

BEYOND PINK: LIVING WITH A TERMINAL BREAST CANCER DIAGNOSIS

A Project Report

Presented to

The Faculty of the Department of Anthropology

San Jose State University

In Partial Fulfillment

of the requirements for the Degree

Master of Arts

by

Mary Koskovich

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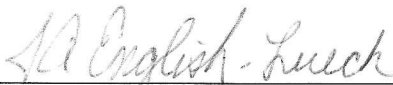
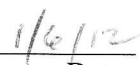
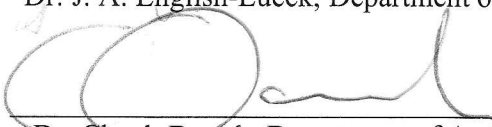
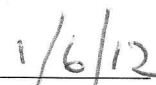
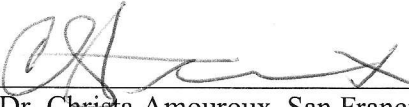
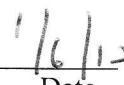
The Undersigned Graduate Committee Approves the Project Report Titled

BEYOND PINK

by

Mary Koskovich

APPROVED FOR THE DEPARTMENT OF ANTHROPOLOGY

	
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Abstract

This project seeks to increase community awareness of the heterogeneous nature of the experiences of those living with terminal breast cancer, their coping strategies, and needs in regards to their illness. This project includes the following actions: (1) identify the varied terminal breast cancer communities; (2) identify a sample of terminal breast cancer individuals; (3) interview 4 to 7 of these individuals on film; (4) analyze the interview materials; (5) present the generalizations and lessons learned to be, discussed, and elaborated by the participants and researchers and aired on public access TV stations. (6) Finally, the team, comprised of myself, Jessica Donohue, and Cassandra Carruth will disseminate information as an educational tool to individuals with terminal breast cancer, those with an early breast cancer diagnosis, their social support systems and their treatment providers, and the general public.

In this project report I discuss the project logistics: goals; sampling, budget; material and methods; theoretical perspectives and biases. I analyze the results identifying the range of coping mechanisms—participating in breast cancer support groups, engaging extreme behaviors post terminal diagnosis, framing the experience using the metaphor “bucket of pain” – “the cancer thief”. I also discuss the Pink Movement’s role in coping. Finally I discuss cancer identities – cancer patient, person with cancer, survivor, person living with cancer, victim, etc. I also reflect on the project and how I could have been improved.

Acknowledgements

The Beyond Pink Project is the result of the efforts of so many individuals that it'd be difficult to include everyone. (The order in which I thank individuals has no correlation to amount and level of help they offered.) First, a heart-felt thank you needs to be given to all the individuals who agreed to be interviewed for the project. These pivotal individuals sacrificed their time, a piece of their hearts- a piece of their souls. Second, I want to thank my family and friends who doled out continuous advice and let me rant incessantly about the project. A special thanks goes to my husband Jack, my dad Jay, my brother Jayson, and my friends: Belinda, Erin, Nina, Sibley, Mayf, Kent, Ben, LeeAnn, Terry, Susan, Jeff, and MaryJane.

Without Jessica and Cassandra the project would have been impossible. And my graduate committee was endlessly supportive and essential. Thank you Dr. Jan, Dr. Darrah and Dr. Amoroux.

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Introduction

At 1pm on March 16th 2009 when I was only thirty-eight years old; a healthy, vivacious, avid rock climber, mountain biker, runner, paramedic, paramedic school director, and eager student finishing my master's degree in anthropology; I received a phone call from my oncologist. A few days earlier I had undergone a complete head-to-toe medical body scan and was anxiously awaiting the results. What the doctor told me altered my life in ways that went far beyond my ability to express it in words: *"Oh Mary- it's not good... The breast cancer is in almost every one of the bones in your body. I am very sorry."* This shocking phone call was shortly followed by an in-person appointment in which my physician informed me that I had stage IV (also known as incurable, metastatic, or terminal) breast cancer. She estimated that I'd live between one and five years with standard Western chemotherapy and anti-hormonal treatment - eleven months without it.

