.

The last hundred years have brought about many changes in status for women yet areas within society still lag in equal representation. The history of negative rhetoric regarding women in education has perpetuated the lack of female representation in a variety of roles in higher education. In 1960, only a third of female high school graduates were enrolled in college as opposed to over 50% of their male counterparts (U.S. Bureau of Census, 2011). By 2001-2002, female students comprised approximately 57% of undergraduate students enrolled at post-secondary institutions nationally, according to the United States Department of Education (2005). During the same year, of the doctorates awarded nationally, 46% were to women. Despite women making up almost half of the PhD's being awarded in the United States presently, their progress advancing in academia is less rapid than their male counterparts.

Women who continue on to pursue careers in academia enter a male-dominated environment (Cotterill, Jackson, & Letherby, 2007, p. 2). According to Bagilhole (2007, p. 23), women hold 42% of full-time academic posts overall, 27% of senior lectures, 13% of professors, and only 12% vice chancellors. The achievements of women in higher education are often met with a plethora of challenges that contribute to the absence of women as faculty members, administrators, and leaders at the university.

While in academia, women are subjected to many pressures and expectations. Acker and Webber (2006) suggest the culture of the university is highly masculinized. They argue, "Women academics in universities find themselves in a university that was created and developed by men and with men in mind" (p. 486). The university fosters a culture of competitiveness and presumptuousness, more in line with men's constructed gender identity than with women's (Leatherwood & Read, 2009). Francis (2000) suggests that women who might behave with similar characteristics of competitiveness are more likely to be viewed as "manipulative" or "bitchy" (p. 17). In her research study of women educational leaders, Blackmore (1999) found the participants felt judged differently from male colleagues as "being too female or not female enough, too feminist or not feminist enough" (p. 206).

The effects of stereotypes and gendered standards of female faculty are equally disadvantageous (Pribbenow et al., 2010, p. 20). Cotterill, Jackson and Letherby (2007) discussed the "double binding" women in academia face. *Double binding* suggests, "a female academic is expected to be a professional - efficient, expert, detached, and objective while also being a woman - encompassing, caring, and supportive" (p. 4). Friedman (1985) explores the 'double bind' relationship between those in authority and female professors. She states "to be 'woman' she has no authority to think; to think, she has made herself 'masculine' at the cost of her womanhood" (p. 206). Such double binding can impact performances and role expectations and contribute to the barriers women in academia face on multiple levels. The American Association University of Professors stated, "The barriers for women in higher education not only raise questions of basic fairness, but place serious limitations on the success of educational institutions

themselves" (West & Curtis, 2006, p. 4). West and Curtis suggest institutions of higher education are disadvantaged and suffer when a gender balance is not present amongst their faculty members (p. 5).

#### Roles and Performances in Academia

Throughout the history of higher education there has been evidence of distinctions of roles in departments based on gender that, in many cases, still exists today. Nidiffer (as cited in Roper-Huilman, 2003) points out a gender differential in higher education between the concepts of "theory" considered masculine and "practice" is considered feminine. The disparate rates of research conducted and produced between women and men faculty members highlight an example of how gender disparities have manifested in academia. In 1979, Cole reported findings of a study examining women's place in scientific communities that suggested male scientists were more productive in term of publishing than their female colleagues. He continued by stating women produce fewer and less frequently cited papers while receiving less academic recognition (Cole, 1979). As noted in the research of West, et al. (2013), since 1990, women represent 26% of single-authored papers in the JSTOR dataset compared to 15.1% of authorship from 1665-1989. Scholars offer a few suggestions as to why gender disparities exist in publishing. One suggestion is that men tend to negotiate more than women (Babcock & Laschever, 2007). Another is that women are not sufficiently included in collaborative research projects (Fox, 2001).

There are gendered reasons for such patterns. Warwick (2004) suggested that female faculty members are expected to take on the majority of teaching and student advising responsibilities while male faculty members are allotted more research

responsibilities. Bagilhole (1993) adds male faculty members often avoid roles where students can take up their time when they feel their time is better served conducting research and publishing findings which often lead to financial reward, higher status, and attainment of tenure/promotion. Male-dominated assumptions and structures within departments can create barriers for the success of women academics and lead to lesser representation of women, different challenges in promotion, and different experiences in their tenure track roles.

These gender differences are manifest institutionally in a variety of ways. The National Education Association Almanac of Higher Education (Allen, 2010) reports that disproportionately women academics have been: "(1) relegated to part-time or contingent faculty slots, (2) concentrated in lower academic ranks, (3) represented in traditional female-dominated academic disciplines, and (4) employed in non-research institutions with heavy teaching loads and lower salaries" (p. 44). According to the American Association of University Professors (AAUP) Faculty Gender Equity Indicators, research institutions are not hiring women at the same rates as men and continue to pay women less (West & Curtis, 2006). The report also revealed that despite more female faculty in full-time positions compared to 30 years ago, the pay differential between men and women persists. On average, in 2005-2006, women faculty members' incomes, across all ranks and institutions, were 81 percent that of male faculty members.

## **Tenure Processes and Procedures**

The practice of tenure was established in 1915 to protect educators from being dismissed without cause (Sheehe, 1994). Tenure is a term used to describe an educator given a permanent position (Brock & Butts, 1998). According to the American

Association of University Professors (AAUP) 1940 Statement of Principles on Academic Freedom and Tenure (1984), tenure has two purposes: academic freedom and economic security. Academic freedom "enables educators to choose content and to teach in a manner that provides students with a spectrum point of view without fear of retaliation" (Brock & Butts, 1998, p. 5). Featured in *The Scientist* (Anonymous, 2007), Combest, staff member with AAUP, suggests tenure's purpose is to provide job security while enabling researchers to challenge the status quo. Economic security, as a purpose of tenure, provides the stability of a position while simultaneously paying a salary.

Tenure ostensibly commits the university to a contract of a lifetime salary while allowing the educator the liberty of choosing his/her own content and to teach in a manner without retaliation (Brock & Butt, 1998). The 1940 Statement regarding tenure that reflects this guiding principle of higher education is "indispensable to the success of an institution in fulfilling its obligation to its students and to society" (1984, p. 4). In this vision, tenure ensures academic freedom.

There are more than 130,000 full-time, tenure track faculty in the United States. As of 2007, 20% of full-time faculty across all disciplines were in tenure track positions; approximately 1 in 5 who apply are denied each year (Anonymous, 2007). Most often, the tenure processes consist of a probationary period of 7 years. Within this time period, it is suggested the professor will establish a pattern of productivity involving teaching, scholarship, as well as service. Scholarship is often the defining characteristic of the tenure candidates' work and a foundation of their career. In the final year of the 7-year period, the tenure candidate will go through a review process by administrators and fellow professors in the department. A committee reviews the candidate's work and

decides whether to award or deny tenure. Dismissal from a tenured position is rare but could result for reasons such as immorality, incompetency, insubordination and changes in institutional structure. Denials can also emerge from academic politics. The practice of tenure is the dominant professional structure used within higher education institutions and the United States professoriate. Although there are few alternatives to tenure in academia, it has become a topic of controversy for a variety of reasons. Trends speak to people's perceptions that the rigor and lack of flexibility in the tenure process are not appealing to new professionals, particularly women. Several aspects of the tenure process impact male and female faculty differently.

According to Park (1996), the three major categories for obtaining tenure, although not equally weighted, are research, teaching, and service. Park suggests the criteria generally include:

(a) research criteria - conducting quality research relevant to discipline ultimately to obtain publications in refereed journals, presenting papers at national and/or international conferences, reviewing books or journals, and writing grants and getting them funded; (b) teaching criteria - earning high appraisal on student and peer evaluations, advising, and counseling students; and (c) service criteria - serving on college and university committees; participating on local, state, national, and/or international boards or task forces; giving time to public service and the university regarding administrative and student concerns (p. 47-51).

Park concluded that when making the determination for awarding tenure, the most important factor of the criteria is research. Gibbons (1992) suggested that because the

criteria for tenure are flexible and often subjective, they can provide an environment that supports discrimination against women.

Universities have attempted to implement policies "intended to counteract adverse effects of situations that may interfere with faculty members' satisfaction, achievement of tenure and retention" (Pribbenow, et al., 2010, p. 18). Sullivan et al. (2004) conducted a study that stated 43% of the 255 institutions surveyed had an institutional-wide formal policy to permit "a tenure track faculty member to have a temporary pause in the tenure clock to accommodate special circumstances" (p. 25).

Pausing or stopping the tenure clock is an option offered by some universities and institutions to accommodate life events, special circumstances, and other situations that impact progress toward tenure. Health issues, pregnancy, or family commitments are examples of when the tenure clock extension policies can be utilized to allow additional time to meet the requirements of the department or institution (Pribbenow, et al., 2010). Some institutions have extended the tenure clock as a policy to accommodate faculty members in regards to family formation adding a new child to their family whether by birth or adoption, for example (Ward & Wolf-Wendel, 2004).

In a recent study examining tenure extension policies at the University of Wisconsin-Madison, Pribbenow et al. (2010) found that of 508 faculty members who attempted to achieve tenure in 1994 and later, 116 of them utilized the tenure clock extension policy. Of the participants who reported using the tenure clock extension 74 of the 116 were female faculty members. The most common reason given by those surveyed cited parental leave. Female participants reported the barriers to tenure were "family responsibilities, the stress of the process, and lack of support, both tangible and

intangible" (p. 23). McElrath (1992) suggests male-gendered policies and structures have an impact on the tenure process for women especially those with families. Even when leave policies are in place, many women hesitate to use them for fear of discrimination (Wolf-Wendel & Ward, 2003). Wolf-Wendel and Ward (2003) suggest although these policies exist, it is the climate of the institution that needs to become more supportive. Vital to changing the climate, according to Wolf-Wendel and Ward (2003) is educating administrators and departmental chairs of institutional policies pertaining to work and family so they are in positions to provide information and assurance to faculty as they seek out their institutional options.

# Tenure and Female Faculty

Despite the increase in women pursuing degrees in higher education, a disparity in the numbers of female to male faculty in tenure positions persists. At all levels of university academics, from lecturer to presidents, men still dominate (Leathwood & Read, 2009). Harvard University, the oldest institution in higher education (Rudolph, 1962) recently celebrated its 375<sup>th</sup> anniversary in 2011. It wasn't until 1912 that the first woman, Alice Hamilton, was appointed to a faculty rank position in Arts and Sciences at Harvard. A striking note is that it took Harvard 312 years after it was founded to tenure the first female faculty member, Helen Maud Cam (retrieved from www.faculty.harvard.edu). Harvard provides one institutional example of this pattern but echoes how, historically, universities have lagged in promoting female faculty members because institutions were originally designed with a male student in mind. Women have continued to struggle in making progress toward equal representation, whether in positions of administration or as faculty members.

According to U.S. Department of Education (2005) in 1972, of all faculty in higher education, women comprised 27% with only 9% of full professors being women. By 2003, women filled 43% of all faculty positions, 39% of full-time, 48% of part-time and 24% of full professors. Of the 39% of full-time women faculty at 4-year degree-granting Title IV institutions, only 35% of women were tenured compared to 52% of men. In 2005, (West & Curtis, 2006) women were 19% of full professors at doctoral institutions and 28% of tenured faculty at baccalaureate and master's degree institutions.

Research has suggested that male-gendered policies differentially impact women's chances for tenure (McElrath, 1992). The Committee on Maximizing the Potential of Women in Academic Science and Engineering (NAS, 2006) sought to examine gender disparities in the STEM (Science, Technology, Engineering and Math) fields, as they tend to be less represented there than in most other fields. Issues were found to include "lack of women in sciences, gender stereotypes and bias, workplace structures, differences in faculty workloads, lack of support for the tenure process, and family responsibilities" (p. 83). These issues have functioned "to impede women's entrance, retention, and success in tenure track faculty positions" (NAS, p. 83, 2006).

Etzowitz et al. (1994) stated because there are fewer women faculty than men (particularly in the science fields), the environment in higher education can become very isolating. As many have noted, the nature of faculty jobs can lead to isolation for both men and women. However, Bagihole (1993) suggests feeling isolated and less integrated into the university setting can contribute to female faculty members feeling "less confident in their abilities, less willing to take risks, and less able to negotiate for their

needs" (p. 442). Due to these struggles, female faculty members are likely to experience performance pressure and marginality (Bagihole, 2007).

### Female Faculty Experiences

Women are often disadvantaged due largely to it being a male-dominated arena without the assistance of sufficient numbers of female department head and colleagues. The isolation some women feel in their professional positions can also be a result of the academic climate in which they work. In fact, the connections to others in the field and relating to colleagues personally tend to be more vital to success than research and publishing alone (Bagilhole & Goode, 2001). Crucial to promotional decisions are connections made via academic networks. These networking connections provide collaborations benefiting careers and career planning, sharing of knowledge and contacts for research resources, as well as professional support and overall encouragement (Bagihole, 1993).

Menges and Exum (1983) have noted that for female faculty members, the lack of mentorship and support needed to be successful in the tenure process can make the process very difficult. Pribbenow et al. (2010) stated the effects of gender standards and stereotypes disadvantage female faculty members during the tenure process. Frequently without mentorship and other female colleagues to turn to for a support system, the environment of academia can perpetuate the culture of patriarchal and masculine hegemony. A male dominated atmosphere can reinforce gender differences in the practices engrained within departments and among colleagues. Due to the fact that men often hold senior positions, men have easier access to these support systems (Bagihole & Goode, 2001). Gibbons (1992) suggested female faculty members often have more

difficulty developing a mentoring relationship with older male colleagues in comparison to their male counterparts. Young female faculty members commonly cite the lack of role models to help prepare for the expectations of a faculty role as a reason for leaving higher education, contend that mentorship is vital to academic success (Bronstein & Farnsworth, 1998).

In essence, healthy relationships, connections and mentorship with colleagues and superiors are critical to advancing of women faculty members and many institutional factors intrude on supporting and building such relationships.

# **Family Formation**

Balancing professional and personal decisions is often a negotiation for most women at some point during their career. For example, family formation and all of the implications involved with balancing children and a career affect women and men differently. Mason and Goulden (2004) suggest 'babies do matter' in particular within the institution of higher education. Obtaining both tenure and having a family is often much more difficult for female than male faculty members. Women in a tenure track university job have a one in three probability of having children, and those women who do have children often have fewer children than those outside of the university while trying to balance careers and motherhood (Mason & Goulden, 2004).

Armenti (2000) found that the personal lives of female faculty are often silenced by their professional life in their academic careers. Academia can also create "taboos" for female faculty members who are mothers in terms of being a parent and directing attention to their family rather that their work. Within the same study, Armenti suggested female faculty members without children were worried about the deleterious effects

children might have on their career. The demands of academic jobs can make mothering a complex role to schedule and negotiate for professional women. Female faculty members, more commonly, are choosing to not have children. Women who do choose to have children may wait until after tenure is achieved and most often tend to have fewer children (Finkel & Olswang, 1996).

For female faculty members, there is a concern for those aspiring to have a family that "the tenure clock and the biological clock tick simultaneously" (Wolf-Wendel & Ward, 2003; Varner, 2000). Mason and Goulden (2004) suggest for most women, the busy career-building years of the "fast track and the reproductive track are on a collision course" (p. 13). Caplan (1997) suggests that females in academia often experience contradiction and confusion in their daily roles. As an example, female faculty members are often judged on the basis of being "not real women" if the women do not have children and the women who do have children are accused of not devoting enough time to their career (p. 67). These tensions can create a 'double bind' for women—either choice potentially garners criticism.

#### Gendered Embodiment

The complexity of gender is visible throughout academia and is embodied in various aspects of education. Silbergleid (2009) discusses critical issues of balancing work and family life as a pregnant professor. She explores becoming a gendered subject with her pregnancy, motherhood as a faculty member in Gender Studies, as well as the university as a whole. Silbergleid suggests those who could benefit from a lesson about gender are not just students in the classroom but more importantly, those making the hiring decisions in the administrative offices and setting tenure standards. Pregnancy,

Silbergleid suggest, brings femininity into university environments that have "historically rendered bodies invisible in privileging the mind" (p. 132). Pregnancy is impossible to hide but as Silbergleid and others point out, the body can be a teaching mechanism.

Smith (2003) states, "perhaps the body, as it has been for many of us in the study of our lives, is the most important text of the course" (p. 32).

Echoing a similar sentiment, Wallace-Sanders (2003) suggests "The pregnant teacher's body is a vessel of pedagogical possibilities" (p. 197). Wiegman (2000) suggests for women the private life of maternity can provide a public narrative. The display of pregnancy in a professional venue, is likely to invoke questions pertaining to their personal life. Silbergleid claims this public narrative was an advantage and assisted in her professional life as a professor. However, the complexity of exposing the personal life and the gendered bodily experience, pregnancy being an example, while at the university can bring about challenges. Pregnancy is a unique experience for female faculty members that displays aspects of their personal lives on the body that, with or without their consent, evokes others' commentary and involvement. Other situations such as a major illness like cancer can also occur putting a woman's personal life on public display.

## Women and Cancer

In the United States, 1 in 4 women will receive a diagnosis of breast cancer in their lifetimes (American Cancer Society, 2009). Of women diagnosed with breast cancer, 50% are 60 years of age or younger. Once diagnosed with cancer, thoughts about the possibility of death as well as physical and emotional pain are almost inevitable. For

women dealing with a compromised physical well-being, while balancing daily professional and personal responsibilities, can be challenging.

Society has found universal meaning in the symbolic pink ribbon to promote breast cancer awareness; however, there is still a great need to support the lived experiences of women diagnosed with breast cancer. Although the disease can mark women's bodies and leave women exposed to the gazes and opinions of others without their consent, there are a number of hidden elements associated with maneuvering breast cancer. Scars and body modifications are often an unfortunate part of breast cancer. Visible markers can invoke emotionally responses and sensitivity towards the woman's gender identity and sense of sexuality. Raz (1999) stated, "A woman *is* her body. Cancer that threatens the breast, the marker of gender and the maternal, the female erotic and aesthetic, may also threaten traditional definitions of identity..." (p. viii).

Baez-Hernandez (2009) stated, "Breast cancer dissolves the normal habitual appearance of the body while the subject attempts to preserve the breast's cultural meanings, to control intimate interactions, and to retain memories" (p. 151). Baez-Hernandez states, "Breast cancer, diagnosis, treatment, and prognosis have a power of fragmentation" (p. 153). Morris (1998) suggests this fragmentation of cancer threatens to break down or alter identities that eventually lead to reclaimed and reframed identities. Audre Lorde a well-known African-American feminist lesbian poet and author, wrote about her experiences with breast cancer in *The Cancer Journals* (1980). In this text, she wrote about fragmentation as well as reclaiming and reframing her own identity. Lorde details her experience of breast cancer and a mastectomy in a very personal and revealing way. She states, "There is a commonality of isolation and painful reassessment which is

shared by all women with breast cancer, whether this commonality is recognized or not" (p. 10). It is from these experiences of isolation that this study hopes to bridge the commonality and connection of women to tell their stories for those who have remained silent or unheard. This study is founded in the statement of Raz (1999) "I believe that language can save us from isolation" (p. xiv). Too often, women with breast cancer have historically been silenced. Through narratives and photographs, the women of this study give voice to their experiences.

## History of Breast Cancer

The understanding about and visibility of breast cancer as a disease has come a long way from early research to the present pink ribbon awareness campaign easily recognized today. Knopf-Newman (2004) discusses one of the first patient accounts, English novelist Frances Burney who writes about her own mastectomy in 1811. Burney wrote at a time when little was known about or done for breast cancer. Her words served as a historical context for her painful procedure but more importantly, gave voice to so many women's experiences. Much of the early history of breast cancer was kept hidden and often not publically discussed. There was often a sense of shame with breast cancer and was often kept quiet and not discussed openly. More significantly, breast cancer was inevitably a death sentence.

In essence, the breast cancer awareness movement has evolved in two main waves (Riter, 2005). The first wave was labeled "It's OK to have breast cancer". This was a response to the history of breast cancer being hidden and private. Even into the 1960s, a breast cancer diagnosis was a shameful experience and not often discussed openly. The Civil Rights Movement and the Women's Rights Movement were both

monumental historical events that helped change the perceptions that women should be keeping quiet about many issues including breast cancer. Standing up for awareness with these movements gave women a sense of permission to be vocal about having the disease without being shamed. Empowerment was instilled in women 'survivors' to be more in charge of their treatment as well as telling their stories. Empowering women to speak publically about their diagnosis is and was necessary in changing the stigma associated with breast cancer. The second wave was labeled "It's not OK to have cancer". This response is a call to action to answering the question, "why is breast cancer so prevalent?" This most recent wave advocates criticizing and analyzing potential causes of breast cancer while calling out corporations for exploiting marketing the pink ribbon (Ehrenreich, 2010).

Today, we have an entire month dedicated to breast cancer awareness flooded also with pink beribboned everything and anything to support the cause. In *Breast Cancer: Society Shapes an Epidemic* (Kasper & Ferguson, 2000), authors discuss in several essays of how breast cancer has been socially constructed at different points in time. Understanding more thoroughly how research, the medical industry, and public's heightened awareness is vital to promote societal changes in perceptions about breast cancer and the future of treatment. Crucial to the discussion is how to keep the pink ribbon accountable for more than awareness but advocating progression towards a potential cure. This is in part due to the evolution of social advocacy and awareness of the health issues involved. More specifically in this instance, cancer advocates initiatives to impact health policies and procedures.

According to Keefe, Lane, & Swarts (2006), there are six strategies that cancer advocates have used to promote policies in regards to health: 1) advocates to empower individuals to possess control of their health, 2) advocates for language surrounding the disease (e.g. 'survivor' rather than 'victim'), 3) advocates for research and federal drug approval procedures and agenda, 4) advocates for allies and lobbied officials, 5) advocates for alternative treatment centers as well as preventative care, and 6) advocates for change in legislation and hindering procedures as well as funding for research and programs (paraphrase, p. 58). The medical field is highly vested in breast cancer research and treatment. With the changes of breast cancer it is more and more significant to use the voice and experiences of women to contribute to the realm of policies and procedures, as ultimately, women are those affected.

#### Feminism and Health

Examining the historical context of women's experiences with health care and women's health as a field is important in regards to understanding how policy has changed through connection of knowledge and power. Reverby (2002) suggested the women's health movement began in the 1950s with the birthing movement and expanded in the 1960s and 1970s pertaining to abortion, reproductive rights and general women's health. Currently, she clarifies that women's health has evolved to different interest groups to include as, an example, breast cancer community organizing (Reverby, 2002). Through health initiatives, the feminist movement "found ways to make knowledge become power" while "thinking through bodies to larger political forces became a second way to structure both history and political action" (Reverby, 2002, p. 12). Reverby (2002) argued that women's health initiatives weaken by having a history of relying on

one way of understanding our histories, rather than being collective and united in various perspectives.

Women's health care has been influenced by various dynamics of race, class, and sexual identity. Knowing the histories and the intricacies of how it has been shaped is important. By empowering women with greater information regarding the full spectrum of their history, we can then begin to promote political change. It is necessary to know these histories for the greater good of all women and to spur important political changes that make a difference in women's health care and public awareness. This is summed up by Reverby, "We cannot make policy unless we understand what kinds of histories, representations, and cultural experiences shape our underlying principles, and make some strategies possible and limited others" (p. 16). The lesson to take from women's health initiatives is the power in understanding the histories of how particular health policies and medical procedures shape diverse women's lives.

Lather (1988) stated "The overt ideological goal of feminist research in the human sciences is to correct both the invisibility and distortion of female experience in ways relevant to ending women's unequal social position" (p. 571). Advocating for bringing voice to the women's experiences can contribute to providing power and knowledge to ultimately inform change.

# Summary

This chapter provides an overview of the history women in higher education that has contributed to their present roles and responsibilities. Examining the process and procedures of tenure provides a better understanding of how female faculty members' experiences vary from that of their male counterparts, and accordingly, how their

standpoints might differ. Men and women negotiate family formation and caregiving responsibilities differently, which can have an impact on their careers at various levels. Gendered embodiment explores how gender is on display and plays a role in academia. The remainder of the chapter explored experiences of women and cancer, the history of breast cancer and the connections between feminism and women's health movement. In essence, these issues provide insight as well as the foundation and framework of this research. After examining the literature, this study contributes to a better understanding of the experiences of female faculty members in a tenure track position who have been diagnosed with cancer. These experiences are examined through a feminist lens to explore the discourses of the participants in regards to professional and personal roles.

#### **CHAPTER III**

#### **METHODOLOGY**

Governed by a Constructionism epistemology, a feminist theoretical perspective, with feminist standpoint theory serving as the theoretical framework, this qualitative study employs narrative inquiry to better understand the experiences of female faculty members having been diagnosed with cancer in a tenure track role. This chapter introduces, first, the research design and rationale for the methodology and methods for this study, second, the details the specific methods use to gather data, then turns to the reflection on positionality as the researcher and finally, the criteria for validity of this study. The data collection methods used were online journaling and photovoice techniques to provide insight into their experiences, including how they navigated their professional and personal roles, the challenges they faced, and the sources of support that were meaningful to them. These methods are feminist by providing various ways of giving voice to the women's experiences.

According to feminist researchers, common research methodologies can often contribute to oppressive ways of seeking information, even silencing more than speaking to participant's actual experiences. Standard research practices such as surveys may not allow for creative opportunities to share fully or fluidly. How researchers carry out their methodologies determines whether their research is feminist, liberating, or objectifying. The complexity of emotions and such personal experiences can be difficult to share in-

person and the necessities of preserving confidentiality is also important to the ethics of feminist inquiry about sensitive and intimate topics.

In contrast to standard research methods, the research design in this study provides opportunities for women to give voice through various avenues allowing them to choose their most comfortable approach. This also provides insight into the spectrum of various ways of knowing and expressing complex emotions the women shared. Qualitative research allows for interpreting a situation based on the perspective of the participants (Strauss & Corbin, 1994) and feminist theory allows for considering the gendered nature of these perspectives. Not only does this study provide an opportunity to consider and analyze participants' perspectives on their experiences, but it also explores the ways gender shapes their experiences of these complex roles. The primary source of examining participant's perspectives was the online narrative journal entries that reflected what I am calling, based on the work of Audre Lorde (1980), "autopathographies" of the participants. Photovoice was utilized to provide the women an opportunity to submit a photograph, giving a visual depiction supporting their narratives as they saw fit. This chapter will describe the qualitative research methods used in conducting this study to answer the following research questions.

# Research questions

The following research questions were developed to attain the objective:

- 1. What are female faculty members' experiences with a breast cancer diagnosis during their tenure track role in academia?
  - i. How do tenure tracked women in academia maneuver professional roles and expectations after a cancer diagnosis?
  - ii. How do tenure track women personally express voice and provide visibility after a cancer diagnosis?

- iii. How did the institutional structures of academia contribute to the gendered power relations the women experienced with breast cancer?
- 2. What are the implication of the finding that can inform policies and procedures regarding academia and the tenure track processes for those impacted by a cancer diagnosis?

## Online Narrative Journaling/Autopathographies

Autopathographies, a narrative form of writing about the self, are autobiographical entries focusing on or inspired by a disease in the writer's life. Audre Lorde developed the term to provide a human aspect, a story, to an illness and medical treatment. Many researchers have found narrative work a fitting approach for writers to process their experiences with illness and loss. Ellis and Bochner (2002) state that in participants' autopathographies:

concrete action, dialogue, emotion, embodiment, spirituality, and selfconsciousness are featured, appearing as relational and institutional stories affected by history, social structure, and culture, which themselves are dialectically revealed through action, feeling, thought and language (p. 739).

Online narratives were utilized to grasp the lived experiences of the women of this study, specifically focused on such autopathographies to provide a raw, personalized, honest examination of what the women wanted to share, and to what extent they felt was significant to bring awareness to regarding their circumstances.

I began by exploring some of the various technologies that were available to potentially fit the needs of protecting confidentiality while allowing for photo and journaling submissions. When none of the options proved to encompass what I hoped for, I developed a website. Having had little experience in web design, I found a site that

was user-friendly and provided a template that included options for submitting narratives as well as photos efficiently. The features of the website and how I set it up were very intentional in providing an opportunity to submit information without revealing identity as well as allowing for submissions to take place whenever and wherever the participants felt was best for them. It was important to allow flexibility and provide opportunities for the women to submit as much as they wanted to share as well as without any restrictions prohibiting length or time. Once the website was developed, I sent the link to several colleagues and faculty members to ask their opinions on the design and ease of using the site. After minor adjustments based on collegial feedback, I submitted the information for IRB approval.

The study was designed to align with feminist methodology in that such methods, Inckle (2007) suggests, reveal "the multifaceted, complex, and emotive layers of embodied human experience" (p. 30). Online journals were the platform utilized to seek the participant's narratives while providing a safe and confidential space to write their experiences as they chose to. This data source was an important choice for this study because the online format provides opportunities for women to remain anonymous and to thus choose how they share their stories—an option they rarely had in their work life. Allowing women to speak to their experiences yet feel a sense of power in knowing anonymity was of utmost importance was vital to this study. An important reason in keeping the identity of the women secure was addressing the issue of resistance to sharing fully for fear of retaliation.

This study design ensured privacy to the women and was intentional in allowing them a space to share at convenient times of their schedule. Also, the method allowed the women an opportunity to write when they felt it best to delve into the potentially emotional content of visiting their personal story without feeling reserved or uncomfortable as someone might be when sharing in person. In a similar approach, Kasper (1994) also focused on understanding and honoring the women's point of view. She suggests that feminist research has expectations of equity and fairness both in intent and in practice. In creating knowledge, the women revealed their personal experience as it pertains to having cancer in a tenure track position.

Bringing together creative and critical aspects of inquiry can be a challenge and has often been viewed as controversial due to perceptions that "rampant subjectivism" shapes this kind of work (Crotty, 1998, p. 48). However, feminist researchers accept an overt political stance in their work that lends itself to diverse data sources and methods. As the Personal Narratives Group (1989) points out the subjectivity of personal narratives is what makes them significant. The creative practices of narratives provide the writer and the reader a moving and personal encounter (Inckle, 2007). Riessman (1993) states, "Nature and the world do not tell stories, individuals do" (p. 2). Traditional forms of research are often not conducive to the complexities of participants telling their lived experience, particularly when dealing with an illness such as cancer. Seeking purely the perspective of the participants, the autopathographies provide insight into women's experiences for this study. The creative analytic practice involved in narrating their experiences with illness, recovery, and their working worlds, is a useful approach to be expressive as well as critically examining the way women reflect on their experiences.

The method of writing narratives can also offer a corporeal and emotional opportunity for participants to process the illness in a different way by revisiting and

remembering the intricacy of the illness that might provide new insights. Illness narratives provide individuals afflicted with illness an avenue to explain and conceptualize their disrupted lives and how they want to be known in their stories. Raz (1999) suggests that writers, particularly those who have had breast cancer, can articulate their experiences while providing insight to inadequate and often obscure stories regarding the impact of dealing with the diagnosis. Narratives can also provide a way of sharing experiences for those who are unfamiliar with the situation. More specifically, in regard to the obstacles of dealing with cancer and the university, Soltis (1995) suggests personal narratives can provide, "a way to see into and meaningfully navigate the complex professional landscapes" (p. vii) to bring awareness to others facing similar situations.

Pennebaker's (2000) research examined how putting emotional upheaval into words can positively affect an individual's physical and emotional health. The act of constructing stories in writing helps a person understand his/her experiences and self. Expressing one's experiences through words, especially experiences of a traumatic event, provides an opportunity to "confront anxieties and problems by creating a story to explain and understand past and current life concerns" (Pennebaker, 2000, p. 11).

Narratives and expressive writing provide an outlet to document changes in life. While I can't be certain what women in this study experienced in writing their narratives, the design offered the opportunity to process and reexamine their lived experiences.

Pennebaker stated that translating personal experiences in writing "may accomplish for us what oral storytelling must have accomplished for our ancestors - improvements in physical and mental health as well as the development of closer social bonds" (p. 15).

#### Photovoice

The second mode of inquiry was photovoice. Photovoice, as an additional tool for gathering data, provided an opportunity to engage participants in expressing their lived experience visually with photography and it provided another avenue to explore experiences that complemented the online narrative journaling. Photovoice (Wang & Burris, 1994) is an innovative participatory research method that incorporates photography to capture the voices and visions about an individual's life, community and/or concerns. The use of photovoice with this study is based in the understanding that images provide participants an opportunity to express their feelings and perspectives along with, or entirely in place of, conventional narratives (Wang & Burris, 1994). These photos can also be used as a platform to communicate their meaning to the public and policy makers. Photovoice provides a glimpse into the participants' social realities and an avenue for insight into the community of the participants and their cultural narratives (Rappaport, 1998). Photovoice provided a different form of data, and touchstone for further identifying and representing participant experiences, through the outlet of photography. According to Wang (1999), photovoice has three main goals: "(1) to record and reflect personal and community strengths and concerns, (2) to promote critical dialogue and knowledge about personal and community issues through photographs and (3) to reach policymakers" (p. 185). The participants submitted a photo while also provided their own interpretation and stories about their images through descriptive captions to go with the photos.

Feminist research has been instrumental in developing and embracing the creative forms of narrative analysis as both political and personal (Inckle, 2007). Approaches

such as photovoice are one possible way of developing, as Lather (1991) suggests of other forms of feminist research, "less oppressive ways of knowing" (p. 95). Weiler (1988) identified three themes of photovoice that are rooted in feminist inquiry. First, photovoice is a method that allows women to present images to express, reflect, and communicate their everyday lives. This theme suggests photovoice provides the women with photography as a tool to be subjective of their experience as a researcher, an advocate, and a participant.

The second theme recognizes that women's everyday experiences are significant to women's experiences. Essential to this study is how female faculty members' everyday lives, professionally and personally, are influenced while dealing with a cancer diagnosis. Feminist practices often politicize subjectivity by departing from women's experiences as women (Amigot & Pujal 2009). Historicizing the female experience beyond a static understanding of sex/gender allows a "more refined attention to the different contexts in which women are located, thereby avoiding homogenization and exclusion" (Amigot & Pujal, 2009, p. 662).

The third theme suggests photovoice makes a political commitment to the participant's focus on improving life and wellbeing (Wang & Burris, 1994). Offen (1988) suggests feminism critically analyzes male privilege and the subordination of women in society that encompasses both an ideology and a sociopolitical movement of change. To emphasize this point, famed African-American feminist scholar bell hooks suggests that women bring a diverse spectrum of thoughts, ideas, and backgrounds; however, women need to seriously address themselves "not solely in relation to men, but in relation to an entire structure of domination of which patriarchy is one part" (hooks,

1989, p. 716). Experiencing these structures of domination are not easily verbalized therefore avenues such as photovoice are important creative alternatives to visually depict the impact of their experiences. In this study, photovoice has accomplished all three of these themes by providing women opportunities to record and reflect, critically confront their personal experiences, with the eventual hopes of reaching policy makers.

According to Wang (1999), key concepts that are associated with photovoice are *images teach* and *pictures influence policy*. The concept of images being able to teach suggests that an image such as a photograph can provide an opportunity for learning while also influencing an individual's state of health. Wang suggested, "Images contribute to how we see ourselves, how we define and relate to the world, and what we perceive as significant or different" (p. 186). Wang (1999) states the significance lies in the participant's interpretation of the image rather than on the actual physical content of the image. Participants in this study provide images to teach others about their lived experience with the ultimate goal of reaching other women, other colleagues who would like to provide support, and also influencing policy.

The method of photovoice proposes images used as a tool of influence by documenting and illustrating the scope of the participants' experiences. By narrating their perceptions and experiences through images, women can visually express the cultural significance of their situation. Using visual representation to define and explain how the women relate to the world around them, photovoice can enhance understanding. Photovoice has been used to research the experiences and health status of diverse phenomena and experiences including village women in China (Wang, Burris, Ping, 1996), elderly women with HIV/AIDS (Gosselink & Mylykangas, 2007), and youth

community perceptions of in South Baltimore (Strack, Magill, & McDonagh, 2000). The variations of research being done utilizing photovoice ranges from empowering individuals, speaking to social barriers, as well as a tool to promote community-based research initiatives. Photovoice strengthens this study by providing women the opportunity to record and reflect through photographs, an image of providing dialogue, with the hopes of informing change. The participant's caption and the reflection are the primary focus of analysis. Together with the response from the online journal prompts, the two methods will allow different avenues of narrating their experiences and the data sources for this study.

The women's photographs have the power to represent how participants see themselves, the environment they occupy, and their experiences overall. Image-based data contains cultural significance and symbolic meaning behind its content. This speaks to the understanding that visual research methods such as photovoice are not purely visual but rooted in culture and context. Photovoice is not constructed merely to focus on the collected images but, more importantly, in how the participant interprets the image. Conceptually, the images of photovoice can be used as a tool to teach as well as to speak of the women's experiences in dealing with illness. The image or actual visual content of the photo serves as a way to supplement the narratives in the online journaling and capture how women interpreted the meaning of the picture for representing their experiences.

The use of photovoice is very similar to one form of narrative inquiry (Rappaport, 1998) as it aims to capture the story of the participants lived experiences (Foster-Fishman et al., 2006). Narrative approaches "organize experiences, give coherence and meaning

to life events, and provide a sense of continuity, history, and of the future." (Mankowski & Rappaport 2000, p. 481). Narratives take many forms and have many community and cultural purposes. For some people, narratives are lived stories and "in the telling of them reaffirm them, modify them, and create new ones" (Clandinin & Connelly, 1994, p. 415). Rich (1971) defined narratives in terms of a "re-vision" meaning looking back at an experience with a new perspective. Rich suggests that women's life narratives are "more than a chapter in cultural history: it is an act of survival" (p. 18). The act of survival for female faculty members' with a cancer diagnosis speaks to the importance of sharing how they maneuvered the rigor of academia.

Combining the role of expressive writing in the form of online journaling and supplementing with photovoice, this study drew from feminist approaches to collect and interpret narratives in order to provide voice for and increase visibility of women in these circumstances in tenure leading positions.

## Participants and Recruitment

The study involved purposive sampling to recruit a sample of female faculty members. The participants for this study all identified on the website and in their narratives as female faculty who had experienced cancer during the tenure-track. After opening the website, as mentioned above, and obtaining IRB approval, I moved forward with attracting participants to the study. My first step was to contact the women I knew personally to ask for their participation. Next, I sent out the information to close colleagues and friends to ask them to disseminate the information to help recruit participants. When I was unable to get participants to successfully complete the study, I submitted modifications to the IRB to include recruitment of participants via social media

and listservs. With the help of many colleagues, faculty, and friends the IRB approved description was posted via Twitter, Facebook, LinkedIn, blogs, listservs and countless emails. The difficulty of recruiting subjects extended the duration of data collection for the study, which raised important questions about what other methods and additional venues could I do to reach more participants and required rethinking how I would collect narratives. For months, I spent a great deal of time researching blogs and social media that I felt would be viable sites to reach women, being cognizant of not invading safe spaces with solicitations. I also was very intentional in meeting new people and sharing my study in the hopes of snowball sampling, reaching someone who knew someone. There were also several occasions I made contact with women who committed to doing the study and yet didn't follow through. In these situations, I followed up approximately 5-6 emails, in some cases, spanning 9 months' time period, to send reminders about the study in the hopes they would finally complete it.

Knowing other women who had access to the website, but chose not to participate, suggested the discomfort women might have had in confronting telling their story and potentially reliving some of the painful experiences of cancer. Writing can be cathartic and yet allowing the time to process and confront questions specifically about such a personal experiences, needs a great deal of time that, as faculty, might be challenging. I also feel as faculty members, there is a great deal of emphasis on writing demands for their profession. This study and their participation could have felt as an additional work type of responsibility. And since many of the women were intentional about structure, content, and flow of their narratives, rather than a free writing approach,

it is my assumption there was a great deal of care and consideration in presentation that was an additional time consumption, and again, more work.

In the end, five participants, most with whom previous rapport had been established through a variety of formats, participated in and completed the study. It is notable that none of the additional recruitment efforts, carried out over social media and email recruitment over several months of length of time, including in feminist organizations, resulted in additional participants. My aspirations were to reach a wide array of diverse women from varied institutions, to see how their experiences might speak to a variety of different aspects. In the end, I was very happy to obtain five women who successful completed the study. Inclusion criteria for this study were that participants were required to be female faculty members in a tenure leading position at an institution of higher education and have experienced a cancer diagnosis during their tenure track period in academia.

#### **Data Collection**

Upon agreeing to participate in the study, the participants were given access to the secured website I created and described earlier. The participants were instructed to designate a User ID with no identifying information that included a combination of letters and numbers. The first submission signed with their User ID was the initial consent form and with each entry thereafter, their User ID was required to designate their submissions. The importance of confidentiality was essential to this study due to the sensitive nature of information being disclosed. Due to my familiarity with some of the women as well as their honesty in their responses, I was able to draw conclusions as to some of the respondent's identities. It was my focus to ensure the details were not revealing and only

allowed responses to be altered slightly for the reason of retaining anonymity.

For the online journaling exercise, a total of four open-ended prompts were provided for the participants to reflect and respond to. The instructions asked participants to respond within a two week timeframe in completing a journal response for each question. Submission of the narratives were all done differently. A couple of the women chose to submit all of their responses within the same day. While others took several days if not more than a couple weeks between each submission. From the beginning of receiving the first submission of my initial participant, to obtaining the final submission from my fifth participant, was approximately nine months. I do believe, however, the women might have viewed the questions, wrote their responses in another format other than the website and submitted all the entries by copying and pasting from a document. Therefore, gauging time committed to submissions was hard to evaluate.

The first phase of data collection and the first question participants encountered through the web portal asked them to tell "Her Story." This phase directed each participant to discuss her childhood, up-bringing and background demographics. The prompt was as follows: *Describe, in essence, your story - describe your upbringing in regards to family dynamics, background demographics and how you came to a profession in academia.* 

The second phase of data collection addressed "Diagnosis, Duration and Dealings." This phase directed each participant to discuss how she learned about her diagnosis, what her experiences were throughout the duration of treatment, and how the experience impacted her personal roles and responsibilities. The prompt was stated as follows: *Describe your experience of how cancer entered your life, how the diagnosis* 

might have had an influence on you personally, and how you maintained balance of the personal side of dealing with cancer.

The third phase of data collection explored "Professional Practices." During this phase participants described how professional roles and responsibilities at the university facilitated and/or hindered the circumstances of dealing with cancer. The third prompt was as follows: While dealing with cancer, describe how professional roles and responsibilities, interactions with colleagues, administration, and/or students played a role within your experiences.

The fourth phase of data collection addressed "Aspirations of the Profession." This phase brought insight to the intersections of dealing with breast cancer and the expectations of the faculty position. The fourth prompt requested the following:

Describe how experiencing cancer as a faculty member in higher education may have shaped or played a role in the reappointment, promotion, or tenure process.

Participants were provided a text box to enter their narratives, as much or as little as they chose to submit to each prompt. There were no parameters on what they included or the order in which they chose to answer the questions. It was impossible for me to tell how long each participant spent online, or how many participants logged on but chose not to engage in the study. However, the participant responses appeared to indicate each question was well thought out and responses were well-organized as one might expect from individuals who write as part of their professional life.

Each participant was also asked to take a photo or photos that best represented her experience in each of the four topical areas mentioned previously. She was asked to submit her pictures via the website with a written statement describing what the picture

meant to her. Specifically, the instructions stated, "Here is an opportunity to provide a photo or image you feel best represents your experience to this prompt." The limited instruction was intentional to provide a space to submit what they felt would be most in line with their narratives. To provide more fully a creative opportunity for the women, no parameters were suggested. The women then provided their own caption to the photos to clarify why the photo was chosen what it meant to them and why.

## Data Analysis

This study incorporated both narrative analysis of the online journals as well as narrative analysis of the caption given to the images of photovoice. As with most qualitative research, analysis begins with the organization of the data, immersion in the data, and then finding themes. Narrative inquiry is the method that produced the units of data from the narratives the women submitted. Although there are different ways of conceptualizing narrative analysis and what it can reveal about the "real" world, Patton (2002) suggests the central idea of one form of narrative analysis is that it offers "translucent windows into cultural and social meaning" from stories and narratives. Riessman (1993) clarifies a slightly different type of learning that can emerge from narrative analysis than cultural and social meanings; she suggests that narrative analysis "takes as it object of in narrative analysis investigation as the story itself" (p. 1). For some, narrative analysis focuses on teasing out stories; for others, narrative analysis provides a window into people's experiences, or into cultural processes. Each of these different perspectives are rooted in epistemologies and theoretical foundations of research (Crotty, 1998).

Narrative analysis was utilized, more specifically, thematic analysis (Riessman (2008), in which the content of the stories and preserving the content by keeping it "intact", was imperative to this study. Thematic analysis focuses exclusively on content of narratives to examine and establish meaningful patterns. In contrast, structural analysis, another form of narrative analysis, focuses on the format or structure of the data and how language used makes up the particular data (Riessman, 2008). Riessman (1993) suggests that narratives "must be preserved, not fractured" through the process of analysis, while respecting respondents "ways of constructing meaning and analyzing how it is accomplished" (p. 4). Keeping the content of the stories intact was important to preserve what the women shared, illuminating their experiences in their own narrative voice, while speaking to the purpose of this study. Essential to the form of narrative analysis I use in this study was preserving the authentic content of participant writings.

Thematic analysis was also utilized because it allows for larger data units that can include entire stories to serve and speak for the data. I used narrative analysis to examine the online journal entries and interpret the stories or specifically the text that tells the stories. Once participants submitted their entire narratives, I read thoroughly several times before analyzing. The narratives that emerged from each prompt were examined inductively and individually for content and broader implications. Then, I reviewed all the narratives for each woman collectively. Each of the women's narratives were interpreted as a whole and then examined more closely to see how themes emerged. Once I felt familiar with the content, I began highlighting information that I felt was significant pertaining to the women's individual story as well overall experiences dealing with cancer. As I read through all of the women's narratives, I asked a series of analytic

questions, including "what am I hearing each of the women say? what are the women saying collectively? what are they each saying consistently? and what do the narratives have in common?" I began highlighting comments or parts of the narratives that spoke to their experiences in professional and personal circumstances. From the analysis of the narratives, themes and ideas emerged. I examined the data analytically by assigning conceptual labels to which I felt the women were somehow speaking to in their narratives about their experiences.

The narratives from the online journals as well as the captions from the photovoice photos were analyzed using a feminist perspective to examine the participants' experiences as well as social implications. Questions emerged such as "how does being a female faculty member with the gender disease of breast cancer, present itself in academia? do the women speak to their experiences as being a women? And how does the expectations of displaying femininity, such as hair, impact women differently when dealing with the visible display of losing it?" This analysis bought to light various aspects of the participants' discourses of their experiences.

# Researcher's Reflections on Positionality

Reflexivity as a researcher, according to Patton (2002), consists of an ownership of perspective, a strong sense of self-awareness, and a consciousness in both political and cultural realms. As the researcher, it is important to acknowledge my position in collecting, interpreting, and representing the data. Having never been diagnosed with cancer nor worked in a tenure track faculty position, my experiences regarding these situations are limited. Therefore, it is imperative to give voice to the women of this study in the most genuine and authentic way possible. As the researcher of this study, I

disclose that my research purpose and agenda has been shaped by personal experiences and background. During my collegiate career, I have had several female faculty members who have been in the situation of being diagnosed with cancer while in a tenure track position. Having witnessed their experiences, I was moved to take on this research initiative and provide an outlet to tell their stories. Reflexivity as a researcher, according to Patton (2002), consists of an ownership of perspective, self-awareness as well as a consciousness in both political and cultural realms. My passion for this study stems from circumstances of the injustices of treatment I witnessed of women with breast cancer in academia. This study is so important to me to bring awareness and help enlighten those who have not been exposed to such circumstances. Through the research, I hope to bring visibility of the women's experiences and the potential need for support in academia in hearing the voices of the women in this study.

As the researcher, I am aware of my positionality due to my own experience, or in this situation, the lack of experience with the personal perspective of having cancer. Although I have colleagues and individuals I am close to, there is a cancer culture that is hard to grasp unless you have experienced it. I am cognizant of this and want to let this study speak for those who have had cancer, while not ever imposing that I understand the full dynamics of what it must be like. My role is significant in the process of interpretation of the data and in the production of the findings. The concept of reflexivity acknowledges and explores how the presence of the researcher connects knowledge with meanings and interpretation (Inckle, 2007). I am aware it is my understanding and ideals that are organizing and interpreting the data overall.

Cognizant of my position, I hope this study adequately interprets the women's writings to create themes that best describe and represent the data the women have so graciously provided me. I relate to Inckle when she states, "I wanted to hear each woman's experiences from her own perspective; issues that were important to her; the themes she wished to focus on; and the connections she made for herself" (p. 26). My personal values and beliefs were invested in telling the stories, encouraging support systems, and genuine relationships in a professional setting while dealing with cancer. I was diligent at keeping the data authentic and as true to their original words. The integrity of the data was kept by presenting it in its most genuine form, and it was interpreted through a feminist lens for data about experience, gender and agency.

# Quality Criteria

When conducting qualitative research, validity is important to consider. Joppe (2000) states "Validity determines whether the research truly measures that which it was intended to measure or how truthful the research results are" (p.1). According to Patton (2002), validity needs to be considered while designing a study, the analysis of results, and assessing the quality of study. Triangulation is defined to be "a validity procedure where researchers search for convergence among multiple and different sources of information to form themes or categories in a study" (Creswell & Miller, 2000, p. 126). By combining several method or data, Patton (2002) states, strengthens a study with triangulation. For this study I used triangulation of different methods of data collection. Online journaling and photovoice were both utilized. I also utilized peer debriefing, a term meaning consulting colleagues who assist in critiquing the accuracy of the data collection and analysis process (Creswell, 2003), throughout this process. Other

individuals were utilized throughout this study to consult and process the research as well as to seek emotional support analyzing the very heavy data.

### **Summary**

Inckle (2007) states:

Creative practices engage the researcher/author, participant(s), and the audience in a process of knowledge production that I intended to be affecting and transformative. In conveying the complexity, ambiguity, and pain of lived, human experiences, they also incorporate precisely the aims and ethics that are set out in a theory (p. 15).

Inckle's quote speaks to how the methods of this study were chosen to provide written as well as a visual opportunities in expressing experiences of cancer and its complexities. I hope the methodologies which make up this study contribute to a greater picture of the female faculty's experiences, and that the rigor of the techniques provide a quality and credible study that has allowed for creativity as well as confidentiality of the participants. The emotional content of the responses to the prompts and reliving the experience of cancer contribute to the challenges of gathering data. Also, since confidentiality is imperative, following up with participants is not a possibility. Although these are challenges, it also speaks to the importance and necessity of why such a study is needed. This chapter outlined the research methods, approach to gathering data and the data analysis for this study. Also, this chapter presented my role with the research and the basis of pursuing this project, as well as the criteria I followed to make this study as credible as possible. In the next chapter, I introduce the women's profiles.

## Chapter IV

### PARTICIPANT PROFILES

Description of the Participants' Background - Her Story

The following chapter highlights each of the women in this study with giving a glimpse into of "her story". This section provides an overview of who each of the women are as they describe themselves narratively, based on the information they shared, and allows the reader some insight into how their personal characteristics provide a foundation for their experiences. In thematic analysis, the exclusive focus is content (Riessman, 2008). There is an intentional effort to preserve and present accurately each of the women's narrative. The first level of data analysis will be on an individual level examining the participants' personal narratives. In the theoretical position I am taking to approach and analyze the data, I see the online narrative journals as "giving voice" to the participants genuinely and authentically, speaking to their personal experience.

The second part of this chapter provide a brief overview of the women's personal description of their diagnosis. I feel this is an important aspect of this study and the women's experiences as the ordeal was revealed in different ways for the women, but for each of them, it was life-altering. After taking into consideration each "her story" and the description of the women's diagnosis as a whole, the next step of the analysis in Chapter 5 is closely examining the themes identified through the commonalities from the narratives. This overview provides some insight into the women as individuals getting and a sense of

their personalities and circumstances and how these might have contributed to their experiences as faculty members.

The first part of the analysis provides an individual examination of each participant. Each participant was given a pseudonym of a noted researcher with similar characteristics, who was invested in women's issues and had also experienced cancer or serious illness. Audre Lorde was a strong, vocal, beautifully poetic woman whose work inspired this research project. The author of *The Cancer Journals* (1980), Lorde documented her experience with cancer in her autoethnography. The participant given the pseudonym Audre showed similar characteristics, believing in her purpose to make change and being a voice for her experience for others. Gloria Anzaldúa was a vivacious spirit as well as a Chicana author, poet and activist. Anzaldúa wrote in her text *Borderlands/La Frontera: The New Mestiza* (1987) about a new identity and sensibility "the new mestizo" which expressed an individual's awareness of conflicting and meshing identities in a world constituted by both conceptual and physical borders. The participant given the name Gloria was a woman of great strength and ambition.

Susan Bell is a scholar and women's health activist who has used art and photography as tools to represent the politics of cancer. The participant given the pseudonym Susan displayed a creative energy and a thoughtful nature, much like Bell. Carolyn DiPalma, a researcher in women's studies and political theory, wrote about her experience with cancer as a faculty member. The direct responses and intelligent wit she displays in her writing bore a resemblance to the participant given pseudonym Carolyn. The final participant I named after Barbara Ehrenreich a writer, activist, and critic of the pink ribbon campaigns who, I feel, shares the fighter-type sentiment of the participant

given the pseudonym Barbara. Each of the women provided a unique perspective into their experiences in response to the prompts. The pseudonyms highlight specific characteristics I felt each participant possessed.

Participants provided the responses I share in this chapter in response to the following prompt: Describe, in essence, your story - describe your upbringing in regards to family dynamics, background demographics and how you came to a profession in academia. Each woman answered this particular prompt in a very similar format. Although some wrote more than others, the overall content was shaped to discuss upbringing, childhood family dynamics, and ultimately college and higher education achievements. The varying length of each narrative response may speak to the time invested into each prompt, what they wanted to say and how much they wanted to reveal. To honor the integrity and spirit of the responses, I tried to keep their words intact as much as possible. I worked to preserve the intention of the participant to the best of my ability to capture it from the data - and to convey their own interpretation. This prompt is titled 'Her Story' to provide an opportunity for the women to share as much as possible of what each chose to disclosed about their upbringing and background. Each participants 'Her Story' is as follows. Any information that provided personal details was changed to not jeopardize confidentiality.

#### Gloria

Gloria, the older of two girls, grew up in a military family. The frequent moves and uprooting was a way of life. Traveling throughout her childhood, attending thirteen schools before entering high school, Gloria said she "loved that experience." "Home is where you hung your hat, and family was all that mattered. I grew up learning those

values so that it would not feel as traumatic moving from place to place." With durations of stay ranging from as short as 6 months to as long as 5 years in graduate school, "...being a tumbleweed was the essence of who I was. Make friends quickly, get the most you can out of the time you're there, and then leave," Gloria states. These important lessons learned, she suggests, later contributed to helping her deal with her diagnosis. Regardless of their distance from her at different points in her life, family plays a vital role in Gloria's life, and she still communicates with them on a regular basis (four-five times a week). Regardless of the struggles she encounters, Gloria keeps it to herself to not burden her family. Being strong (and stubborn), Gloria comments, are characteristics she knows very well. Vulnerability is not natural for Gloria; she expresses that being vulnerable during her diagnoses was a complicated process for her.

During her undergraduate studies, Gloria was very involved with student activities. She jokes that her involvement was really more of her major and International Relations was her second major. Volunteering as a student orientation leader, president of programming board, and other activities, Gloria loved her undergraduate experience so much that when student affairs administrators encouraged her to apply for graduate programs in student affairs, she felt she found her life's purpose.

Graduate school took Gloria to the northeast where she struggled a lot. She mentions in her narrative that this was the first time she had ever been on her own. Such tasks as opening a bank account and caring for her car were all new to Gloria. Gloria said she also struggled in graduate school being one of few students of color. No one could figure out she was Mexican-American. "Angry is the only word I can find that is even close to how I felt during those two years." Coming from Texas where there is a

large population of Latinos, there was a great deal of comfort Gloria didn't recognize until she was no longer in the majority; now she "was Othered". It angered her to have people question, "What are you?" or to be asked, "How does it feel to be Mexican-American?" She wrote, "I vowed that one day I would return to Texas and help people like me realize that our world was not real once you left the state. What I didn't realize was that our world was not real after you leave El Paso and San Antonio." These places were familiar to Gloria. Dallas, she soon learned by taking a position at a university there, was a "White place." She worked at the university for 5 years; it would be Gloria's only student affairs position. Aspiring to be a dean of students or vice president of student affairs, Gloria began thinking about getting a Ph.D. Her previous advisor suggested she gather more experience, and after 5 years Gloria started applying to higher education programs, wanting to understand macro-issues as opposed to micro-issues such as student development. Gloria decided to pursue her doctorate in the southwest.

Gloria states, "I have been the first to graduate from college, to graduate with a M.A., to have a Ph.D. I have blazed a trail my whole life, and so it's difficult to ask for help and difficult to accept help when offered."

# Carolyn

The older of two girls by five years, Carolyn grew up in a predominantly white upper-middle class neighborhood outside a large urban city in the Midwest. Carolyn states she "grew up in calm, moderately liberal household with high expectation for success, though 'success' was defined in a variety of ways." She explains this by giving an example that good grades were expected but more emphasis was placed on following her interests and helping her develop as a happy, well-adjusted individual. Carolyn

attended eight years of Catholic school and four years of public high school made up of a very diverse student body. Her parents, still living and married for 44 years at the time of her writing, "encouraged experience over things" allowing her opportunities to travel; "high school graduation came with a Passport." She was also supported by her parents to attend summer camps, play competitive sports, and participate in a sorority. Carolyn never had a strong relationship with her sister and that distance remained.

During her undergraduate program Carolyn stated she had a strong mentorship by people who encouraged her to publish with faculty and present at conferences.

Graduating with a degree in English and a secondary teaching certificate, Carolyn began teaching on the West Coast. Having questions about the profession and missing the "intellectual community of college," Carolyn followed her lines of inquiry into a Master's. After completing her Master's, she left teaching and applied for a full-residency PhD program with the intention of teaching in a university setting.

Audre

From the age of 7 to her early 20s, Audre, the oldest of three girls, was born and raised in a white, middle class household in the deep South. For the first 13 years, Audre grew up where her father maintained financial stability and her mother tended to household affairs. Instilling a strong work ethic, Audre's father was a first generation college graduate who was raised on a farm and had worked "from the time he could walk." Her father's ideologies suggested "the only way to get ahead in life was through hard work and penny pinching," children were expected to respect elders and do what they were told, and the expected, common household language included, "yes sir/no sir, yes ma'am/no ma'am." Wanting the best for his daughters, Audre's father expected them

to go to college and have a career. She notes however, "there was a general understanding that wives did what husbands thought best - cognitive dissonance pervaded." Audre's mother had a college degree in early childhood education and worked as a teacher for a few years prior to Audre being born. Her mother instilled the importance of excelling in the classroom with the expectation of being an 'A' student and in gifted classes. Audre also stated her mother's expectations of "table manners and good grammar," these were "highly revered traits."

Audre shared her mother had a mental illness that her family did not discuss until her parents divorced and they rarely mentioned it thereafter. It was her father's belief for many years that prayer can help people overcome mental illness. When her parents divorced, her family was forced into situational poverty. Living with her mother in their middle class home, often without lights, running water and a telephone, Audre says her "home wore a mask;" we were "outwardly looking [like] a middle class family but on the inside we were not." Disguised by this mask, Audre says it was "a household of loss." Her family sold furniture, toys, and other cherished items to maintain the cost of living. Audre learned how to adapt dealing with different dynamics of poverty. She knew how long it would take for checks to clear at each of the local grocery stores. Hiding from unfamiliar cars and knocks at the door became strategies of survival mode to avoid bill collectors or the police coming because a bounced check. Because Audre's mother had been a stay at home mom since Audre was born, her teaching license had expired, which prevented her from getting a job within the school system. Her mother began working at a home daycare for less than minimum wage. At age 15, Audre began working to contribute to maintaining household earnings and helping with expenses. Participating in a work-study program, Audre dropped out of accelerated classes in the 10<sup>th</sup> grade. Audre states, "We depended on each other, protected each other and developed a sense of survival at all cost."

A source of strength for Audre was her maternal grandmother. She did not live in the same town, nor did she see her often, but it was comforting for Audre to know her grandmother was there. At the age of 15, Audre's grandmother died of cancer. Having cared for her grandmother in her final days, Audre found herself overwhelmed with the grief of losing her grandmother, and as the oldest child in her family, she felt a grave sense of responsibility for her sister and mother. Despite being consumed with pain and only a teenager, she felt she had to be strong as consistently as she could. Her parents' inability to communicate with each other left Audre alienated at times from her father and his side of the family. Sharing care of her mother, Audre stated she felt fearful to leave her alone worrying she might commit suicide. Because of these complex personal circumstances, Audre "left for college with a sense of liberation and guilt."

Having grown up in a small town "where similarity was embraced and difference abhorred," Audre was intrigued with and found comfort in the university environment and felt inspired by professors and course content in anthropology, religion, and African American studies. The university was a "place where women were told what they can do and not what they can't or shouldn't do;" it was "a safe place to learn of and be inspired by difference." There were few, if any, of Audre's undergraduate professors who were female but many had experience working in developing countries in areas of deprivation. Although Audre aspired to have these experience of working in developing countries, she didn't believe it would happen. She admits she did not envision a professorial path lead

by publications or acquisitions of grants but rather imagined working to inspire students to embrace principles of social justice.

Audre states she "was a dreamer and believer in the university as an environment for invoking liberal thoughts, exploring difference, and effecting social change." Inspired to make a difference, she "wanted to help make the world a better place and was able to converse with like-minded misfits who questioned or were affected by capitalistic hierarchical structures." Audre marched for equal rights and attended human rights festivals. She felt "privileged to be able to traverse the university and wanted to help people who would not be afforded such luxury."

As an undergraduate, Audre wasn't sure she was on a path to becoming a professor, but the university was a very safe and inspirational place for her. Graduating with a liberal arts degree in an unstable economy, she worked as a substitute teacher during the day and waitress at night. Audre sought out a Master's degree as a means to employment and became the first in her family to obtain an advanced degree. She was given the opportunity to be a teaching assistant and continuing on to a Ph.D. Audre's degree was a true sense of accomplishment and a great source of pride for her parents. *Susan* 

Growing up in Texas with her parents, older sister and two brothers, Susan says she had a happy and fulfilled childhood. Both of her parents were heavily involved with the children; her father was a professor and her mother took care of the household. The school district Susan attended was excellent, and she excelled with great grades and good group of friends. When Susan was a small child, she dreamed of growing up to become an elementary school teacher because she loved school and her teachers. In high school,

her vision for her future shifted as she decided she wanted to be a physician because it was service-oriented, it was hard, and it wasn't a traditionally female thing to do.

Susan's joy of being with children and her fascination with their development, sparked her desire to be a pediatrician.

During a church youth group in middle school, Susan met James. James was her first and only boyfriend. They both went off to the same university together and dated until Susan was a junior; then they got married. After taking elective pre-med classes while completing her degree in a Liberal Arts honors program, Susan had the grades and MCAT score to be admitted to medical school. Susan struggled in the courses. The work was all memorization and she couldn't seem to do it. Susan's grades were low enough that she had to go before a board of medical faculty and justify staying in school. She realized in preparing her speech that she didn't want to be a physician. She dropped out of medical school and had a bit of an identity crisis. James had started a master's program and decided he wanted to get his Ph.D. He was accepted into a program, prompting a move to the East coast.

Susan began looking into graduate programs and found Child Development.

Although she never took a class in child or family studies, or in psychology, she nevertheless thought studying children would be interesting. She was admitted as a special student in a doctoral program because she hadn't taken the GRE. She came home from her first graduate class and told her husband "This is it! This is what I want to do! You get to read these articles, and decide what they mean, and you learn about theories, and can come up with your own questions and research idea..." This was the exact opposite of her experience in medical school.

One professors from her first semester received a large grant and asked if Susan would be his research assistant. She worked with him the rest of her graduate career. She realized from this experience that she wanted to teach and conduct research, and her training helped provide the foundation for this goal. Having a father who was a professor, Susan knew a faculty position provided flexibility and was a good lifestyle for someone who wanted children. Susan also realized that it fit her preferred ways of learning and thinking — analytically and creatively. The switch from medical school to graduate school was never a decision she regretted. Dealing with and helping children and families was the reason she wanted to be a physician in the first place.

## Barbara

Growing up in California, Barbara was a one of two children in her middle class family. Barbara's mother was a nurse who was originally from Sweden. Her father, an electrical engineer from New Jersey, was a descendent of a Russian and Polish Jewish family. Her mother stayed at home until both Barbara and her brother were in high school, and then she returned to nursing. Barbara attended public school with the exception of 7<sup>th</sup> grade when she attended private school. That year, due to wildfires, her house burned down. Although her family rebuilt their family home, she returned to public school for the remainder of her secondary education.

For her undergraduate education, Barbara attended a university in California.

After marriage, she lived in the Southwest where she pursued her Ph.D. while also putting her "husband through school too." Once finished with her Ph.D., Barbara's husband pushed her to apply for a job in academia. She enjoyed her previous experience of teaching part-time in a graduate program and "was ok with this idea."

Although Barbara's father has passed away, Barbara's mother lives with her. Barbara writes, "...at 92 [my mother] is quite needy and has memory issues." Barbara's maternal grandmother died in her 60's of a brain tumor. With the exception of Barbara and two of her female cousins on her mother's side, in two generations on either side of her family, no one has had breast cancer. These incidents of cancer were all dealt with by lumpectomies. A self-proclaimed "health nut" since college, Barbara said she never smoked, took birth control or even drank coffee.

Barbara experienced her first lumpectomy two years prior to her first child.

Barbara was an assistant professor at the time and the results were not cancerous. "I did not talk about it to my colleagues," Barbara states. Starting as a visiting professor,

Barbara was then hired in a tenure track position. Three years later her husband was "hired in the same department" where "he received tenure and was the darling of the administrations." Barbara's husband suffered from severe depression and when a colleague made his life unbearable, he "quit in a huff and decided to move out of the country (back home for him)." Two years later, when Barbara was up for tenure, she was denied "partially as pay back." She separated from her husband for several years before eventually divorcing. When Barbara was denied tenure at her institution, she fought this decision and won; however, the president of the university refused to reverse the decision. Barbara "found a better job" and with full custody of her son, she moved to the Northeast. Despite being further from family, Barbara was happy with her move and at her new institution she found a "very small supportive faculty."

## Discovery of Diagnosis

The following section will provide narratives from the women describing their discovery of their diagnosis. I thought it was important to keep intact raw narratives as possible with only surface analysis on my part to preserve the intent of the women's submissions. Each of the women shared various aspects of their diagnosis experiences. Some of the women went into depth sharing specific dates, family responses, and even doctors specific conversations delivering their diagnosis. Others kept their narratives brief but personal. Because of the differences in responses, lengths varied from multiple pages to others writing a couple paragraphs. Following are the synopses of women's diagnosis stories.

## Gloria

"I had moved to [state] for my faculty job in August of 2008. Six months later, I was diagnosed with breast cancer...I was in a bit of a denial about a lump I had found in early January. I can't say how it happened that I found it, but it was palpable and actually hurt me. I said nothing to no one and then had a conversation with my friend [name] that was incredibly vague. I told her, "I think I hurt myself or something. I'm not sure what this pain is in my chest." Super vague. But another week or so later I told her, "[name], this lump isn't going away." And she said, "Lump?! You need to go to the doctor immediately!" It is somewhat embarrassing to say that I had been in [city] for 6 months and still didn't have a general practitioner or any doctor. The only other surgery I had ever had was a tonsillectomy. Generally, I was in good health, although my last year in [state] I contracted Valley Fever, which is a fungal infection in your lungs and very common in dusty locations. But, that was it. So I didn't worry much about getting a

doctor and now had to shop around. I found a good gynecologist and went on Friday, February 13<sup>th</sup>—very ominous! At this point, I had been aware of the lump for a month. When I went, the nurse practitioner did the breast exam and it was not difficult at all to find the lump at 12 o'clock on the right breast. It was not even really in the breast tissue mound, but above that near my clavicle. I yelled in pain and broke down a little. The nurse seemed frightened and recommended that I get a mammogram at the local hospital. So they scheduled me for a mammogram and ultrasound for Feb. 17th, enough time for me to panic.

I called my family that weekend and explained what was happening, but feared the worst. Again, I did not say a word to anyone in [state] and went about teaching class on Tuesday like it was not a big deal. On the 17th I was supposed to have lunch with a couple of faculty from my department and thought that I would be done with the mammogram by that time. They did the mammogram on the right breast. And then, as I was sitting in the waiting area, they asked me to do the mammogram again. And then, it was recommended that I do the ultrasound. So I enter the darkened room and encounter what I know in my heart is a picture of the tumor. The technician did not and could not tell me what I was seeing, but I knew it was cancer. And when she photographed how blood was flowing to the tumor, I knew for sure that this was something alive and growing. After some time, the radiologist entered and said to me, "I cannot say this with 100% certainty, but I believe that the tumor is cancerous. We can do a biopsy now or have you schedule one." I smiled and said, "Well, I am in a gown already, so let's do this!...I watched as the doctor numbed the area and cut into my skin. And then I focused on the ultrasound that would help me see how he was extracting portions of the tumor.

After he was done, I asked if I could see the samples that had been placed in the test tube. They looked like little bits of raw chicken. I then drove home and took a nap. The biopsy results could take up to 3 days and would be sent to my gynecologist. But I didn't need to wait for the results. I knew. And so I spent those 3 days researching breast cancer sites. The American Cancer Society has a great website that had a list of questions that you should ask your doctor when you get diagnosed. So I wrote those down. And then I waited.

On Friday, February 20, 2009 at 8:15am I was supposed to be at our Ph.D. admissions day, interviewing potential doctoral students. I texted one faculty member to say that I was getting some tests done and would not be able to attend. She asked if I was okay and I told her that I would let them know on Monday. So, there I was, in my doctor's office. The doctor came in and she said, "Well, I'm sorry to tell you this, but it is cancer." And I said, "Okay" and took out my notebook and started asking her, "Okay, are you sure?" "Yes, Gloria, you have infiltrating ductal carcinoma. You have cancer." "Okay, how big is it? What stage is it at?" "Gloria, you have cancer." "Yes, but I need this information!" I start shouting at her. "I can't cry right now!" I yelled, "You have to answer these questions!" And, of course, that's when I break down. I couldn't believe it. I was all alone, thousands of miles away from anyone I could really trust. Ugh. Poor doctor. She's not an oncologist. She really couldn't answer any of these questions, but she was thoughtful enough to know that [city] would not give me the type of treatment I would need, especially because I was young (34) and the cancer seemed to be quite aggressive...As most survivors would say, this was really devastating. I had no history of

breast cancer in my family—aside from my great aunt and I was 34 years old. Who thinks of breast cancer at that age?...

Right before I started chemo, the doctor realized that they didn't have a mammogram on the left breast. So I had the mammogram and they found another mass. I had another biopsy and this time they found that it was a very rare form called secretory carcinoma. Rather than a hard mass, it was more like a secretion—some sort of goo. Hard to describe. When they did the pathology report, they found that it was ER-positive. So, now we all knew that I had 2 different primaries in two different breasts...During one of those chemo treatments, I was encouraged to get genetic testing because of the two primaries. Treatment started in [Spring]. I found out that I was BRCA-1 positive [a few months later] and then began discussions about a bilateral mastectomy because there really was no choice.

Two cancers, two different locations. Having the gene that causes breast cancer. There were just too many factors and too much risk. In August I had the bilateral mastectomy and reconstruction—my mom flew over to help me for 3 weeks. After removing the breast tissue, the doctors create a flap in your chest muscle and put in a water balloon. Over the course of several months, they inject water into the balloon to stretch out the flap and make room for the implants. By the time I was done with the water injections, I looked like I had very large grapefruits stuck under my very stretched skin. In December 2009, I had the exchange surgery and flew home to [state] with new boobs—thank you, Santa!"

Carolyn

"I found a lump in my right breast in Spring semester of my second year of teaching on the tenure track. I came from a family of women with "lumpy breasts" and I had been having hormonal fluctuations as a result of changing birth control, so I chose to monitor it for a few months. It grew. A biopsy determined Stage III invasive breast cancer and extensive DCIS with node involvement. The semester ended and I started chemo, followed by several unsuccessful lumpectomies, a mastectomy, more chemo, and six weeks of radiation. This treatment continued through my third year on the tenure track and recently ended with the completion of my third year of Tamoxifen on Jan. 1." *Audre* 

"Cancer entered my life before my personal diagnosis with it. My grandmother was diagnosed with and died from cancer when I was a teen. She did not even want to say the word because she had seen family members die from the disease. "Why did ya'll have to tell me I had that old mess" was her first response when learning of her diagnosis and she died soon thereafter. The extent of her cancer was beyond treatment and so cancer first entered my life by way of fear, death, helplessness and hopelessness. I also had 2 great aunts with breast cancer. I did not know them very well because we did not live close by but I remember one of my aunts having a breast prosthetic. I was very young when they were diagnosed and so I don't remember too much conversation about it. It stuck with me though... A little over a decade after sharing with my college friend that I would develop BC, I found my right breast in pain. It felt like my breast was on fire. It became excruciatingly painful to the point that I could barely lift my arm when I was in a department store one day trying on a dress for a follow up interview as I was considering a position move. I told my husband that something was definitely wrong. I

scheduled an appointment when we got home which took forever. When I finally got in to see the nurse practitioner, she said that it probably wasn't cancer but that we should run some tests to see. The wait was trying and ever so frustrating... My husband and I waited for months to get through appointments and wait for the next one to be scheduled.

During the wait, I went to my college reunion in the mountains. I had not revealed to any of my friends that I could possibly have cancer before arriving but into the night I revealed to 2 close friends what may be in store for me. We drank, reminisced, danced, drummed and cried the night away. I woke up in a fog the next morning—hands blistered from drumming, a good way to relieve the stress, frustration and pain, and went about the next few days in facade of good health. Business and life as usual. I had conferences to attend, presentations to prepare and my preschool child's life to love. I put on my mask and went about business as usual, or so I pretended."

Susan

"I always did breast mammograms and every few years also got an ultrasound, because I had fluid-filled cysts in my breast and therefore didn't trust my self-exams. My husband had been diagnosed with cancer on his birthday, in [month/year], and we spent 6 months at [medical center] where he was treated, ultimately receiving a bone marrow transplant. The experience was traumatic for several reasons: He almost died; his siblings weren't a match so it was iffy, searching for a donor; the chemo he received made him extremely sick; he had to be isolated for part of his treatment, so I had to just watch him through a window; and we were separated from our children--my son was in college and my daughter was in high school--from our friends, from our work, from our dog... We returned [home] in mid-November. James was still very sick, and had to be isolated at

our house, where I was his 24-hr caregiver. Then, [right before Christmas], I was diagnosed with breast cancer. I'd gone for my yearly checkup as soon as we returned, and the mammogram and follow-up tests showed cancer."

#### Barbara

"In 1993 I was told I had a suspicious lump on the radiograph. I should have run the other way. He was an older man and now looking back inept. He tried a needle extraction but he was shaky and it failed so he said a lumpectomy was needed. It was not cancerous. But the scar on the left breast was ugly! My mother the nurse did not approve of his skills.

My son was born in 1995. I nursed him for 2.3 years. In 2003 I had a cluster of calcium spots on the mammogram and another lumpectomy near the same area. Then in 2008 I had another calcium cluster in the same area, and after needle aspiration, it was positive for cancer. So in a week and a half I was scheduled for a lumpectomy. But before that about 5 days later I had a fatal heart attack, but I had it at the annual health [event] and there was an AED and cardiovascular surgeons and EMT people there and they resuscitated me after multiple attempts and in a 1/2 hour I had a stent put in... Turns out this was genetic (my grandmother's brother on my father's side died this way too apparently and I was the lucky one to inherit this)...I had the lumpectomy a month later in summer when I could reduce the blood thinners etc... They then went in again to get the margins. Due to the heart attack we skipped the chemo, and I had a radiation therapy that was targeted... I forget what it was called. They put a balloon in and then I went for 10 days 2xs/day to have a radioactive rice kernel put in. I did this at the end of summer and into the start of fall semester. It was rough, but good timing in general."

# Summary

As a researcher, reading and grasping the emotional and sensitive content fully how it must have felt putting these experiences into words was overwhelming. My emotional response to their narratives stemmed from how the women described their personal perspective and referred to their families while telling their diagnosis stories. The narratives encompassed so many levels of women's relationships with children, spouses and parents, as well as other connections, and how the diagnosis affected them. Overall, they revealed the complexities and challenges the women encountered. The women shared a vast array of details of their experiences ranging from differences in health care experiences, family history of cancer, and even their chemo treatments. Some of the women provided many details while others were very specific in what they shared; some of the women spoke of vulnerability, the silences, masks; the various levels of emotions.

I felt it was important to share first the women's "her story" about their lives separately from their diagnosis narratives. Although each of the childhood and family experiences are vital to the women's experiences, I didn't wanted to incorporate the women's stories of upbringings and their experience with a cancer diagnosis together. I thought doing so would emphasize the experiences as separate aspects of their lives. However, the overview of what they describe was essential in providing a foundation for an understanding of their experiences as individuals, as women, as faculty, and as women who have had breast cancer.

This chapter provides an overview of each of the women's 'her story' including the moments the women described when they first were diagnosed. These personal

narratives, as Laslett (1999) suggests, allows "individual and collective action and meaning, as well as the social processes by which social life and human relationships are made and changed" (p. 392). The narratives allow the women to process their experiences and connect them to their relationships and the changes these experiences have made in their lives. The next chapter will provide an analysis of themes and commonalities in being a female faculty member and making sense of their past experiences of being diagnosed with breast cancer.

# Chapter V FINDINGS

This chapter will provide an overview of key themes across the women's narratives that demonstrate how the women experienced cancer while in academia and how they expressed their voice and provided visibility to how cancer impacted their life. This chapter presents the research findings by exploring the themes that surfaced through inductive analysis from the narratives and the photovoice submissions. However, the women's narratives provided many levels of complexity contributing to the challenging aspects of data analysis for this study. I hoped to preserve the integrity of the content of the narratives as the women submitted them, and yet the intersectionality and depth of the topics were important to highlight and examine on several levels. This chapter teases apart connected aspects of the storytelling provided by the women that brought together this research project.

I first begin this chapter with an example of the depth and complexity from the narratives with an excerpt from Audre to demonstrate the many layers and aspects of the women's writing and the challenges of pulling from the rich data the themes. Audre states:

My treatment was no short affair, the treatment spanned nearly a year including the chemo, radiation, bi-lateral mastectomy and hysterectomy. Then, 1 year later, I went through reconstructive procedures which was major surgery.

In this narrative, Audre conveys a year worth of treatment and surgeries equating to what had to be a great deal of time, energy, effort and emotional exhaustion and yet

she minimizes these complicated processes to one sentence. Immediately following, she shifts in her narrative to describe how unsupported she felt by her administrators:

Throughout these processes, I did not feel a great deal of support from administration when dealing with cancer. Performance expectations remained the same. For the first time on an annual appraisal, I got a review that said I 'did not meet expectations'. The appraisal meeting was 5 months into my treatment.

The structure of higher education and those who filled the roles of administrators held the same professional expectation for Audre despite her having to deal with the traumatic circumstances of cancer. Although she was trying to contribute to her work even while undergoing treatment, Audre describes how hurtful it was to get this performance review:

My body was broken and my spirit felt crushed, so I broke down and cried in the meeting, something I did not want to do but a deluge of emotions overcame me, not because I did not meet expectations but rather because I had put so much effort into missing as little work as possible and scheduling my chemo around class, research and other duties.

The struggle Audre felt describes a broken body and crushed spirit yet it is her frustration of crying in the meeting that caused her the most conflict. Audre's use of the words "broken" and "crushed" provides such a vividly desolate state that it evokes for the reader a variety of emotions to process. Her anger and pain provides a window into the intricacy of her internal emotions dealing with an unsupportive space.

Chapter 5 presents the data in themes that examine different aspects of the narratives. I focus on both women's personal and professional perspectives. The data

was initially examined by reviewing the responses of the participants as a whole, and then moving to seeing commonalities of shared experiences, similar issues, and common struggles to which the women referred. I read the narratives and sought commonalities through inductive analysis, which entails "discovering patterns, themes, and categories" from the data (Patton, 2002, p. 453), I noted how the women expressed various components of how higher education contributed to their experiences. After examining the data of both narratives and the captions of the photovoice submissions, as Riessman (2008) suggests "the researcher zooms in, identifying the underlying assumptions in each account and naming (coding) them" (p. 57).

The themes begin with examining how the women negotiated the structural aspects of higher education and all that entails in their professional role environment. The aspects of professional life that surfaced in their narratives focused particularly on facets of being a faculty member, relationships with colleagues in academia, the classroom and students. Themes relating to the aspects of personal overview detail how the women provided voice and visibility to their experiences. Specifically, the narratives offered insight into the gratitude and living for others, reassessing, telling, waiting, relationships and creative avenues of maneuvering cancer. The final level of data analysis examined the research questions pertaining to the gender experiences of the women's narratives and photovoice. The social and political implications as they pertain to potential policies and procedures will be explored and discussed in Chapter 6.

## **Negotiating the Structural Expectations of Higher Education**

My reappointment was derailed by cancer experiences and lack of support from administration. – Audre

Theme 1: Finding agency and supportive spaces: Managing, Adjusting, and Responding

This theme speaks to how the women experienced and maneuvered the structural expectations of the institution and their role as a faculty member. They managed, adjusted, and responded in different ways. The women shared how they managed to keep their classes on schedule while also finding solace in their work as a faculty member provide a sense of control during the uncertain times of dealing with cancer. The women also shared how their departments and administration contributed to their experience; some of the women revealed positive experiences, some did not. In essence, when all things in their lives were filled with uncertainty, the women share how the climate, colleagues, and responsibilities helped them negotiate their roles as well as contributed to their performance in their profession while dealing with cancer.

Maneuvering the Structure: "Professional Expectations Remained the Same"

An important aspects of negotiating the structural expectations of higher educations, is how the women shared they maneuvered and found agency in their positions. This includes how to approach choices in relation to the tenure clock, decisions regarding class room management and responsibilities while managing cancer treatment. Audre shares a poem she wrote regarding her cumulative experience in academia and how this climate contributed to her decision to not pursue tenure, ultimately leaving her faculty position:

I was angry and hurt and did not think the path was for me anymore. I wrote the poem below a year or two after my decision. The poem is the culmination of my experiences in academia at the time, a graduate student's experiences with her

major advisor throughout her thesis process, and what I observed when more than a few professors left the department.

Hier Educashun

Sitting atop your ivory treetops Knot tied dressed, regressed oppressors Emotionless, self-obsessed professors

Accolades built upon the backbones of hier education's shunned

Mothers of brown nosed molds Stench of patriarchal residue old

Throw down your authoritative, administrative shoe

Beat down unfamiliar ways Kick out the wayward strays Pave paths for mother mays

Shun those of lesser means Clone minds from narrow streams

For you we do endure Small circles ensue Strategize to undo

Liberate the down and trodden Overcome the craven fodder

Bourgeois professors be obscure

From this it is obvious that I did not feel support from administration, nor the professorial route at the time.

The poem Audre shares is raw and revealing yet provides a genuine perspective to the harsh realities of the culture of higher education she experienced. Audre speaks from her own personal experiences while also those she had witnessed. Her wording, "Emotionless, self-obsessed professor" and "Shun those of lesser means" provides a vivid depiction of faculty as individuals who are heartless and egocentric in an environment of academia that cares little for others. This poem provides a critical confrontation as the title suggests of "hier educashun" playing on the word education in using the word "shun" to again emphasize the feelings of being ostracized by academia if you are of "lesser means". The political elements of academia can have significant effects on and the culture fostered in particular departments. And yet, sometimes this environment does lend itself to the human aspect of the people who contribute to the departments.

Audre's frustration at striving to meet expectations in her performance review while dealing with the difficult dynamics of cancer left her feeling broken with a crushed spirit. She seemed to feel even more vulnerable by crying in the meeting, and insignificant, because her performance review did not take into account the enormity of what she was facing and the work she had accomplished in these circumstances.

Ultimately, she left the position, not because of her disapproval of the work, but the process and how the situation was handle left her disenchanted.

Although there are challenges maneuvering the climate of academia, Susan shares how the structure of academia served to support her scheduling and wrestling with the condition.

## She writes:

I think being in academia and having cancer was probably easier than some other jobs would have been, because of its flexibility, and because of the multiple people that can jump in and help.

The particular role supported Susan's experience by providing flexibility and a support system. She recognizes that not all work scenarios are as giving and as lenient. An hourly position or not having access to sick leave time would make the experiences of cancer much more strenuous for someone not salaried. This atmosphere definitely contributed to her circumstances of providing opportunities of various people being able to contribute and help.

As tenure track faculty, each of the women spoke about how they had to make adjustments to meet the expectations of the position. In maneuvering the structural aspects of this role, the following narratives explores how the women managed their experience of cancer in academia and the steps they took throughout the process. Several of the women spoke about making adjustments to class schedules and teaching appointments.

Susan shares how when she received her diagnosis how the institution responded to her circumstances and how she was able to manage her faculty commitments. She writes:

When we got back and I got diagnosed and treated, I had a reduced teaching load.

They covered my classes and committee work when we were gone to [cancer center], and helped out whenever I needed them to during my treatment.

This data speaks to the kind of help she had and the ways the institution and her colleagues provided support for her roles. Yet making the decisions as to how to manage all these aspects and still take care of the personal side of cancer in a professional setting was vital. Susan shares, the emotions and shakiness she felt in the classroom during the period in which she was receiving treatment:

I did teach a 1-hour course the semester I was getting my treatment (lumpectomy then brachytherapy) and I brought in guest speakers every class period (It was a Speaker Series class). I ended up getting teary-eyed and choked up every class meeting (clearly I was shaky emotionally).

Clearly going through treatment can be an emotional challenge and yet, we only see a glimpse of how treatment and teaching intersected. Barbara also shares how she was able to manage her classroom commitments while undergoing cancer treatment:

I had 2 classes and I got guest speakers to come in for me for 2.5 weeks and then I went back and taught classes until the end of term (3 more weeks).

The women were able to make their teaching schedule work by having speakers and colleagues contribute to their teaching commitments. Despite the many ways of juggling their responsibilities, the women shared how they were able to make it all work. Carolyn shares how she was able to manage a major surgery during the semester:

When I missed two weeks of class for my mastectomy, my one supportive colleague took over my class I told students I simply was unavailable, and most assumed I was at a conference.

Carolyn chose not to disclose to her class her illness. The extreme difference of her students thinking she is at a conference while in reality, Carolyn was having a mastectomy reveals the stark difference in perspective. The personal side of cancer is concealed while on the professional front, her class was completely unaware of what she was really encountering. It is hard to grasp the internal contrast of what this experience must have been like for Carolyn and the other women who also were in the same situations.

Classroom management, advising, research agendas and specific duties of tenure were also a part of these negotiations. The women had to make decisions regarding the tenure process, whether to stop the tenure clock for appraisal or continue despite dealing with cancer. The tenure process most often has a great deal of requirements within specific time limitations. The follow responses address how the women negotiated these structural aspects of the professional expectations. Barbara states:

I did not stop the tenure clock. I kept going... I had to for my son and to be sure to not blow tenure.

I think it is important to note here that Barbara expresses her determination to persist as to not 'blow tenure'. Yet the reality was she was dealing with cancer and all that consists of and still the process of tenure was significant enough to move through and not delay the process.

Gloria shares her experience, as others shared as well, of the uncertainty of the policies and procedures that directly impact the circumstances of having cancer while in academia:

When I was diagnosed, I chose not to stop my tenure clock. Part of this was because I was not sure if that could even happen considering that I was still on probationary status with the university and would not quality for the Family Medical Leave Act until my one-year anniversary.

Similar to Gloria, Carolyn mentions that she is uncertain about which policies and procedures were available to aid in such circumstances. She writes:

A \*very\* long story short: I didn't have a publication in the year following my diagnosis, and in that annual review letter, the Chair wrote that I was not making

adequate progress toward tenure. (It was my third year, when junior faculty get a special review.)

As Audre's narratives showed at the beginning of this chapter, Carolyn was also given an evaluation that referred to not making adequate progress towards tenure. In Carolyn's situation, her Chair did not know of her cancer diagnosis. Although she was dealing with these difficult circumstances of cancer, it was more important for her to preserve her privacy and not to share this information. However, Carolyn didn't feel her department to be a safe space and as the next narrative demonstrates, the pressure she felt was the only reason she eventually explained her situation. Carolyn's administrator apparently suspected something was affecting her. Carolyn wrote:

She made clear over a series of several meetings that she knew "something was up" and that if I didn't tell her so she could "advocate" for me, my contract would not be renewed. (What I didn't know then but I know now is that that never would have happened--the tenure and promotion documents are clear about established research trajectories, of which I had sufficient evidence. Therefore I never would have been let go because of one year without a publication).

As with Audre, Carolyn also speaks to having a Chair that was not supportive, which could help to explain her reasoning behind not wanting to share her diagnosis. It wasn't until later on in her tenure process that Carolyn was made aware of the details in the tenure and promotion documents. Carolyn clarifies that threats her Chair made regarding her contract not being renewed were unfounded. This information was not provided to her accurately and in fear and in an attempt to protect herself, Carolyn felt she had to share the information about her illness with her administrators. The narrative

suggests Carolyn may have felt betrayed and coerced into sharing information she would have preferred to keep private. Many of the women shared they were not aware of the policies and procedures available to them and instead, this made their situations more challenging. In reality, had they been given the correct information, it could have been beneficial to them. In a sense of desperation, Carolyn states:

I then told the Dean about my illness, and filed papers to officially stop the tenure clock so I could protect myself. It turns out I didn't need that extra time, as I've met and exceeded the baseline requirements for scholarship, which makes me confident for my tenure application (due next Fall).

Gloria also writes about having low numbers of publications and the results of not meeting the standards of expectations. When she realized she no longer wanted to stay at her institution, Gloria became aware of how having low publications might impact her marketability, she states:

Eventually, I realized that I didn't want to work at my institution anymore and started thinking about going on the market again. I soon realized that I had been meeting the expectations of my current institution, but that did not mean that I would be marketable or competitive to any other institution. I had little trouble getting on-campus interviews, but I soon realized that my low publication record affected my ability to get the offers.

Due to her challenges at her institution and her marketability, Gloria began to question and doubt herself:

I wasn't sure if I was a good scholar. I had a lot of doubt about that, especially because I didn't have much to show for it in terms of publications.

The low publications was in a sense a symbol affirming Gloria's productivity.

Not only were publications something administrators and academia used as a source of their professional worth, it also become a source of some of the women's own judgment of themselves. Specifically for Gloria publications were a reassurance she was indeed a good scholar.

The doubts that accompanied the low publications and the less than favorable appraisals were shared by several of the women. As for Audre, her painful and exposing experiences contributed to her decision not to pursue reappointment for her faculty position. Most significant about this decision was in how administrators contributed to not just Audre's experience, but those she witnessed having left the department:

My reappointment was derailed by cancer experiences and lack of support from administration. My annual performance appraisals were not as favorable during the cancer treatment and recovery as they had been. I was given an opportunity to extend the reappointment process but I felt that I was not supported during treatment and recovery and I did not see how this would change in the coming years if I were to extend the process. Cancer, the lack of support and observations of faculty who left our department to go on to other universities and lead exceptionally successful careers caused me to reevaluate the system and the suitability for me at the time.

Audre submitted a photo (See Figure 1) with the caption that said, "The link to the image I am including is a derailed train. My track to tenure was derailed and I was broken down through the process. You will note the somewhat passive observation of the train wreck."



Figure 1

The photovoice submission provided a powerful visual of how she was broken down in the process of her track to tenure; mostly her assessment was due to the lack of feeling administrative support in the process. Furthermore, Audre also experiences a variety of faculty incivility:

I experienced faculty incivility that has been well documented in university systems. It was this incivility that I both experienced on a personal level as well as witnessed that changed my views of the process... Other faculty could not be as supportive due to a fear of retaliation. I had observed junior faculty leave the department without support of faculty despite expressed disagreement with some of the administrative decisions.

The various dynamics of a department which fosters an unsupportive environment can be toxic on many levels. Twale and De Luca (2008) write about the culture of academic bullying in higher education and describe how the space of academia can be used to marginalize victims and sabotage their careers. Furthermore, Twale and De Luca (2008) suggested that the tenure process is a particular time in which academic bullying presents itself more prominently making the process even more difficult to maneuver.

Hostile environments accompanied by faculty incivility can contribute further to women's feelings of isolation and alienation in these circumstances. Audre dealt with some very unfortunate circumstances and brings awareness to the importance of a supportive department. In her narrative, Audre comments also about how other faculty could not be supportive for the fear of retaliation. Audre's photovoice submission (see Figure 2) caption states, "Cancer entered my professional life like a tornado wreaking havoc on my position as I knew it. Without the administrative support to recover from the storm, I reevaluated my position and place."



Figure 2

Audre provides a visual depiction of how cancer entered her life and left it in disarray. Unfortunately, these negative experiences were enough to clarify for her that a tenured faculty position was no longer her aspiration. Without the support of her professional system, even given the option of an extension, Audre no longer want to be a faculty member. She resigned:

I was later told that I could be given an extension for reappointment due to my illness. However, I had become so disenchanted with the processes during my illness and recovery that I chose not to take the offer and resigned from the position. It was not just my personal experiences that lead me to leave the

position, but also the shared experiences of some other colleagues around this time.

Audre never blatantly states it was having cancer that contributed to the incivility she experienced in her position; she suggests it was more of the lack of support she felt during the process having had to deal with cancer in addition to the tenure expectations. However, in other narrative data, several of the women were very clear in stating that despite academic expectations, they do not believe cancer played a role in tenure process. Susan shares how she addressed the review committee about her cancer, apparently drawing from the documents she submitted at the time:

I don't think it (cancer) impacted my RPT. I went up for Full Professor and referred to my cancer and my husband's in an introductory paragraph, so the reviewers could see why I didn't teach certain semesters, etc. I wrote, 'Since obtaining tenure, my contributions to the department/college/university have changed somewhat in that, since Spring 2010, I have led the Department in an undergraduate curriculum review and revision. During this time I was appointed Undergraduate Coordinator for the [location] campus. Concurrent with this, my husband received a [medical procedure] and I was his caregiver for 6 months in [city] and then upon our return to [city], at which time I was diagnosed and treated for my own cancer. During this period, although my teaching load was reduced at varying levels to accommodate both the administrative work and the family leave, I maintained my graduate advising and my research program and contributed to the work of the department in other ways.

Susan was very upfront about her experience with cancer in the Reappointment, Promotion, and Tenure (RPT) paperwork. She felt it important to explain why certain semesters were not as active as previous semesters might have been. Susan provided details into her personal circumstances while also highlighting administrative duties, advising appointments, and other commitments she continued to maintain.

Barbara also shared a similar sentiment that cancer did not play a role in her tenure process:

I do not think that the cancer played a role beyond my department in tenure considerations. I think the heart attack may have provided some level of sympathy, but I do not think either played a significant role in the end.

It is interesting here that although Barbara feels that cancer did not play a role in her tenure process, she does however mention that the heart attack evoked sympathy. Had there been an opportunity to follow up with the women, it would have been of interest to ask additional questions as to why Barbara felt the heart attack contributed to more sympathy than breast cancer. Based on previous discussions with colleagues who have gone through the experience, it is in my opinion breast cancer is a more difficult disease to know how best to address. Heart health is much safer to discuss. Breast cancer, however is often viewed as a gendered disease that might cause others more discomfort in knowing the best ways to approach and be supportive.

In a faculty role it is not just administrators that evaluate one's progress. An important structural aspect of faculty work pertains to being evaluated by the students. Each of the woman shared various narratives in how the students responded.

Student Responses: Empowering to Hurtful

The women taught undergraduate and graduate courses although most spoke more supportively of graduate students. The various aspects of the work of faculty and how students play into the dynamics of their positions is essential to take into consideration of how the women experienced their cancer diagnosis within their classrooms. Susan states:

My graduate students were very supportive, sympathetic, and understanding.

It became very evident the women shared an overall genuine tone as it pertains to the students. Both Susan and Barbara speak highly of their student's supportiveness. For example Barbara shares:

The students were great and did not hold it against me. They did not take advantage of me either. They did their work and were diligent in the two courses. I was grateful. My cancer was taken care of during summer and the radiation treatments into the fall meant I was not around a lot but they were forgiving.

Barbara's gratitude for cooperation and support is evident also in her submitted photovoice entry that shows her posed with students in cap and gowns. The caption said, "Here I am with the graduating class of 2010. They are the students who went through this experience with me so to speak."

Gloria also suggests her students showed support and expresses how much the things they did during her treatment were meaningful. She shares a sense of commonality with them since they started the program at the same time she started her position. During this time, there was a sense of connection and growth for Gloria and the students. Below Gloria shares her a speech she presented to her students:

When the first-year cohort graduated in 2010, they asked me to be the keynote speaker. Here is an excerpt:

Two years ago, we both applied to University and hoped to be accepted. I did not choose you and you did not choose me, but, goodness! How the universe conspired for us! Had we known all of the struggles we would endure. The doubt, the frustration, the anger, the miscommunication, the surprises, would we still have taken that step? If I had known what would come to pass 6 months after coming here, would I have taken this job? Dear students, there will be days when you will struggle. There will be days when you will say the wrong things to the wrong people. There will be days when you wonder if you have really done anything at all that served a need or created a change. On those days, and they will happen, I want you to be patient with yourself, with your colleagues, with your students. I want you to remember the people who walk with you tonight, the moments when you advocated for your fellow students, the times you asked a question that led us and the class down a better path. I want you to remember the days when just being present was a saving grace. Although you may think that you have not made a difference, know that you did in the smallest and kindest of ways, for you helped to save this profesora when she needed you the most. On those hardest of days, I want you to think of those moments and know that you are valued and loved. Always.

This touching excerpt of the parallels she shared with the cohort of students revealed the personal aspects of her growth, their generosity and more importantly, the role these students played in her life; serving a purpose when she needed them the most.

A tangible source of appraisal the women spoke about was course evaluations. Susan remembers a vivid example:

On the course evaluation, one student wrote, "Dr. \_\_\_\_\_ is crazy." However, another student, in answering a question that asked, "What is passion for a profession?" and she wrote, "Passion is teaching even when you are getting cancer treatments." That made me cry (ha ha).

Susan laughs at the irony of her evaluations and the continuum the evaluations encompass. Even with positive student evaluations, as with most circumstances, the harsh ones are more difficult to ingest as Carolyn states:

My course evaluations that semester were slightly lower than usual. I assume my low energy (which delayed the return of graded papers) and unplanned absence were, in part, responsible.

Carolyn attempts to justify possibly why her evaluations were a bit lower during that semester of her treatment even though her students were unaware of her circumstances. Although there was a great deal of effort on her part to maintain the normalcy of the classroom, Carolyn still dealt with balancing low energy and aspects necessary with caring for herself. This provides an example of a glimpse into the many aspects of maintaining a faculty role while having to balance a cancer diagnosis. The women were still human. Audre spoke to the cruel nature of the student responses from the evaluations:

Student comments from the end of the semester evaluations were a bit hurtful. A few students commented that people should not teach when they have cancer. I also received comments about my physical appearance indicating it was distracting and hard for them to look at me-there were comments about baldness. I was already bald at the beginning of the semester and I remember thinking after

reading the comments that I was glad I was already bald because it would have been more traumatic for them if they would have had to see me go through the hair loss.

The nature of the comments, particularly taking into consideration the dedication and effort in negotiating filling work commitments while also dealing with a life threatening disease, is saddening. Here Audre is doing everything she can to maintain some sense of normalcy by continue to teach and yet her efforts are darkened by student comments. Even in her narrative, Audre states being thankful for already being bald as having the students witness her hair loss would have been much more traumatic. Her care and concern doesn't even take herself into consideration, it is her students that she worries about. Although there were many challenges in being in a faculty positons with cancer, the women found a sense of comfort in the role and habits of their profession. "Focused Mode"

As faculty members, it became very evident in the data that the work the women were doing in their career echoed in how they researched, responded to, and asked questions about their cancer. Even the physical content of the narratives presented in the online journal were constructed in ways that reflected common behaviors of that of a faculty member. The submissions were beautifully constructed, organized and often without grammatical or spelling errors. Habits of writing were evident in their submissions. Some wrote of their research instincts kicking in when they learned of their diagnosis. Gloria comments here that her instincts of faculty work helped hers:

I don't know how it is for other women, but I went into a very focused mode after diagnosis. There were checklists and questions and organizing. There was still

teaching, especially because, unfortunately, I didn't have a real choice. According to my university, I was still on probation and so would not qualify for the family medical leave act until August 2009. Plus, I needed to keep my paycheck and medical insurance... As a researcher, I also started seeing patterns and learning a new language. ... There are ways to introduce yourself and label your diagnosis.

Gloria shares it was her research skills that are still readily available to make sense of the circumstances she is facing. After her diagnosis she went into what she calls "focused mode" and her practices of questioning as well as seeing patterns within her own experience was evident. Familiar habits she had become accustomed to within her work, was now adapted in her personal life and were ways of practice. Gloria also states, as a researcher she started to see patterns and learning a new language and how she began to introduce herself and label her diagnosis. As the women's narratives suggests in different ways, a cancer culture did begin to become clear in which learning the language and the labels and learning what their diagnosis meant were essential in how they confronted their cancer. Gloria describes as to how she dealt with her cancer as a faculty member:

For me, I was very calm and, in a very morbid way, curious. This would be the first time but not the last time that my research instinct would come into play and I have to say that being a faculty member was such an asset because I could critically observe and evaluate what was happening. I could ask questions in a detached way that would make it feel like and educational opportunity than what it actually was: sheer horror.

Here Gloria gives credit to her practices as a faculty member that she felt aided her during her cancer diagnosis. There is almost a sense of these skills providing a distraction or moreover a detached way of experiencing what she was going through by enacting another lens of seeing her circumstances.

Audre shares that her research skills however, were difficult to manage all the information she was generating:

I read endlessly about treatments and survival rates. This was not helpful and I cut myself off. I was not going to be one of the numbers.

Audre, however, shares how these habits of research and reading appeared to be overwhelming. The amount of research seemed to provide a dismal view that as Audre states, was not helpful. The comment regarding not wanting to be a number is a very strong point of what all that entailed.

Susan's photovoice submission caption stated, "I chose this photo because it shows me giving a seminar at [location]. The date is April 2011, so this was about 8 weeks after I received my radiation/brachytherapy treatment. It looks like I was doing fine. I did just "keep on going" through all the challenges. I love teaching and research so I imagine I was feeling glad to get back to it." Here Susan states getting back to teaching and research was imperative and yet she refers to the fact that she "looks like" she was doing fine which speaks to performances that might be different than that which was hidden beneath the surface.

"Uncancered Spaces": "Something Other Than Cancer"

The women wrote about wanting to have spaces in their lives where they were not reminded of cancer. In maintaining a balance, professionally as well as personally, the

women needed the spaces of support where cancer wasn't the main focus. Carolyn provides insight into the importance of continuing teaching and the necessity of having what she calls 'uncancered spaces':

What I want to emphasize here, however; is my firm belief that teaching through my treatment (as opposed to taking a leave of absence) played a significant role in my recovery. \*The classroom was the <u>only</u> uncancered space in my life\* I relished those hours each week when I was simply "Professor X" and not someone's sick daughter, or the bride that had to give up her wedding, or the receiver of the pity face or the heavily affected, "how <u>are</u> you? Or the patient in the infusion room.

Carolyn's statement is powerful to understanding the significance of the classroom for her as being that "uncancered" space in her life. She shares some of the spaces she has to confront the realities of her cancer continuously. Carolyn also states that teaching helped her recover from her cancer treatment. Standing in front of her classroom was safe and allowed her to continue the normalcy in her life. Normalcy and routine were also important to Susan:

Regarding the work I did long-distance with my graduate students (e.g., reading dissertation revisions), it was actually a relief sometimes to think about something other than CANCER.

Just having a space, as Susan states, for her work to provide the comfort of being involved or thinking about something other than cancer was significant. A very similar sentiment of the importance of being able to accomplish her faculty commitments without having to focus on cancer was good for Gloria. She shares:

I would teach and attend meetings and not focus so much on cancer, which was nice.

Some of these descriptions reflect the value of academic work during treatment and recovery, and higher education overall, for the participants. Audre's photovoice submission (see Figure 3) is captioned "I faced many roadblocks and challenges throughout my upbringing-too numerous and personal to convey all. I developed a sense of perseverance despite adversity. The university experience was a light at the end of a dark time in my life. It was the place where I learned that I wanted to help people overcome social, cultural and economic constraints. I wanted to be part of a path towards equality and better life by breaking down systems and structures that impose and support such obstacles".



Figure 3

While, for the most part, the women found motivation and a sense of stability in their faculty role, and as Audre shares, 'a light at the end of a dark time', Gloria speaks to the difficulties of being rejected for publications and how that played into feelings of

devastation during her treatment process. For Gloria doing the work as a researcher was important to continue but much more difficult:

Writing my research was a lot more difficult. There were 2 papers that I wrote during that time—both of which were rejected and it was really devastating because I felt that if I could be successful in getting something published during my treatment, that it would be a big slap in the face to cancer. But it didn't work out that way and I just barely resubmitted one of those articles this summer and have yet to look at the other one in 4 years.

Gloria speaks to how much she wanted to be able to prove a point to herself during her cancer that she was still capable to do the work effectively. She struggled when the articles were not approved. The statement she uses, that she wanted the acceptance so it "would be a big slap in the fact to cancer" is very striking. Despite all the energy and effort being put into the work as well as the personal aspects of cancer, Gloria wanted to feel as if she had a sense of cancer being beaten out of the space in which she hoped to find accomplishment.

There is an aspect of working diligently during such a crisis in a person's life, and yet when the work is not appreciated, there ensues an element of self-doubt and internalization that goes along with the process of feeling inadequate. Moving through a process of not only self-doubt but the continued stress of dealing with challenges can indeed take a toll. Gloria states directly that the struggles of being a faculty member contributed to her cancer:

I cannot say if I had had this mentality before cancer that maybe I could have prevented cancer from occurring, but I will say that I firmly believe that the

negative and trying experience I had during my first 6 months as a faculty member, the amount of stress I felt, the way I had to fight for every single thing I did and how I taught wore me down so much that I really do believe, without a shadow of a doubt, that the stress I felt triggered the cancer.

Gloria's bold statement is shared by many women who have shared their experiences with cancer. I have heard this comment anecdotally as well. Other narratives mention the idea that stress contributes to cancer, particularly women's fear of a cancer reoccurrence if their workload proves to be strenuous. Through all the narratives, the women shared the significance of, both the good and the bad, support systems and the relationships that contributed to their experiences.

# Recognition of Relationships in a Faculty Role

Theme 2: Connections for Preservation: Support, Comfort, and Reassessing
...my interactions with colleagues and administration were very positive and supportive
and allowed me not to worry about work, but rather focus on healing. -Susan

Previous discussions in this study have alluded to the importance of women's relationships. The work environment consisted of connections, or lack thereof, with colleagues and staff. An important aspect of the connections made, the women suggested, was the environment of the department, in part, because of the supportive nature of their colleagues. Barbara speaks of her colleagues being very supportive not only in her professional life but also within in her personal life:

My boss was the first person at my side after the heart attack in the hospital. The secretary went to pick up my son and take him to sleep over at a friend's house. I was home in 2 days. Never had so many well wishes from so many.

Susan also shares how her colleagues supported her after she received her diagnosis:

My colleagues were super supportive...I have friends at work and they texted and emailed and spoke with me on the phone whenever I wanted... I guess my interactions with colleagues and administration were very positive and supportive and allowed me not to worry about work, but rather focus on healing.

Susan says the support of her colleagues allowed her an opportunity to not worry about the details of work but rather, helped in ways that allowed her to focus on healing. I believe this to be very important statement and key to helping women deal with such circumstances as treatment from cancer.

Although Audre shared many experiences of an unsupportive environment, here she shares how colleagues did help along the way:

However, I did feel support from some of my colleagues. A few professors in the department offered to teach for me and help out in other ways. These were sincere gestures and I appreciated them so very much. I became very close to one faculty member during this time because of her genuine desire to help out. Later she expressed that I just looked so sick and tired that she thought I needed someone... At any rate, she was very right I was tired and I did need someone. We developed a beautiful friendship during this time.

Susan's photovoice submission was a photo of her and her research team which included four faculty members who have worked with her on a longitudinal study for more than five years. The team received an award shortly after she was treated for cancer. Susan's caption stated, "They were very understanding about what James and I were

going through, and kept the project running when I couldn't. I am close friends with them in addition to being colleagues. Their religious beliefs are quite divergent (two atheists, a Mormon, and a devout protestant), but they each expressed basically the same kind of love and wishes that they could help, and let me know they were sending up "prayers" or "positive thoughts" for us." The group picture was symbolic to her as it portrayed a diverse group of various backgrounds that came together and supported the same message of love and care for her during her time of need. The significance of these relationships being both professional and personal also came up in some of the other women's narratives. There seemed to be a great deal of trust in those the women called both friends and colleagues. Being able to focus on healing when she couldn't contribute to the research project was very important to Susan.

Barbara shares how her colleagues were supportive in a genuine way:

My colleagues were great, they would say you look tired or encourage me to be careful or go with them to yoga, and my chair asked someone else to be associate chair.

Barbara speaks to her colleagues being supportive and assisting when she was most in need. Being genuinely caring and being present was significant to Barbara. Barbara submitted a photo which she describes in the caption, "This is our Dean presenting me with my awards for excellence in mentoring and service. It was a proud moment!"

Being recognized for her work and service, Barbara shares how important this moment of honor was for her. Overall, the support of her Dean contributed to making

this experience so positive. Gloria shares how her colleagues contributed to being there when she needed them:

I had one good friend who was in the department but in a different program who lived in [the city] and knew how to get to [hospital]. She offered to go with me to take notes, which was a lifesaver in so many ways.

Gloria's colleague's offered to help by taking notes, and yet at the time, she did not realize how crucial this act would be. A small act of taking notes can be just as vital as being there to teach a course. The women wrote about how it was the little things that really made a big difference.

"The Little Things"

Throughout their experiences, the women each shared how much the support mattered. In a lot of ways, the women spoke more about the small, simple gestures that meant the most to them. Here Gloria shares acts her students contributed:

The students were incredibly generous and thoughtful. They kept their distance, but did small things that really made a difference. One student took charge and made the Dr. \_\_\_\_is my homegirl t-shirts and we raised at least \$1000 during my treatment that went to a local breast cancer group, which is fantastic. One student bought me a beautiful scarf from Qatar when he returned from the summer. The second year cohort sent me care packages every week with notes and fun gifts. I received cards and notes, flowers.

Similarly, Susan shares some of the things her department did to support her:

The department sent flowers and cards. My department head gave me a beautiful handmade silver necklace from Sundance that said "Heal." The university held a silent auction to help us with our medical expenses and raised \$10,000!

Although these were examples of the nice things that were done, they also display how being supportive and genuine in various ways really contributed to the women's experiences. Audre shares another example of small gestures that she remembers fondly:

Another colleague kept soft drinks in his fridge for me. I lost my taste for coffee during chemo and he would have a caffeinated beverage for me if I needed it. I didn't have to ask for it, he would invite me in for one.

Barbara also provides examples of how the small acts lead to a bigger meaning for her personally:

Everyone understood my situation and helped or just left me alone at times. Another secretary came and weeded my garden for me! Amazing. My colleagues came to the house with food (snacks I could no longer eat, but my son appreciated) and books.

Again, the genuine nature of her colleagues was most significant. The extra thought and care into what was important to Barbara, was what really mattered most. Audre speaks of her experience of random acts of kindness:

There were other random acts of kindness from colleagues during this time that I very much appreciated. Other colleagues would say "if there is anything I can do for you let me know". This was very well-intentioned but now, removed from treatment and recovery, I will say that in the midst of treatment it can be hard to know what you need. So, what I have learned since is that when my colleagues or

their family members are sick, I try to think of something to do for them-some random act or small gesture that may help in some way.

Audre shares that what she has learned from these experiences is the importance of intentionality and genuine consideration for others who are sick or need help in any way. Recognizing the significance of intentionality that plays in the grand scheme of the relationships was vital throughout the narratives.

"Negotiating Relationships": "Some Became Strained, Others Flourished"

Relationships were at the core of most of the women's narratives. Various levels of relationships, new and longstanding, close and strained, were discussed and praised. This point aligns with the literature in varied ways. Jordan (1997) suggests, the "deepest sense of one's being is continuously formed in connection with others" (p. 15). Kayser et al. (1999) continue by stressing that mutually, supportive relationships are important given that "a women's ability to function in other aspects of her life (work, community, parenting tasks) has been compromised" (p. 734).

Jean Baker Miller's (1987) Relational Cultural Theory suggests that women's sense of self is conceptualized as "being in relation" and a women's identity includes identifying the feelings of another as well as to recognize her own feelings. Kayser et al. (1999) discuss the importance of relationship factors of women coping with cancer.

When dealing with a serious illness such as cancer, women, according to their study, find it important to feel they are fully participating in their close relationships.

A women's connection with those close to her contribute to her attitude and approach to cancer while also helping to develop a stronger sense of well-being. For example, Carolyn shared how her relationships changed as a result of her cancer:

Relationships with friends and family shifted (some became strained, others flourished), while my partner and I grew closer.

As the women evolved internally when dealing with cancer, so did their relationships with others. As Carolyn shared, there was a reassessment following the diagnosis and treatment that allowed the women to examine their relationships and their importance. Gloria explicitly addressed negative relationships that she severed:

I was tired of dealing with little issues that didn't matter in the bigger scheme of things, so I started severing ties with negative people, friends, who couldn't deal with my cancer, family who said the most horrid things to my parents-that God had planned this because we weren't 'saved'. Ugly.

Several narratives mention the importance of severing relationships that were negative or unhealthy, as if there was simply no time to waste with extraneous or negative energy. Women stressed how important it was to have positive, supportive people throughout their experience. The challenges of dealing with different aspects of cancer often strained relationships during their most difficult times. Women reported that fostering the connections to people around them was important and in some situations, were relied on. There often were strains on relationships during their most difficult times.

Families and significant others were discussed in the narratives regarding the changes in relationships and role adjustment within their family. Audre shares how her cancer impacted her role as a care-giver for her young son and how he was deeply affected by witnessing her illness. Her comments reveal a sense of guilt for exposing him

to her experience with cancer and its treatment as well as the change in roles of him taking care of her; these experiences weigh heavy in her words. Audre shares:

After chemo, I usually had 1 fairly decent day and would then be down for the weekend. I seldom emerged from my room over the weekend. My husband cared for our son through the weekend while I got better...At home after treatment, my preschooler began to care for me. What a horrible change of roles. Tremendous guilt also accompanied my illness. I felt guilty that my son and husband had to see me go through this. This was not my role. I was the care-giver, that had always been my role. I had always felt I was strong, I was the rock but I came to rely a lot on my husband during these times. Both of our families lived states away and we did not have a lot of in-house support. We did have family and friends visit and help out throughout the duration but it was mostly just our family of 3. There was so much more to cancer than just getting better.

Audre shares her feelings of guilt for her strained relationships and roles within her family. She reveals that she is to be the care-giver, the rock, and now was having to rely much more on her family. Sulik (2007) states negotiation of roles and asking for help is necessary "to protect important relationships from the burden of care work, many women prefer to rely on themselves and their own resources instead" (p. 873).

Audre's photovoice submission, Figure 4, is captioned, "On the personal side of cancer, it was a season of change. My role in the family changed, my body changed, my mind changed. At times there was a feeling of extreme loss as trees lose their leaves while at times my family, friends, and support from patients filled my heart and soul with loving warmth just as the sun shines on autumn leaves in early fall."



Figure 4

Here Audre shares her feeling and thoughts about how things changed, not just her role in the family, which in itself is very significant, but also her body and her mind. In one segment of this caption there is a feeling of great loss and yet in the end, there is a sense of resilience and appreciation for those who supported her the most.

Gloria shares how her friends supported her and how they volunteer to take turns to help:

And then, my friend [name] organized "Team Gloria" and 5 of my friends took turns flying to [state] to be with me during my chemo weeks after my parents left.

In her narratives, Gloria speaks to the importance of her parental support as well as friends who were there for her. Although mentioned previously, it was also difficult to rely on others and being vulnerable was not easy, but she also was very aware her self-care was of a greater importance.

Cancer Culture

Throughout the responses, there was an overarching theme of speaking of their experiences that was very intimate in terms of how they approached their diagnosis.

Some of the participants discussed the loneliness and isolation yet also the connections made with other women in the chemo room, support groups, and other spaces affected by cancer. In *Cancer Journal*, Lorde (1980) states "There is a commonality of isolation and painful reassessment which is shared by all women with breast cancer, whether this commonality is recognized or not" (p. 10). Gloria's comments seem to echo Lorde's in this regard:

I also knew that, even though my friends and family were with me on this journey that only people who had gone through it would completely understand.

There is something to say about being able to relate to the experiences as Gloria states:

Breast cancer has a culture that, unless you're in it, you don't know about it.

There is a sense of understanding that comes with being entrenched with the culture of breast cancer. As the researcher, learning the terminologies relating to diagnoses, treatment options, reconstruction and plastic surgery, were all important to understanding the culture that Gloria and Audre mentions.

Part of this cancer culture is the familiarity of those who have had previous experiences of cancer. Those who have had past experiences with cancer, whether personally or someone close to them, tend to be more empathetic. Having been part of a cancer culture, provided a sense of support in being able to relate to some extent. Susan mentions:

...there have been many women in my college with breast cancer--in fact, our young department head from a few years ago died because of breast cancer--so it's something that people are sort of used to dealing with and talking about. I had been the Captain of our departments Relay for Life team for several years (before I had cancer), in fact. So it wasn't something that needed to be hidden or that made people uncomfortable.

Having worked in an environment that had previously been impacted by cancer, potentially contributing to a more positive atmosphere. She adds that because of the history of breast cancer in the department, people were less likely to feel uncomfortable.

In contrast, Gloria shares in her current institution she has not shared with her department she had cancer. However, the former department chair did know:

Not everyone in the department knows about my diagnosis and I am okay not sharing that with them. My program knows and the former dept. chair (a cancer survivor as well) knows. At this point, my cancer should not be a factor in tenure and promotion, but we'll see.

Although she doesn't go into detail, Gloria mentions the former department chair was a cancer survivor as well. Perhaps the commonality of the culture of cancer was shared in order to provide the opportunity to be safe. Not only does the culture of cancer provide a space of understanding it also allows a support system by those who have experienced such circumstances.

Barbara share's the secretary's personal family experience:

The secretary at work had a 28 year old daughter going in for a double mastectomy. And then a re-occurrence thereafter!!! She was really supportive.

Barbara brings up the unfortunate situation many face of the re-occurrence of cancer. This is sadly not uncommon. Audre speaks to her experiences of what she titled the "come back club":

For so many patients it was not their first diagnosis but for most they approached the treatment with a sense of hope and inspired others of us to endure. I did not know it at the time, but I would also join the come back club. It came back 7 years later, but that is another story.

Audre alludes to the "come back club" and although she didn't know at the time, she later would also have her cancer reoccur. She ends this narrative with "but that is another story" and doesn't divulge further about the situation. Had the opportunity to delve deeper into the narratives, it would have been interesting to ask why Audre chose to not speak more to the "come back club" circumstances.

Gloria, through the encouragement of others and knowing the importance of being able to relate to others who understood this culture, joins a breast cancer support group.

She states:

So I decided to join a local support group and that is where I met one of my dearest friends: Nicky. She was 35 when she was diagnosed and a grad student at the university. I met her right as she was finishing up her chemo. There are no accidents. God put her in my life on purpose. I mean, in this support group, we were the only ones under 40, we were academics, we were Catholic, AND we lived just down the street from each other! How crazy! There is no way this was a coincidence. I was so grateful to meet her because she was honest and raw and was much more angry than I was. She also went through things one step ahead of

me, so it was helpful to see that, although visiting her after her bilateral mastectomy was a bad idea. The diagnosis led me on a path that was far better than anything I could have imagined on my own. Yes, it would have been preferable not to have to deal with this, but I knew there were things that were meant for me to do with this diagnosis. So, I had the chance to support my friend, Nicky, who taught me how to cook using organic products and from scratch.

Gloria's comment relating to relationships formed from her diagnosis leading her down a path that was better than what she imagined on her own, is similar to a quote from Lorde (1980) where she states, "I would never have chosen this path, but I am very glad to be who I am, here" (p. 77). Neither, I would suggest, are stating they are grateful for their diagnosis but rather are suggesting that since they have had this experience, they are finding gratitude in who they are and who they have had in their lives through the journey. As Audre and Gloria share, there is a connection of those who spoke the same language; a whole culture that you can only really know if you are in it. The relationships helped the women find some understanding in their diagnosis.

# Comfort in the Treatment Room

Not only did the women rely on existing relationships with family and friends, but there were incidents the women wrote about involving other women going through treatment who they became connected with. In various narratives, the women stated the importance of connecting to others that had experienced cancer as well. Being able to relate to others while receiving treatment seemed to be very significant in regards to sharing and receiving support, as Gloria writes:

During my first chemo treatment, there was a woman sitting across from us who was very kind and understanding. She had a port and was able to easily move around. She sat next to me and told me her story. Her name was April and she had kids and a husband in the military. She had stage 4 cancer. We became Facebook friends and she informed me about head scarves and wigs. She would be the first person I knew who would die from the disease. How grateful I was to know her for at least a while. She helped me cope on that first day.

Not only were the connections with other women going through similar situations significant, women learned from them. Gloria shares her friend April was the first person she would know to die from cancer, with little else about how this impacted her other than her gratitude to know her for a while. Those who wrote about meeting other women shared how these women contributed to helping them through their process of treatment or at some segment of their cancer experience, as Audre shares:

When I went to chemo, I enjoyed the company of the fellow cancer patients. One of my favorites called herself "short, fat and sassy". She was in for her 3rd bout which made me realize how vulnerable I was and would be. She was a light hearted mother who talked, laughed and cared. I still quite vividly remember her stories. I really enjoyed and looked to the companionship of fellow patients. It was a place of shared understanding—we spoke the same language—we didn't have to explain anything to each other or answer questions. We were there for the same reason to get better.

Audre can reflect back on her experiences in the treatment room to provide her with a sense of understanding and companionship – experiences she still appreciates.

Living for others and for the future

One of the primary commonalities emerging from the narratives was how the women connecting their life, or dealing with the threat of their life, to wanting to live to be able to see the future. The concept of the future was not based on their own personal perspective but more for the purpose of their families and their role in their family. A cancer diagnosis seemed to give the women a sense of renewed perspective in looking toward the future that was different or more significant from their previous viewpoint. This approach promoted an attitude of positivity, less stress and a reevaluation of what was important to them. Women expressed that living for their children, spouse, and their family was more significant than just for their own sake. The need to live for the future generations rather for their own personal purpose was evident in their responses and a sense of being grateful was prominent as well.

Audre shares the importance of getting through treatment for others as well. The reasons she provides in this excerpt are solely reflecting on her husband and her son and the future she looks forward to with both of them - her vision of the future:

I was me, healthy (except for the cancer) with a child to care for and husband to grow old with. I needed to focus on starting treatment and get through it...I approached treatment plans with extreme fear and also verve. I was ready to get started, to move on, to live for my child. I wanted to see him grow up, drive a car, go on his first date, graduate, get married, and I wanted to be a grandma. I cried endlessly thinking of the possibility of not seeing him do these things.

The possibility of not being able to see her son reach his future milestones in life was a fearful experience for Audre. As for any parent, Audre was passionate in wanting

to live to see her son grow up. Her future and life's purpose became the motivator through her cancer.

Gloria, in time of uncertainty, waiting to hear a diagnosis, shares her worry mostly for her parents' sake. Gloria's concerns were not about the circumstances of the actual procedure but more in how her parents felt about the ordeal. This echoes that during their cancer diagnosis, most of the women focused on the care and compassion for their family during their most challenging times rather than focusing on their own feelings and thoughts concerning themselves.

Gloria imagined her parents' reaction as she picked up the phone to tell them what was happening:

As they prepared for the biopsy, I called my parents to inform them that I was going to get the biopsy. I can't even begin to imagine what the news must have felt like for my parents.

Susan shares her experiences, interwoven with the experience of her husband also having cancer. In much of her narratives, she focuses on having her cancer as somewhat secondary to her husband's:

Because my husband's illness and treatment were so much more serious than mine, I think I kind of minimized my experience....I had already learned so many lessons from James' cancer, mine just seemed like "one more thing to deal with". When I tell "our story" to people, sometimes I forget to mention that I had cancer, too!

The experiences of having cancer alongside one's spouse created distressing circumstances for the family as a whole. In discussing her husband's cancer, Susan

comments about the difficulty of having to tell the news to her daughter. The challenge of having had one parent endure such a life altering experience, then to be faced with having to contemplate two parents with cancer is unfathomable to imagine how extremely difficult this must have been:

It was hard to believe that my husband and I both had cancer at the same time! It was especially hard to tell my daughter. She got tears in her eyes and said, "I thought things were going to get back to normal."

Gloria's photovoice submission (Figure 5) provides a visual depiction of living for the future. As a caption to the photo she states:

This is my graduation from [university]. My niece is holding my hand. So much of my work is about paving the trail for other Latina/o children. You can see how long my hair was. Less than one year later, I would have cancer.



Figure 5

One of Barbara's photovoice submission is a picture of her and her son, both smiling, sitting amongst pumpkins and gourds. In the caption she states:

This is taken in fall 2009 after recovery from the 'final' lumpectomy, before sending my son to boarding school and taking my Mom in to live with me, and 3 years into my assistant professor position at [university]. We did not do vacations or other fun things often, I worked weekends and he had lots of sports activities, but this was one of the few things we did outside of the normal...It's a fond memory.

This fond memory, shared with her son, was cherished as a rare moment. And despite all of the circumstances that were involved, Barbara gives a glimpse into their complicated schedules so the rare moments shared together were greatly appreciated.

The importance of family is evident in other photographs as well. Susan's photovoice submission was of her family at her son's college graduation. In the caption she states:

I chose this because I remember thinking, 'What would this be like for me if James had died?' 'What would it be like for them if I had died?' I don't usually think that way, but I just felt so strongly how our lives could have easily tipped the other direction. Life is so fragile, I just try to hold it gently in my hands and look on in awe.

Beautifully poetic, Susan shares her vision of the fragility of life; how it must be held gently and how it is important to look toward its future in awe. This finding speaks to how the women found a sense of their purpose and drive from those they loved in wanting to be there for them and their loved ones future.

#### Control and Boundaries

Boundaries are part of the balancing act. Sulik (2007) describes that a woman who has been diagnosed with breast cancer has to negotiate her own needs as well as the needs of others. This balancing act Sulik suggests, "...is both a process of resocialization and problem-focused strategy" that help women dealing with an illness exercise a sense of control under circumstances in which they, otherwise, feel they have very little control. Barbara speaks about her son being taken care of if something happened to her. She felt a sense of control, yet her uncertainty of the future was concerning.

It was stressful and busy all the same but I put my son in a boarding school so that if I died again suddenly, he would be taken care of. I felt in control, but not knowing what was around the corner.

Barbara shares this important aspect not knowing what is around the corner yet wanting to have some sense of control. More significantly, her response of having to be prepared in case she died is quite striking. Having a system in place to care for her son in the event that she suffered another heart attack would seem to be a difficult task to come to terms with. Yet, it was the control in which she needed to maintain in a time of such uncertainty. Many of the women shared how, in their best efforts, they tried to maintain a sense of control in their situations and including their schedules. This was particular in scheduling their treatments, Carolyn states:

I scheduled chemo on Fridays so I had the weekends to recover.

In a similar sentiment, Audre shares:

Emotions were heavy and physical strength waned through the days of treatment.

I scheduled my chemo on Thursday so I would not have to miss much work.

Audre mentions here the balance of keeping work a priority and both Carolyn and Audre mention allowing recovery time on the days they would not miss work.

Scheduling weekends to recoup from chemo treatments, also meant precious time away from family, Audre later shares. As mentioned previously, it was very important to continue to work and for the most part for many of the women became a priority, as Gloria shares:

One thing that was essential to me was to keep my professional work life separate from what I was going through. I didn't go to the office every day, but I had planned it out so that I could spend half of the week at school and half of the week recuperating from chemo.

Scheduling treatment to still allow commitments to her professional life was also important to Gloria. It was essential to be present for work and professional commitments while allowing the weekends, their time, to recuperate.

In the interests of maintaining control, women chose to set boundaries for themselves, their work, and the people that were in their lives. Gloria emphasizes balance and boundaries:

I'm not sure how one maintains balance in regular life and I can't say I learned much about balance during cancer, but what I did learn was the importance of boundaries. I was not interested in going into hiding during treatment. I was just going to be, to live, to survive.

In continuing the conversation regarding boundaries, Gloria shares how there were situations that she felt were essential to keep others at a distance. Here she shares a specific incident that demonstrates the importance of her reasoning:

Boundaries were really important to me. I kept my colleagues at a distance throughout my treatment. At one point, some had offered to drive me to [the city] and I just wanted none of that. I didn't want them to see me vulnerable. I did not trust that they had the best of intentions for me. I felt that some used my cancer as a way to display their own emotions and shine the spotlight on them. One example in particular still gets to me. The students had organized a team for Relay for Life and I decided to visit them for the opening ceremony. I didn't realize that the survivors would have to walk around the track and then walk with their families/friends/supporters. My parents were staying with me, but they didn't want to go. They had heard plenty about my colleagues and wanted nothing to do with them. So I went by myself and then had to take this walk and I remember being so sad about even walking around the track and then the faculty started walking with me and I thought, "What hypocrites. Just a few weeks ago you were ready to throw me under the bus because of changes I was making. You went out of your way to make me feel marginalized and here you are, taking the spotlight." Yes, I was bitter about that. So I made sure that even when my parents left that they would not get within 10ft of my cancer.

In the efforts of maintaining a sense of control, it was important for Gloria as well as many of the women to set boundaries. Gloria's personal space was not shared with many of her faculty colleagues and as she notes she didn't want them to see her vulnerable. Boundaries were very important in setting particularly with the individuals whom Gloria did not trust and felt were insincere hypocrites.

Reassessing and prioritizing

The women's narratives spoke to the reassessment of what matter most or what was imperative to them and how their diagnosis influenced, in part, their change of meaning. One of the primary lessons the women describe in their narratives was the awareness of what was most significant in their lives and reprioritizing their time and efforts. Mishler (1999) states, "As we access and make sense of events and experiences in our pasts and how they are related to our current selves, we change their meanings" (p. 5). An aspect of the women's narratives that supports the women's view of living for the future that came up was the concept of changing perspectives - a reanalysis of priorities of what mattered the most. The women all stated their diagnosis called for an examination of their lives and how they were currently living them. Gloria writes about how relationships change and how seeing the world changes:

For a good 6-8 months I was just living or striving to live and that puts everything else to the side. But the reality is that problems that you had before cancer are going to come back to you after treatment is over. The adjustment to actually living is difficult because you have just been trying to survive for so long. It was easy to sever ties when I was going through chemo - having any semblance of control is important during that time. But there are consequences for that, ways of looking at the world that change. One thing I knew for sure was that I wanted to leave [state of residence].

Here Gloria mentions how stressful her work environment was at the time of her diagnosis. Changing her environment was an important choice she made to not allow the pressure to trigger the disease or even to make life better. Changing for her health was vital. Barbara also changed her daily routine to reflect a healthy lifestyle. Barbara's heart

attack proved to be very disruptive and the need to be in control of caring for herself was essential:

The heart attack was frankly a bigger deal, but I was weak and exhausted and did not do much other than teach and take care of myself. But I made a good recovery on both fronts...So it scared me but the heart attack was so much more disruptive and required and requires major lifestyle changes. I have cut out sugar and I am on again off again with exercise but this needs to be a bigger part of my life.

In the reassessing and changing priorities, Gloria begins to examine her profession, and what was her 'normal':

The transition after treatment was very difficult. I couldn't return to what was normal. The "new normal" was a very unproductive space where I often wondered if my job had any meaning and would really matter.

The challenges of treatment, both mentally and physically took a toll on many of the women. Here Gloria shares questioning her job and its meaning as she felt she had been occupying an unproductive space and doing her best to know what is her normal. Audre shares how her diagnosis personally affected her and continues do so:

Reassessing and prioritizing importance of friends was the real motivation.

I began rethinking life and my place in it. I began to reassess what was important....I didn't know exactly what I was in for but I was ready to start something, please...I must say the diagnosis continues to affect me personally several years later—it began my realignment with life and what is important. I am still being influenced years later. I continue to re-

prioritize as a result. I used to stay late into the night in my office. I realized the insignificance of those hours, how insignificant (the) position was and is, how much my life beat depends on the love and support of family, friends and contribution through real action.

Audre in this statement echoes Audre Lorde as they both discuss the transformation of silence into language and action. Lorde (1980) states, "In the transformation of silence into language and action, it is vitally necessary for each one of us to establish or examine her function in that transformation, and to recognize her role as vital within that transformation" (p. 22). Audre reevaluated all those long hours and her position, recognizing the love of friends and family and using her life to contribute to real action. While some of the women were reassessing their positions and its work, Gloria shares how she was attempting to do what she was expected to do yet the treatment and after effects contributed to prohibiting progress:

I did manage to present papers and work on manuscripts after treatment, but it was very difficult to focus while going through treatment. As many survivors share, there is "chemo brain". It is real and sometimes I feel like I still have it...

Gloria provides insight into the difficulties of transition back to work and the challenges and aftereffects of chemotherapy called "chemo brain". The difficulties in concentrating and focusing as chemo brain has been discussed by those who have experienced cancer as a real effect but has only recently begun being studied (Boykoff, et al., 2009). Despite the fact the not all of the women vocalized chemo brain, many did share characteristics that were similar to effects. Although aspects of cancer hindered the

women in many ways, their narratives gave insight to how they personally provided visibility and vocalized their experiences.

### Giving Voice and Visibility to the Personal Experiences of Cancer

Theme 3: Expressing Cancer: Laughter, Fears, and Sharing

I wanted to be sad so I would cry by myself at night. I wanted to be positive, so I was cheerful and humorous when I was at work. -Gloria

This theme pertains to how the women handled the personal side of cancer with voice and visibility. In an attempt to get through their diagnosis and treatment, many of the women voiced their experiences by writing about the little things that mattered, creating rituals, creative writing outlets, and humor to deal with their situations. In being visible with their diagnosis, the women actively participated in spaces that helped them process their situation. For example, Gloria mentioned in a previous quote she joined a breast cancer support group. She also discusses joining a dragon boat racing team made up of breast cancer survivors. "It was good exercise, it got me outdoors, it got me to build my upper-body strength which is still weak." This experience also led to her being involved in a project about triple negative breast cancer and the boat team. Gloria was a keynote speaker for her sorority's national convention that raised money for breast cancer awareness as well as helped her students through the death of another student due to leukemia. Many of these approaches were personal to taking care of self while many of the women spoke of ways in which they approached voicing their experience with cancer. Voicing with Humor

Many of the women shared a similar sentiment that handling their circumstances with humor was essential, as Gloria states:

I think that, because I approached my diagnosis with humor and optimism –folks on campus were pretty supportive and just let me teach.

Gloria's statement is a good example of the front stage performances of humor and positivity "of a desirable self to preserve "face" in situations of difficulty" (Riessman, 2002, p. 701). She continues with similar sentiment in sharing her performances between night and day:

Even telling this story, you can see the ebb and flow of pain and sorrow coupled with humor. And that's what you have to do...It is so hard to face the realities, the horrors that you're experiencing, but I was not to be in denial too much anyway. I wanted to be informed so there were times I was detached. I wanted to be sad so I would cry by myself at night. I wanted to be positive, so I was cheerful and humorous when I was at work.

Gloria shares how important it was to be realistic but yet, needing to be in the back stage, emotionally real, while presenting herself at work to be a person who was humorous and cheerful. Susan shares her recipe of handling her husband's illness and the difficult situations with laugher and friends:

I used the things I learned/leaned on when James became ill: Reliance on friends, being open to help; optimism and focusing on the positive; laughing every day; talking and texting and crying with friends; being honest about what was happening; reading some devotional piece every day and praying; running; listening to music; thinking about people besides me; being grateful for the good things. Big 3: Optimism, Gratitude, Friendship.

Susan expresses here the various aspects of personally dealing with cancer such as being positive, humor, friends, and gratitude while also engaging in running and listening to music. During Susan's husband illness, she mentions the importance of being the image that she hopes he would be remembering her by:

Then I realized, if he dies, I don't want his last weeks to be with me as a scared person; I want his last weeks to be with me like I usually am, happy and content and funny.

Using laughter and humor were coping mechanisms to handle and approach cancer. This was, in some sense a protective measure of handling the heaviness of dealing with cancer while also a preservation mask of what lied underneath.

### Renaming

Another important aspect for the women they wrote about was the significance of using renaming terms. As mentioned previously, there is a culture with cancer and terms and language that come with being in it. For the women, changing the names of certain aspects were significant. Susan explains:

We had adopted this pattern of naming everything as a positive term rather than a negative...When we had cancer, we called the chemotherapy drugs (which most people called "poison") "the healing liquid".

Susan incorporated positivity in the harsh nature of cancer which helps to demonstrate how women construct their own personal ways of managing the experiences of their lives being altered by the disease. Gloria here shares how important it was to change the language that was associated with cancer:

I didn't like talking about breast cancer all the time, so I created nicknames so that if people didn't know I had cancer (aside from the headwrap), I wouldn't have to talk about it. My cancer was called "Bunny Chacon". I have no idea where I came up with this name, but it was funny and I could use it as imagery to fight the cancer. She also had invited her boyfriend, "Benny Chavez" (my other primary) to set up house in my body.

Naming was also something of importance to the women and to many who have encountered similar circumstances. Creating nicknames was significant to not have to talk about cancer specifically. Language and labels were important to maintaining positivity and add an additional layer to remove the concept of cancer in their daily language. As Raz (1999) suggests, "Metaphors can help us to understand experiences alien and unfamiliar in our lives. But metaphors also can be used to simplify complex ideas or express and perpetuate common assumptions" (p. x).

Susan's photovoice submission (see Figure 6) is an example of a visual she would use to help her find a space to calm her and remind her of things that meant something.

Her caption read:

This is a photo of my Happy Place. I would look at it and do relaxation breathing and visualization when I felt I needed to calm down. I liked the photo for many reasons, including the seat (it looks like the ones in my grandparents' front yard when I was little, the dog (looks like mine), the hills (reminds me of [state]), and the green, which seems fresh and cool.



Figure 6

Not only was it important to change the narratives to language they found most fitting, many of the women wanted to be in control of how they told their stories. Many chose methods that helped to speak to their experiences. Here Carolyn describes how she managed and found voice and visibility:

I established a blog and wrote regularly to help me: 1) process my experience and feelings, 2) frame for my readers (select friends) how I wanted to narrate my cancer experience (e.g., please don't call me a "survivor"), 3) learn about and push back against the "Pink Ribbon Movement" and the larger social expectations that promote positivity and shame non-normative breast cancer experiences. I suppose this helped me maintain "balance," in that the blog gave me a sense of control over an otherwise chaotic life event.

Carolyn stresses educating others and using a blog to voice her cancer to employ political agency and control of her experience. The rhetoric surrounding breast cancer

discourses were significant to Carolyn to acknowledge and confront with those who read her blog. Ehrenreich (2001), a strong critic of the pink ribbon movement, shares much of the sentiment in Carolyn's statement. The concept of being a fighter or using the war rhetoric assumes that there are winners and losers and those who did not win somehow did not fight hard enough. "The mindless triumphalism of 'survivorhood' denigrates the dead and the dying. Did we who live 'fight' harder that those who've died? Can we claim to be 'braver,' better, people than the dead?" Ehrenreich asks (p. 53). Garrison (2007) adds that the "war" rhetoric can also lead to the mentality of the public viewing women as passive victims who must rely on the paternalistic "medical professionals as infallible heroes" in the medicine-as-warfare cultural context (p.1). Garrison continues by saying "Just as the stigma of breast cancer itself once silenced women, today's prescription of "healthy" language can be just as silencing leaving many women without a validated means of expressing their experiences." Carolyn's approach to her blog was to make certain she called attention to realities of the breast cancer rhetoric and she used the platform of her blog to not be silenced.

Gloria also found a blog a significant tool. Gloria mentions the pressure that comes with keeping others informed.

I also thought it would be easier to have a blog to keep folks informed rather than having people ask me every day how I was doing. Because people really don't want to know. They think they want to know, but there is this pressure to try to be positive and any sense of negative thought or anxiety is difficult for people to deal with. So, I would update students, faculty, and friends through a carepages site.

Gloria makes a point that the research speaks to the idea that writing about illness can provide a release to the present experience and, as Pennebaker (2000) would suggest, physical and mental health improvement, she states:

And the writing was really a life saver because I could just type out all of my anxiety and then polish it up for the folks who would read my blog posts.

Here the reader can sense how Gloria used her writing as agency to release her anxiety. She mentions how writing in that way was a life saver. Utilizing a blog to express herself and yet inform others about her experiences was instrumental to processing and making sense of her situation. Not only was it important to express herself for others, it was also important for Gloria to express things for herself:

In my house, I had a cork board near the kitchen that was filled with cards and letters, medical bracelets for every round of chemo, dried flowers, pictures. It was really a beautiful wall of love that I could look at from time to time and think, 'Wow, I am loved'.

The mementos and tokens of her experience served for Gloria a purpose to show her, in times of need and reflection, she had people who cared a great deal for her. Gloria submitted a photovoice with the caption:

I am getting ready for chemo, wearing my cancer couture (as I called it). My eyebrows are painted on." She describes the "cancer couture" consisting of t-shirts made by her students and says, "I would wear this outfit to chemo every time I went and had my friends wear the t-shirt as well. So I would go with my t-shirt, a sweater (because the chemo is kept in a refrigerator and is very cold when injected), jeans, and my low-top Chuck Taylors. I wore big earrings and a pink

bracelet that said "La Profesora" which students and friends also wore." The consistency and meaning behind the details of what reminded her of her personality, style, what was important to her was evident in this narrative.

Susan's photovoice submission, (see Figure 7), reiterates the importance of positive terminology and using humor throughout her experience. Her description of the photo states:

After James got the transplant, we had to rent a little house—he had to be 10 minutes from the hospital at all times for 100 days...So we called the rental house 'the healing cottage.' It was kind of a joke and kind of serious. Anyway, James' brother would always forget what we called it, and one time he said, 'Are you guys going back to the Love Shack—is that what it's called?' So we changed the name to that, and then I found this sign at the hospital gift shop. When we came back home, and I got cancer, we hung the sign on our door. Obviously I chose it because 'love saw us through'.



Figure 7

# Voicing Gratitude

Throughout the narratives, the women framed their processing in terms of gratitude, never towards having the cancer, but in finding good or appreciation of the positives in circumstances that can be so negative.

Once Gloria received her diagnosis, she describes going home and composing an email to her friends and family. An excerpt of this email, describes her gratitude:

...I am so grateful that the lump hurt and bothered me enough to do something about it.

I am so grateful that I have a good job with health insurance.

I am so grateful that I am only a few hours away from a really great cancer institute.

I am so grateful that I can send this email to you and, without hesitation, know that you will pray for me and support me.

If you could keep this private, I would greatly appreciate it.

Despite the horrid news, Gloria was able to find gratitude in a variety of aspects of her life during these challenging experiences. It was important to inform her friends and family and at the same time be reassured to know she would be supported. Susan shares her gratitude for the years and time she has shared with her husband:

I also realized that we'd been together for 32 years and that was longer than most people had, and so I focused on being grateful for those years, and if it ended, I still had those years; anything on top of that was extra, more than anyone should expect. So every day now feels like a bonus prize.

Susan's narrative tells the importance of being grateful also for the relationships she had with her husband and how significant she felt it was for him to see her happy.

She cherished the days and valued the memories she and her husband had created.

Audre shared her gratitude for what she had. Despite all the unfortunate circumstances, things could always be worse:

Through many life events, I have endured, I always felt fortunate. I knew others had it much worse, that I should be thankful for what I had. I had a job, leave, health insurance and was receiving treatment. I had a husband who loved me infinitely and a son who I adored. I had cancer but through it all I knew things could be worse and focusing on my good fortune helped me get through it. I was extremely optimistic that I would make it. I had to. I wanted to be there for my son. I would give it my absolute all for him.

This voice of gratitude shared by Audre displays her overall outlook of positivity in which she lives her life. The gratitude evident in the narratives displays the women's appreciation and belief that things could be worse. Barbara states her gratitude and feelings of positivity in terms of how she dealt with her diagnosis:

I was 51 and had an 11 year old son and was a single Mom and had been in my new job less than 2 years...Also I brought my mother to live with me a year later since she was having memory issues...It is hard to be mom, eldercare giver 24/7 and fulltime associate professor in a small department where I wear many hats. There was and is not time for self-pity. I am lucky to be here and alive. I was warned I might get depressed after, but I felt positive and thankful.

Barbara's gratitude for being alive and felt positive about what she had despite all of the chaos that surrounded her. She makes a comment there was no time for self-pity and how she was grateful to be alive. Susan shares her expression of gratitude regarding her administrators and how their support was vital to her experience:

I am grateful for the support and flexibility of my college and departmental colleagues and administrators who allowed my work to continue under extraordinary circumstances.

Choosing to respond in a particular way provides agency and even offers a sense of control which appeared to be very significant to women's circumstances that often do not lean in that direction. Cultivation of gratitude is often found in circumstances in which people are facing difficult challenges. This coping strategy is utilized in helping individuals persist through unfortunate circumstances.

Visibility-"hard disease...to see"

The women shared how their experience with cancer was made present in their daily experience; how their cancer was or was not made visible. Being a person with cancer was not how the women chose to be seen. They spoke about how they tried to appear in one manner, how challenging it was for others to see their cancer, as well as their cancer not being seen at all. Audre shares how trying to be present and visible during her treatment was not how she appeared:

I don't think I ever really realized how sick and tired I looked. I was trying so hard to be present and engaged, that I didn't really take time to see myself-Maybe I just didn't want to see myself.

Trying to be one way but in reality appearing differently, can be frustrating. In order to keep up with the routine of daily life and being engaged, Audre stated she didn't take time for herself. Audre's statement of not wanting to see herself is significant in how challenging physically it can be going through cancer. Regardless of the energy and efforts invested, emotionally, it was difficult coming to terms with how it took a toll on their physical appearance. Audre also shares how the effects of cancer contributed to how others saw her:

My chemo treatment was during a semester when I was teaching an undergraduate class. I think it was a hard disease for younger people to see. I chose to wear scarves instead of a wig... My mastectomy wasn't until after the semester. I am sure that would have been hard for students to experience too.

She mentions the effects of chemo and being without hair, and how difficult it would have been had she had to have her mastectomy during the same semester. Audre's concern is the impacted on the students yet doesn't mention how this might have contributed into her own thoughts and emotions.

Carolyn shares not about visibility, but more about her cancer's invisibility:

As with my colleagues, my students did not know I was ill... And the impact of daily radiation was invisible to them.

Despite the scars and the pain that accompanied these scars, Carolyn felt it more important to not share her illness and all that accompanied this experience with those in her classroom. The women shared how their outside appearance did not always reflect what they were experiencing inside. She later shares she recognizes her privilege in being able to hide her disease:

As an aside, I want to acknowledge that I came from a position of privilege in making these choices: my cancer was something I could otherwise disguise (e.g., schedule treatment during non-campus days; maintain the appearance of good health, etc.), and not all cancer patients can. So I recognize that my decision to not disclose was enabled by my type of cancer, the time of diagnosis (right before a sixteen week break), my body's reaction to treatment, and several other factors.

Carolyn shares that she was privileged in the fact she did not outwardly appear to be dealing with a disease. This narrative also suggests how working as a faculty member helped Carolyn to have flexibility to schedule treatments on non-campus days and a sixteen week break, which are not conducive to a regular full-time position.

The concept of a disguise or mask is also mentioned in the women's narratives. This metaphor connects to Goffman's (1959) concept of Presentation of Self, which in his approach means our life is a stage with a series of performances of daily occurrences of how we present ourselves in society. Riessman (2003) comments that "Social actors stage performances of desirable selves to preserve 'face' in situations of difficulty, such as chronic illness" (p. 7). These performances are an example of Goffman's (1959) dramaturgical metaphor, in which an individual's front stage, situated in public or professional settings, is incongruent with an individuals' back stage, situated in private and personal settings. Being able to not have to perform the visible role of cancer contributed to a safety and protected aspect of their illness. These presentations were often conflicting and incongruent, but it was more important to wear the mask to disguise the workings on the inside, Gloria submitted a photovoice of a picture of herself and the caption read:

This is the face of a woman with cancer. Everything looks great on the outside but the inside is still raw and sometimes fearful but always grateful.

Many of the women discussed facing realities and their fears and worries.

### Fears and Worries

While dealing with their experience with cancer, the women spoke to dealing with fears, worries and feelings of loneliness. Susan speaks to her experience and her fears, which were not necessarily for her sake but more of how she found strength to overcome any fear after having had to face her husband's possibility of dying:

Someone gave me a book by a woman who had the same kind of cancer I did (DCIS), and she talked about her fears etc., and I thought, "What a wimp." I had had to face such huge fear—of James dying—that either I had learned that it didn't do any good to be scared, or else I was tapping out!... At one point when James was so sick, I had been very fearful of him dying.

Susan had to deal with the circumstances of her husband also having had cancer. Many of her worries and fears were regarding his prognosis than it was about her own personal situation. Audre shares how her son dealt with a great deal of anxiety and fears during her experience. Throughout this study, we have heard about how the women have maneuvered their cancer, here is a glimpse of how the situation has had an impact on the family:

Our son suffered a lot, he was scared, he was afraid of the hospital and tubes and perhaps on some level me. I was all those things. After one of my surgeries, he visited me in the hospital and I invited him up on the bed to sit with me. He didn't

want to and my heart ached for him so. He experienced a lot of anxiety throughout my cancer treatment some of which continues to this day.

Audre shares how her son dealt with anxiety dealing with her cancer, and, to some extent the fears of reoccurrence as he still deals with the fear today. Many of the women discussed how they also feared reoccurrence of the diagnosis. Gloria shared her greatest fear:

I knew what I valued and cared about. I knew that I needed to let things go and not be so stressed out. The greatest fear is triggering the cancer again.

As Gloria stated earlier, it without doubt the stress of her faculty position she believed caused her cancer. The last thing she wanted was to be in a position that provoked the cancer to return:

The biggest fear is a recurrence and what that would mean here at my new institution. But, I am not going to worry about that. I am going to face each day with hope and appreciation.

Although she is aware of the potential of cancer reoccurring, Gloria expressed her need to be hopeful and appreciative and to avoid worrying about the cancer. Barbara provides insight into the complexities of the women's lives and experiences and shares it's not necessarily the cancer she worries about. It is the stress that might cause pressure on her heart. Barbara writes:

But it was busy and really stressful at the end of each semester. I worried mostly for my heart and still do at those times of the year.

Carolyn offers another point related to fears and worries in sharing during the tenure process that she felt fearful of losing her job. Carolyn's fear of her Chair was the reason she felt forced to reveal her cancer diagnosis:

I was otherwise occupied by treatment and feared losing my job (and, frankly, feared her) so I didn't think to challenge it. Instead I told her about my illness and while she certainly didn't help me, she did stop requesting meetings.

Carolyn feared her Chair would retaliate and wouldn't help her in her situation.

Handling such fears and worries in the workplace can be a challenge and lead to experiences of isolation. Gloria shares how having cancer can be a very lonely experiences:

During the day, things were okay for me. It was when I was getting ready to go to sleep that I would cry and pray. Cancer is a very lonely experience, even when you are surrounded by loved ones.

Audre also felt a sense of isolation in stating:

My views of the process are jaded by these experiences, both realized and observed...During this decision time I felt isolated.

It is during these times of isolation that the women shared the challenges of going through their experience feeling lonely. Despite being surrounded by so many people, it can be a difficult journey fighting for your life, as Gloria state:

You are such a warrior, a fighter, you are fighting for your life that to go back to being just one of the people is very difficult. And the doubts and fears that I had before cancer came back.

All of the struggles and fighting the women encountered, Gloria shares how it was a transition to then know how to be "just one of the people". Although the women spoke of their fears and worries regarding cancer, they also share how waiting was extremely difficult.

Waiting: "It isn't cancer that kills you"

Gloria describes the difficulty of waiting and the uncertainty related to not knowing what's to come because of the interference of cancer. How cancer interferes, Gloria states her struggle:

You are left to wonder what you would have done differently, or how you're going to face the next chemo day or how you're going to deal with the fact that your hair really is falling out and there is a lot of it. It isn't cancer that kills you, it's the treatment, it's the waiting. It is just as much of a mental game (for lack of a better word) as a physical one. The most devastating experience had less to do with the actual cancer and more to do with my identity.

Gloria is not alone in suggesting cancer is not what kills a person, but rather it was the treatment that took its toll. Ehrenreich (2001) states, "...it is the 'treatments,' not the disease that cause illness and pain" (p. 48). Ehrenreich continues, detailing the effects of the treatment, "As my cancer career unfolds, I will, the helpful pamphlets explain become a composite of the living and the dead—an implant to replace the breast, a wig to replace the hair. And then what will I mean when I use the word "I"?" (p. 45).

Audre also shares how waiting was a challenging part of the cancer diagnosis:

Personally I was devastated throughout the wait for diagnosis. After learning that my cancer was very aggressive, my age was young and I would need chemo, mastectomy, and radiation, I was oddly relieved—not relieved that I was in store for such an aggressive treatment plan but relieved to be moving towards a cure.

Gloria and Audre both allude to waiting being a devastating aspect of the cancer.

Unable to control their environment, what happens to them, and the unknown, in general, were agonizing. After the diagnosis, it was then the decisions to make sense of who they would tell and how, if they chose to at all.

*Telling:* "shared only what I had to or when asked"

A personal aspect of cancer comes with how the women approached telling others about their diagnosis. Much of the control in their situation came with who the women told and when they told them. The reactions and pressure of discussing their diagnosis was very burdensome in so many ways and having a say as to who knew was an aspect of controlling their circumstances, as well as a mechanism of protection. Carolyn writes:

As far as privacy, I chose early on not to disclose to many, as I learned quite quickly that I was disappointed and angered by peoples' reactions (e.g., the emotional energy it took to comfort others during bouts of successive bad news; responding to family who thought I was being selfish by not inviting them to stay with us to "help," etc.).

Carolyn brings up important points of her frustrations with telling and how this was emotionally taxing despite the fact she was the one with the diagnosis. Disclosing became less of a priority due to the reaction and energy required on the behalf of others.

Audre tells of the importance of not sharing at certain points with her cancer:

I kept it private to most. I did not tell my family members or work colleagues much during the wait. I did not want my family to worry without cause and I did not want to be asked questions without having answers. I could barely keep myself together and I knew I wouldn't be able to keep it together for others, especially with so little information with so many unknowns.

Not having enough information to share, Audre didn't want family to worry or cause additional stress for others. Carolyn gave voice by telling her diagnosis but kept control of only sharing with a small circle of loved ones:

I simply chose to tell immediate family, a handful of friends, two people at work, and no one else, and lived life like an otherwise "regular" someone who still had to pick up the dry cleaning and go to meetings on campus, but who happened to have surgical drains hanging out of her side and radiation burns.

Carolyn appeared to want to focus on being "regular." Despite what was hidden underneath, there was a need for normalcy. This again reinforces Goffman's Presentation of Self (1959), on the surface everything appears okay, yet underneath, Carolyn speaks of surgical drains and radiation burns. Audre stated that her sense of normalcy was to avoid situations provoking a display of emotions. The vulnerability of tears and hurt was not something she wanted to subject herself to:

I shared as little as possible about my diagnosis with work colleagues and administration, except for those very close to me. I could not discuss the details without tears and I could never mention my son without breaking down. I chose not (to) subject myself to the public display of devastation when talking about my

diagnosis so I talked about it as little as possible and shared only what I had to or when asked.

Here Audre shares that the trust with those close to her were important to counter the vulnerability that came with sharing her diagnosis. Being reminded of how this diagnosis would impact her family, particularly her son, was extremely sensitive and an important aspect weighing heavily on her mind. Talking about it as little as possible contributes to a silencing of cancer.

There was also control in designating who the women shared this information with, as Gloria shares:

...I was tired of telling people. I definitely wanted to control who knew and what they knew and I just had very little patience and energy to tell people personally and then watch them unravel while I had to be strong. It should be the other way around, but that's not how it generally works.

Gloria comments about being emotionally exhausted with telling people the news and how she had to be the strong one. This is mentioned by most of the women in the fact that there is a great deal of responsibility taken on when having to disclose something so personal to others. Despite the fact it is the women living with cancer having to tell others about their situation, it is also the women who have to take on the pressure and reactions of those being told.

Carolyn describes her experience of sharing her diagnosis with a small group of women in her department and their responses. She states, "It was a need to know basis." She details how those relationships were impacted. One woman, told several weeks after the other women quickly stopped speaking to Carolyn. "I was too sick to inquire after her

absence, and assumed she was uncomfortable with my illness. I've been told it was because she resented not being informed immediately and saw it as evidence that I didn't trust her." Another woman was already a "dear friend, and reacted in the most generous way possible: respecting my decision not to disclose to others; covering my classes for me when I was hospitalized; attending doctor appointments (many with bad news) to take notes and provide support sitting with me through all but one infusion; and finally, allowing me to stay at her home during treatment when I was too sick or fatigued to drive to my home (which was 120 miles from the university and my medical team). We are currently writing together, too--an article about social media, breast cancer narratives, life writing, and shame."

The final woman Carolyn disclosed her diagnosis to "under distress", she adds, was the Department Chair. "I resisted sharing my diagnosis with her for a whole host of reasons, including her reputation for bullying younger female faculty (of which I had previous experiences) and her well-documented habit of breaking confidence. (As an aside, I'll note that she has since been removed from her position in the department and has left the university. I can only assume that higher administration learned of her egregious unprofessional behavior.)" The incidents Carolyn shared provide a visual of the ebbs and flows and relationships of colleagues and work place dynamics during a strenuous time. Having to gauge who is trustworthy and will be supportive are unfortunately gambles women relate about to their experiences in the workplace.

Gloria went on the job market after she had had cancer. She was unsure how to deal with sharing her diagnosis as a way of explaining her low publications. Her she explains a specific situation:

I didn't want to use cancer as an excuse and I know that you should never talk about your health when going on the market. When I visited my new institution, one faculty member did ask about my publications and it was so inappropriate.

Afterall, why did you invite me if you didn't think I could handle working there?! I only told her that I had a health issue, but I know that she found out about the cancer and then proceeded to tell the search committee. Incredibly inappropriate. But I got the offer anyway and now I'm here and have been very productive for the past year.

Gloria's situation also brings up interesting points relating to telling a potential employer about medical history, and explaining such circumstances as low publication records, and as Gloria states she "did not want to use cancer as an excuse".

Overall, the women speak to how their experiences with making decisions to share —or not help shape them and share what they have learned about themselves, Gloria writes:

In general, I am a very strong and stubborn person and I realize that cancer doesn't make you change. It only brings out the real essence of who you are.

And I was and I am bright and vibrant and resourceful and loving and all those things I got to be 100 times better when I was dealing with cancer.

Gloria's personal perspective in this narrative expresses what makes her who she is was significant in promoting her strengths of dealing with cancer. Her passion for her work and maintaining a balance personally and professional, did not make her change:

Still, my life is really my own in many ways. Not necessarily because academe supports that, but because I have made it a point to create balance in my life that

may not necessarily be equal parts life and work, but a mixture that makes me feel that I am taking advantage of opportunities personally while maintaining a strong presence in my academic field. However, I did not learn this until after cancer.

## **Gendered Aspects of the Experience of Cancer in Academia**

Theme 4: Embodying Changes: Impact, Expectations, and Consequences

Just because your hair grows back and you seem okay doesn't mean that you are. -Gloria

It is important to note how various aspects of gender play out in the experiences of the women in this study. Breast cancer is a gender disease as cultural aspects surrounding the breast play into a woman's self-perception as well as societal expectations. Often there are conflicts between the lived experiences of the women and social, cultural, and institutional expectations. The breast itself is a sign of femininity, sexuality, maternity and love relationships. Baez-Hernandez (2009) states "The response to illness brings forward our lived experiences of body transformation and the ensuing confusion, pain, and conflicts that arise with cultural codes, gender constructions, and interrogations of identity" (p. 146). Carolyn provides an example in which she felt gender was visible:

...people noticed my changing body, but complimented it—my weight loss, short hair style (wig), growing collection of boxy blazers, etc. I won't go into my thoughts on gender, the male gaze, normative bodies, and societal expectations of women/beauty, but I was struck by how cancer's impact on my body was read by others as positive.

As mentioned, Blackmore's (1999) research speaks to the pressures of women feeling judge based on their appearance of femininity. Carolyn verbalizes the

contradictions of the presentation of self that conflicted with her experiences. Audre remembered another experience that seemed to share elements of Carolyn's:

I remember when I was in college, I told a friend that I would probably develop breast cancer one day too. Knowing that breast cancer was in my family, I felt that I would get it one day too as a punishment for not liking a part of my body. When I developed breasts I was not happy to see them. For me, it brought attention from boys I was not ready for. My breasts were larger than other girls and my sisters. I was teased about them and gawked at by neighborhood boys whom I used to play football with in our yard.

Audre struggled with having disliked her breast so much that she later attributed her cancer as a punishment for not liking her body. The struggle of the socialization of the gendered body attributed to how she felt about herself when she was younger, manifested into a guilt for her breast cancer later as an adult.

An important aspect of femininity is a woman's hair. Here Gloria shares an incident confronting her hair falling out. Because Gloria didn't want to have a passport with her bald, it became a priority to rush out to get her photo taken. Even though she appears sad in the photo, at least, she says, she wasn't bald. She shares:

But my mom did not want to shave my head. She thought it would be better for it to just fall out on its own. But I couldn't take it and I told one of my friends that I was planning to shave it that week. And then we were talking about getting a passport because I was going to Canada in the fall and he mentioned that they wouldn't let me wear a headwrap for my passport photo. So, on the last day I had my hair, I rushed to get the photo. And now I have to wait 10 years to get a

picture that isn't so sad and forlore. But I could've been bald, so I'll take this horrid picture. When I returned from taking the photo, I got my mom to help me. The first cut was just so sad, but we kept on and shaved it. Turns out, I have a small head! Who knew under all that hair!

Hair is significant to much of the cancer treatment process. The value put on hair and its equivalence to femininity is often not acknowledged until the risk of losing it is realized. Having to decide wigs or scarves or shaving the head, as Gloria describes, can be equated to the socialization of the expectations of what a woman is to look like. When those roles are violated, it can produce an internal conflict with the way their bodies appear to others. The outside presentation of self may at odds with experience. Gloria discusses how even a passport picture provoked her to take it so she would have hair in the photo.

Just because your hair grows back and you seem okay doesn't mean that you are. There are some days when I don't think about cancer, but there are reminders whether that is with my scars or when I go to my 6-month check-ups or when I visit my gynecological oncologist to talk about ovarian cancer or when I take my daily pill of tamoxifen, which prevents the estrogen in my body from feeding any remaining cancer cells but, if used for more than 5 years can also cause uterine cancer. You can't win. I am nearing my 5 years and it is a bit of a miracle that I am where I am now. I will be monitored for the rest of my life. There are additional surgeries that are coming soon. There is fear that I won't find someone who will be okay with my diagnosis and the consequences of it. It is possible that

I won't be able to have kids. So, yes, I'm great on the outside, but there are pieces of me that have never fully recovered and I hate cancer for that.

Gloria gives very personal insight into how cancer has jeopardized her chance of having children and to some extent, complicated the dynamics of relationships with significant others. The deeper realities of how cancer can impact the very fiber of femininity is confronted. Gloria as states blatantly that even though one's hair returns doesn't mean she is rid of the fear of reoccurrence. Mary Jane Knopf-Newman (2004) shares her mother's personal narratives regarding such fear, "It's like the monster in Alien[;]...you don't see it, you hope it's gone, but you know it's there somewhere, and that someday it's going to come out and whack you in the back of the head again, and that you're going to have to mobilize all your energy and defenses to fight again" (p. xiv).

Barbara's struggle with being denied tenure at her previous position speaks subtly to the issues of the dean proving his masculinity and the fight she had to endure.

Although this incident was prior to her cancer diagnosis, the struggle within the patriarchal structure of academia still persist. Barbara's photovoice submission shares a photo of herself smiling. Her caption states:

This is a picture of me in 2005 when I was fighting for tenure and doing lots of great work, even being featured in the University magazine for my work while being denied tenure, and not getting support from half my colleagues in the dept., and the new dean was looking for a victim to show he had balls. I was fighting the decision since I had stellar evaluations up to the tenure decision (eventually won, but what did it matter if the president would not defy the dean), but it was

taking a toll being a single mom, writing a book, teaching 300+ students each semester and applying for other jobs. I was determined to hold it all together.

## Summary

This chapter provides an overview of the findings of how women in academia have negotiated a cancer diagnosis. The themes that surfaced inductively from my analysis are the following. First, Finding Agency and Supportive Spaces: Managing, Adjusting, and Responding, which deals with maneuvering responsibilities pertaining to a faculty position, student responses, and faculty work and spaces provided support.

Second, I found what I called Connections for Preservation: Support, Comfort, and Reassessing which explores the importance of the little things, relationships, the culture of cancer, living for others, control and boundaries while also reassessing and prioritizing. Third, Expressing Cancer: Laughter, Fears, and Sharing highlights the importance of humor, renaming, voicing gratitude, visibility, fears and worries, waiting and telling.

Finally, the last theme I provide is Embodying Changes: Impact, Expectations, and Consequences explore at length how the women shared their stories pertaining to their gendered experiences with breast cancer. As I mentioned in the opening to this chapter, these are complex and overlapping themes that demonstrate the challenging circumstances the women encountered in their professional and personal lives. The following chapter will discuss the implications and recommendations for these findings and how these narratives can be utilized to contribute to similar situations of individuals facing a life illness while in academia.

### CHAPTER 6

# DISCUSSION, IMPLICATIONS, RECOMMENDATIONS.

### AND REFLECTIONS

The purpose of this study was to explore the experiences of female faculty members diagnosed with breast cancer. How the women gave voice and provided visibility to their circumstances, and maneuvering the gendered institutional structure of higher education, was revealed in the findings. This study provides a glimpse into the women's lived experience of breast cancer using narratives from on-line journaling and photographs from the method of photovoice. As a Social Foundations study, there is an emphasis in how historical context and contemporary factors influence and potentially contribute to the inequities of female faculty members experiences. Bringing awareness to such circumstances of breast cancer while in a tenure track role, it is hopeful this study will contribute to the awareness advocating for educational justice in academia for those dealing with a life threatening disease.

Using narrative journaling and photovoice, this study provided an opportunity for the participants to express their experiences of being a female faculty having dealt with breast cancer. It is essential to recognize from the data how the women's experiences can translate to informing change in policies and practices in future situations that may impact others in similar circumstances. This chapter discusses the recommendations based on the themes that emerged from asking the research questions that guided this

study. The first overarching question asked what are female faculty members' experiences with a breast cancer diagnosis during their tenure track role in academia? More specifically, the second research question asked how do tenure tracked women in academia maneuver professional expectations after a cancer diagnosis? In addition, the third question asked how do tenure track women personally express voice and provide visibility after a cancer diagnosis? The fourth question asked how did the institutional structures of academia contribute to the gendered power relations the women experienced with breast cancer? The final research question asked how did the institutional structures of academia contribute to the gendered power relations the women experienced with breast cancer?

To commemorate this study and the women who participated, I wanted to use art to present the findings in a more expressive way. Patton (2001) suggests that qualitative research is both science and art. Patton states part of qualitative research, "invites exploration, metaphorical flourishes, risk taking, insightful sense-making, and creative connection" (p. 513). With this in mind, I chose to paint four paintings that capture and express the findings that emerged through the course of the study. After spending much time reviewing and personally processing the data, the images and themes emerged inductively. Audre Lorde's *Cancer Journal* inspired much of this study. Each of the paintings were titled with a quote from Lorde that I felt also spoke to the themes. For each theme to follow, I will provide an explanation of the painting and the quote as it relates to each of the themes.

The remainder of Chapter 6 will first, focus on discussing the four themes and how they relate to each of the paintings, addressing how the implications can inform

policies and practices regarding academia and the tenure track processes. Second, recommendations will be provided for department chairs pertaining to policies and practices helping the women in their circumstances. Third, I will provide a brief personal reflection of my thoughts of this study and share my personal thoughts and perspectives. And finally, recommendations for future research will be discussed. This is most significant in how policies and procedures can be implemented or enhanced, suggest recommendations for department heads and colleagues, and finally convey personal reflections on this study and recommendations for future research.

# Overview of the findings

In this section, I present the themes that emerged from the narratives from this study and represent them with images that I painted to capture the depth and expressiveness of the women's stories. The themes used participant language to convey, in their words, the importance and significance of meanings provided by the women. The first theme, (a) finding agency and supportive spaces: managing, adjusting, and responding; described how the women maneuvered their professional roles and responsibility of a faculty positon. The second theme, (b) connections for preservation: negotiation, comfort, and reassessing; explores the importance of relationships throughout the women's cancer experience. The third theme, (c) expressing cancer: laughter, fears, and sharing; the women shared the importance of humor, sharing their diagnosis and the worries and fears accompanying their experiences. And the final theme (d) embodying changes: impact, expectations and consequences; the women share how their femininity and bodies were impacted by their breast cancer. Each of these themes I

will relate to interpersonal practices, policies or procedures that I suggest this study speaks to implementing or reinforcing.

The first theme, finding agency and supportive spaces: managing, adjusting, and responding, the women speak about the importance of maneuvering the essential aspects of their role in academia. Finding ways in which they were able to respond to such circumstances of dealing with cancer and working as a faculty member was important. The title of the painting (see Figure 8) relating to the first theme is the quote: "I could die of difference, or live –myriad selves."



Figure 8

This quote spoke to how the women were able to adjust and adapt to their circumstances of dealing with cancer while in the role of being a faculty member. Clearly, there is a great importance of policies and procedures to helping female faculty members continue in their positons while dealing with a cancer diagnosis. Implications of policies and procedures were rarely mentioned by the women. The women tended to just continue to do what was expected of them. Throughout the narratives, for the

women in the study, maintaining their work was an important part of their identities and recovery, even during the most difficulty times of their treatments. Providing opportunities to continue their tenure process and not penalize them for having to deal with cancer is an important consideration for administrators. Although these policies are available, many of the women shared the information was not presented to them or made available during their time in which such policies were needed.

Balancing the commitments of faculty work and family dynamics on top of a cancer diagnosis can create many challenges. It is essential for department heads and administrators being more cognizant of these dynamics in the tenure track expectations. Creating "designer" tenure clocks for academic careers, Boxer suggests (1996) can encompass the needs of an individual to benefit the greater campus and university. Making tenure adjustable and overall so that the "challenging assumptions that pit personal against professional needs" will be minimal (p. 480). Centralized stop-clock policies or extended tenure clocks are recommended and should be presented to faculty so they are aware of such policies and can utilized them when needed. Audre shares in her narrative:

...For future recommendations, I find it important for colleges to develop guidelines for appraisal during chronic illness, especially for faculty who have not yet obtained tenure. Both administrators and faculty should be made aware of such guidelines.

As Audre states, many of the women felt a great deal of pressure to meet the expectations of tenure in the midst of treatment. Creating conditions that help faculty continue along in their work can involve policies, practices, awareness, and support.

Training department chairs about leave policies and when their use is warranted is also recommended (Gappa & McDermid, 1997). It is essential those in charge of the departments know what policies are available, how they can be utilized and making sure that information is conveyed to everyone in the department. If policies do not exist, working to establish them so that they do.

It is important new faculty to better understand their options and aspects of policies and procedures related to tenure and promotion. As such, recommendations for tenure and promotion policy seminars for faculty during times of illness are recommended as part of the overall guidance related to tenure and promotion. However, such policies are often underutilized. Hochschild (1997) suggests that only offering policies is not enough as there is also a need to have the support of administrators for faculty to utilizing the policies.

Academia and the rigor of expectations in practices such as tenure, have been based in the traditional ideals where faculty members, historically male, whose family obligations might not be as demanding at home. As the changing arena of higher education involves more women and the dynamics of being care-givers, universities must become more considerate of positive ways to be more attractive and accommodating. Wolf-Wendel & Ward (Roper-Huilman, 2003) state the personal concerns of women in academia "should be of importance to higher education administrators and policymakers from an equity perspective" (p.114).



Figure 9

The second theme, connections for preservation: negotiation, comfort, and reassessing, refers to how the women maintained self-preservation through the relationships. I saw the importance of the connections and circle of support the women utilized during their circumstances. I titled this painting (see Figure 9) with Lorde's quote stating, "I say the love of women healed me." I felt this quote spoke to how the women found such strength in their relationships with others. Relationships they strengthened with friends and family, relationships they formed during their treatment, it was the love of others that helped to 'heal' them during their situations. The significance of relationships was essential to the women of this study. Fostering those relationships are imperative during illness circumstances. It is also important to note that in reassessing their relationships, some were severed in order to focus on the positive support systems. Based on the information the women shared, there was many indicators for a need of colleagues to assist or "help" in a variety of ways. Being supportive does

not always mean asking "How are you?". As mentioned previously, this can be more emotionally taxing than anyone intended. Helping with teaching classes, providing notes from meetings, and offering to bring food, are all ways in which the women shared were helpful to them. A small gesture as a note to helping fundraise for extra expenses when having to travel to treatment, is also suggested as a means for helping when someone is confronted with cancer. Assisting with task such as picking up a child, weeding gardens, or even supplying a soda were things the women didn't ask for but others around them knew the importance of the task being done. This gentle bit of support and encouragement were gestures that might be helpful in reducing much needed energy.

Despite the fact the title of this theme states it was the love of women that healed, what was interesting about the women's narratives was those that wrote about their challenging experiences with their administrators often involved other women in these leadership roles. It brings up an important question as to the dynamics of women holding these positions of Departmental Chair and yet were not supportive of the women dealing with cancer, and to some extent, made their process more difficult. What is most significant is the lack of empathy by those in administrative roles for other women in this study. Such dynamics are important to recognize and explore further. This does emphasize reason for and importance of why mentoring and supporting female faculty members is essential.



Figure 10

The third theme, expressing cancer: laughter, fears, and sharing refers to the importance of humor, the fears and concerns relating to cancer and how the women shared their diagnosis. In this finding I discovered the value of positive perspective and how even in the face of worries and fears, the women found ways to still laugh and look on their brighter side of their situation. I titled this painting (see Figure 10) with Lorde's quote stating, "Being one-breasted does not mean being unfashionable." The women stressed the significance of laughing and humor getting through their cancer. As Lorde alludes to in her quote, that whatever circumstances you've been given, the response is most significant. Armenti (2000) suggests women in academics blend private and public lives, and asserts that the structure of academic careers "silenced" women's personal lives. Traditionally, family and work have been kept separate for professional women. A study conducted by Sorcinell & Near (1989) indicated that balancing family and

professional responsibilities was a source of stress for female faculty. Departments need to provide the space to allow women to have the opportunity to feel safe to share their personal experiences, or keep private their experiences without feeling repercussions for maintaining their privacy. To promote an environment supportive of faculty success might utilize such options as part-time tenure track (allows a reduced workload while continuing to provide the protection and benefits of a tenure track position), extension of tenure, modification of duties, programs to support transition back to the university and family leave (Raabe, 1997). Carolyn spoke of her privilege of being able to conceal her cancer, while most of the other women did not have this option. Most of the women described scenarios detailing "telling" their colleagues. To assist in the personal side of cancer for women, colleagues can help by establishing a departmental communications plan. Development of a departmental plan including a designated person to ask about updates could assist in the strain placed on women related to sharing their story multiple times. It can be especially emotionally taxing as many of the women attested to, having to give the same information over and over, especially during the most challenging stages of the disease. Several of the women utilized a blog to share and disseminate information. This provided a platform to direct friends and family to without having to repeatedly share, stirring up emotions. Designating a person, preferably someone who is close to the faculty member, to obtain and provide information to the greater group is an important step.



Figure 11

The fourth theme, embodying changes: impact, expectations and consequences speaks to the challenges the women faced regarding how gender played into their experiences of breast cancer. I titled this painting (see Figure 11) with Lorde's quote stating, "And that visibility which makes us most vulnerable in that which also is the source of our greatest strength." I feel this theme speaks to the significance of women challenged by the dynamics of cancer impacting their presentation of their femininity and its displays. Visibility pertained to how cancer was made visible for the women; scarfs, wigs, and even fatigue. And yet visibility, or invisibility, was also how some of the women were able to 'pass' meaning they did not appear to have the visible characteristics of cancer. Being vulnerable in the visibility of cancer, from Lorde's perspective, can provide a source of confidence in acceptance and being in the unfortunate circumstances of having cancer.

To be proactive, universities need to be responsive to the ever-changing roles and be more inclusive to include family-friendly policies and circumstances that might involve situations relating specifically to women. Childcare on campus, lactation rooms,

or transitional support for maternity are examples of supportive women-friendly policies. Not only will women benefit from such policies, but the investment can also make institutions more competitive. By providing this spaces can contribute to retaining faculty to continue at the university by supporting them during these important milestones. Barriers and challenges women face overall, make the environment of academia a vital aspect to address, serving as a foundation in promoting a more supportive setting. Developing more family-friendly policies and heightening awareness of issues women face, could help foster a more compassionate setting for woman dealing with a cancer diagnosis. Although not all of the women in this study had children, the overall benefits from having a family-friendly atmosphere could help women maintain a balance of personal and professional lives.

# Recommendations for Chairs

There is a vital role a Chair should serve as a female faculty member is dealing with a life-altering ordeal such as cancer. Promoting policies and procedures to be supportive of women, or anyone having to deal with a diagnosis is recommended. Providing more understanding of the tenure process and policies in also important to educate new hires. Gloria and Carolyn both described their experiences of being unaware or clear of their options available to them during their circumstances. Not only is it important to share widely information about policies and procedures and the tenure process, but there also needs to be an understanding atmosphere that allows women to feel utilizing such policies is met with administrative support and understanding. Female faculty members should not have to fear retaliation or believe there will be negative consequences if policies are used.

Chairs also are critical in setting the standards to be supportive and allow zero tolerance for harsh treatment or comments and discriminatory practices by anyone in the department. Setting a precedent for the environment of departments potentially impacted by faculty members dealing with life altering circumstances is necessary. As Audre mentioned, implementing guidelines for appraisals while someone has been dealing with an illness is important for the faculty member to continue being a valuable part of the department despite illness.

Chairs should work in coordinator with faculty members experiencing chronic illness to assess their individual needs and situations. Such assistance as decreasing teaching load, offering teaching assistants, allowing working from 'home' schedules or offering online classes are suggestions to support the expressed needs of faculty. It is important to work with the faculty member to provide options that best suit her needs and also allow the department to meet its needs.

Returning to the literature, overall women in higher education face challenges.

Breast cancer only adds to the complications and the complexity of their position. The tenure process, balancing family and work, and the overall patriarchal culture the institution is founded in, are all in addition to facing a life threatening disease. For example, it was the flexibility of the position of faculty that assisted the women during their treatment for cancer. And yet, the culture of the institution which supports the rigor of the expectation of the tenure process, the women struggled with during their circumstances. Bringing awareness to the women's circumstances overall was essential and yet how this also contributes to the literature in ways of being critical of the process, procedures, and expectations of women in academia.

### Personal Reflections

Every step of this dissertation process was an emotional experience. From the situations that spurred this choice in topic, to gathering and analyzing the data, at each point tears were present. In making the decision for this research topic, I was aware it would be challenging but was not truly prepared for the struggles.

One of the most important factors I wanted to reassure my participants was their confidentiality. From conversations with women that sparked this study, I knew there were details about job security, uncomfortableness relating to institutional policies and a real fear associated with personal details. It was important to provide a space that would not be connected to the participant, especially when sharing such personal information. Protecting the identity of the women was of utmost importance, and the major reason I chose not to personally interview the participants. Despite my personal preference to do in-person interviews, I chose online journaling to potentially provide a convenient, on their own schedule opportunity to allow for a free flowing writing opportunity. Unfortunately, I now believe this was the reason I struggled to have participants follow through with completing online prompts. The process of data gathering for this dissertation was the most challenging and frustrating part to say the least. Despite the fact I knew several women who qualified for this study, many initially agreed to participate but follow through was problematic.

Another important factor that I believe influenced the lack of follow through, that I was completely unaware of, was that of the characteristics of my selected population.

Something that I now think impacted participants in this study, was being a faculty member with vigorous habits that may be difficult to abandon. Early on from the

participants' entries, I became very aware there was not as much free flowing, expressive writing taking place. There was much thought to the presentation of their writing and a great deal of thought went into how things were being said. Many of entries were very structured and similar to manuscript like writing.

In essence, the most important factor to add is the emotional upheaval writing about such a painful experience must have been for these women to follow through and complete. Writing life narratives can lead an individual to relive experiences and assess a recollection of memories that might have been unvisited, avoided, or even fragmented in the moments of chaos, turmoil, and the most difficult times of their lives. Revisiting, reliving and making sense of their experiences can be a source of vulnerability and raw emotions that are difficult re-experiencing or re-evaluating after a life-altering ordeal such as cancer.

#### Recommendations for Future Research

During my college career I have known 5 women personally who were impacted by breast cancer. Witnessing this from various levels as a student, as well as a professional viewpoint, it is evident their stories need to be told and their needs should be addressed. This study only explores the experiences of five women, yet the unfortunate population impacted is so much greater. Early on in this study, I was sent an email by a man who had read about this research and was adamant in telling me that men also get breast cancer. In no way is this research denying the fact that men also experience breast cancer and associated experiences. Female faculty were selected as I wanted to examine their experiences from a gendered lens. However, I do believe future research needs to take into consideration various illnesses and life altering circumstances that potentially

impact the professional agenda of faculty members. I also believe the conversations with female faculty members needs to have various levels of dialogue to truly examine their experiences with breast cancer while in a tenure track position. Telephone interviews, more web interactions, or a combination of methods to allow participants to choose their method while also allowing more opportunities for the researcher to follow up or probe for additional details is recommended. Although narrative journaling and photovoice contributed to this study beautifully, to examine some of the topics more in-depth, additional methods to allow for clarifications could contribute greatly. Because the research on women in academia who have been diagnosed with cancer is slim, I hope this starts and continues efforts to examine further these circumstances as well as others dealing with individuals dealing with illness while maintaining their positions in higher education.

Putting policies in place is essential to provide optimal assistance while also knowing that all individuals are unique and have specific situations. Development of an environment that supports utilizing policies without repercussions, that is safe, and without judgment is necessary. Colleges and university Human Resources and Benefit offices should also provide cancer or long-term insurance policies for faculty and staff. Most importantly, colleges and universities should provide an atmosphere in which faculty feel valued, even during times of illness. Providing a space of encouragement first by administrators, will, in theory, set the stage for other faculty and staff of the department to be supportive. Academia should work to incorporate human elements as part of the tenure process. Women should be presented with opportunities for assistance in their work as a tenure track faculty member, as this study describes in various ways

how this was important to them both professionally and personally. Ostriker (Raz, 1999) writes, "...although we can perhaps do little to heal either the world or ourselves, we can do *something*. Something is not the same as nothing" (p. 197). It is the hope this study will do something to promote an awareness of the circumstances impacting female faculty members who have been diagnosed with breast cancer and encourage a more positive academic setting.

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# **APPENDIXES**

# APPENDIX A

# INVITATION LETTER

## Dear Prospective Research Participant:

I am writing to tell you about a study that I am conducting regarding female faculty members' experiences with breast cancer. I am a social foundations doctoral student at Oklahoma State University conducting this dissertation study in partial fulfillment of my degree requirements.

The purpose of this study is to better understand the lived experiences of women in tenure track positions whom have been diagnosed with cancer. More specifically the research will examine female faculty members' perceptions and experiences of dealing with a cancer diagnosis and treatment while balancing personal and professional roles and responsibilities in academia. Information gained from this study is intended to understand women's experiences as well as inform institutions of higher education that house policies and procedures pertaining to tenure and illness.

You are being invited to participate in this study if you have been diagnosed with breast cancer and were in a tenure track position when diagnosed. Your participation in this study is completely voluntary and the information you provide will be held strictly confidential. You may withdraw from the study at any point without penalty.

Your participation in this study and the information you will provide are invaluable in providing a voice to your experiences that have been silent throughout the literature. To participate in this study, you will be asked to log on to a website created specifically for this study to share your thoughts in an online journaling exercise. Each page of the website, four total, provides an open-ended topic prompting you to reflect and respond to an online response format. Each prompt will also provide an opportunity to submit a photo or image as a visual expression of this experience. You can respond to each topic at any time during an 8 week period of time.

If you are willing to share your experience and participate in this research study, please email me at <a href="mailto:sara.mata@okstate.edu">sara.mata@okstate.edu</a>. Should you have any questions or like to discuss this study further, please contact me at 580 352-1975.

$\mathbf{T}$	hank vou	for your	time and	consideration	of this	important resea	rch
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Sincerely,

Sara Mata, M.S.

# APPENDIX B SOCIAL MEDIA RECRUITMENT INVITATION

Are you or someone you know a female faculty member who has been diagnosed with breast cancer? If so, and would be interested in sharing your story anonymously by participating in an online journaling research exercise, please visit <a href="http://saramat4.wix.com/discourses">http://saramat4.wix.com/discourses</a> or email <a href="mailto:sara.mata@okstate.edu">sara.mata@okstate.edu</a>.

# APPENDIX C

# HOMEPAGE IMAGE OF WEBSITE



# APPENDIX D

# IRB APPROVAL

#### Oklahoma State University Institutional Review Board

Date:

Tuesday, June 25, 2013

IRB Application No

ED13117

Proposal Title:

Discourses of a Diagnosis: Narratives of Women in Academia

Reviewed and

Exempt

Processed as:

Status Recommended by Reviewer(s): Approved Protocol Expires: 6/24/2014

Principal Investigator(s):

Sara Mata

Lucy Bailey

301 HS

215 Willard Hall

Stillwater, OK 74078

Stillwater, OK 74078

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45

The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

helie M. Kennian

- Conduct this study exactly as it has been approved. Any modifications to the research protocol
  must be submitted with the appropriate signatures for IRB approval. Protocol modifications requiring
  approval may include changes to the title, PI, advisor, funding status or sponsor, subject population
  composition or size, recruitment, inclusion/exclusion criteria, research site, research procedures and
  consent/assent process or forms.
- Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.
- Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and
- Notify the IRB office in writing when your research project is complete.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact Dawnett Watkins 219 Cordell North (phone: 405-744-5700, dawnett.watkins@okstate.edu).

Sincerely

Shelia Kennison, Chair Institutional Review Board

#### **VITA**

#### Sara A. Mata

## Candidate for the Degree of

## Doctor of Philosophy

Thesis: DISCOURSES OF A CANCER DIAGNOSIS: NARRATIVES OF WOMEN

IN ACADEMIA

Major Field: Social Foundations

#### Education:

Completed the requirements for the Doctor of Philosophy in Social Foundation at Oklahoma State University, Stillwater, Oklahoma in December, 2014.

Completed the requirements for the Master of Science in Sociology at Oklahoma State University, Stillwater, Oklahoma in December, 2007.

Completed the requirements for the Master of Science in Community Counseling at Oklahoma State University, Stillwater, Oklahoma in December, 2005.

Completed the requirements for the Bachelor of Arts in Sociology at Oklahoma State University, Stillwater, Oklahoma in December, 2003.

### Experience:

Assistant Director, OASIS Office of Academic Success and Intercultural Services University of Nebraska-Lincoln May 2014 – Current

Grant Coordinator, Department of Nutritional Science Oklahoma State University, Stillwater, Oklahoma Sept 2010 - May 2014

#### Professional Memberships:

NASPA (National Association of Student Personnel Administration)