Aside from my personal feelings that breast cancer is important owing to the fact that I suffer from it, the burden of breast cancer is staggering. "At well over half a million deaths a year, breast cancer is the leading cause of cancer deaths in women worldwide, occurring in about one third of the 1.3 million women who will be diagnosed each year (Mayer 2010:195)." In the US breast cancer stands out as the "most common cancer among American women, except for skin cancer" and it "is the second leading cause of death in women, exceeded only by lung cancer (American Cancer Society 2011)." Additionally, a woman has a little less than one in eight chance of developing invasive breast cancer at some time during her life given that she lives till eighty-five years of age; that is a 12% likelihood of being diagnosed with the illness in a lifetime (American Cancer Society 2011)."

Therefore, due to its high prevalence it's quite likely that one may suffer from breast cancer or know someone that is living with or has died from the disease. Since breast cancer ranks as the second leading cause of cancer death in women, it has garnered intense attention as the medical community tries to address its potent lethality.

In this project report I will discuss our goals, sampling techniques, budget; process and details of how the project was carried out; comparative theoretical perspectives and biases; provide a detailed analysis and summary of the data; and offer speculations/recommendations.

Goals

Because of my diagnosis with terminal breast cancer I was unable to continue with my original master's thesis work in international emergency medical services education and implementation because I was unable to receive my cancer treatments while overseas in India and Nepal where my previous field work was located. My master's committee members suggested that I change course and perform research on terminal breast cancer coping skills. I thought this was a wise idea as that I might easily gain access to the community because of my status as a person also living with terminal breast cancer: a community member. The informants might be more willing to be involved in the project and more likely to open up to me during the interviews. Despite my resistance to this suggestion: my master's committee also strongly suggested that I be an informant (allow myself to be interviewed) and utilize the resulting data.

In addition, to gathering stories of those with terminal breast cancer and their coping techniques, Dr. Darrah suggested that our research team create a documentary as that an applied anthropology film might be more likely to reach a greater number of individuals than a master's thesis. The main goal of the project was to increase community awareness of the heterogeneous nature of the experiences of those living with terminal breast cancer, their coping strategies, and needs in regards to their illness. Dissemination of the documentary as an educational tool to individuals with terminal breast cancer, those with an early breast cancer diagnosis, their social support systems and their treatment providers, we felt would best achieve this goal. Our research team included: Cassandra Carruth, Jessica Donohue, and

myself (this does not include my master's committee members). We all agreed to participate in creating the documentary.

My role in the project was primary interviewer and I was to flesh out coping strategies, analyze them against a theoretical frame, drawing conclusions in my project report. Jessica's primary role was to film and create the documentary. Cassandra's primary role was to use the interviews to ascertain the roles that nurses play in the clinical experience of cancer patients. Ultimately, she wants to present her findings to nursing students as a guest lecturer in an upper division course. Additionally, Jessica, Cassandra and Dr English-Lueck served as secondary interviewers at different points during the project and Dr English-Lueck performed the role of primary interviewer during one interview.

Despite having primary roles each graduate student agreed to edit and thus create the documentary, disseminate it via anthropology conferences, breast cancer conferences and other events, and via a website on the Internet that will not only include the documentary with access to streaming, but include difficult to access information for terminal breast cancer individuals, such as Do Not Resuscitate Orders, Living Wills, Last Wills and Testaments, information on using disability benefits while living with a terminal diagnosis, breast cancer films, reading lists; and a dialogue chamber for discussion and information exchange.

Chapter 1 Project Background and Description

Sampling

After conceptualizing and identifying the goals of the project, and then gaining Institutional Review Board approval, we moved onto our next step, which was to seek out informants. Pelto and Pelto (1978:127) state that: “When we as anthropologists decide to qualify some of our observations of social behavior, we are faced with the problem of defining the universe of observation and devising ways of ensuring that observations fairly represent that universe. In my research I explain in detail the categories of the informants’ behaviors, beliefs, and feelings that fit with Kuber-Ross’s (1969) stages, Moos and Schaefer nine coping techniques (1986), Corr, et al’s (2002) ideas. These informed my thought reaching conclusions, thus qualifying my observations of the informants’ social behaviors.

Pelto and Pelto (1978) state: “No matter what sampling procedures are used, the first task is the delimiting of a population (of people, events, or other units) from which the sample is to be drawn (127)”. The universe I identified for observation of social behavior is the universe of individuals diagnosed with terminal breast cancer. That universe was first delimited from terminal breast cancer patients living on planet Earth to those living within the United States. Presently there are approximately 155,000 individuals living with terminal breast cancer in the United States (Metastatic Breast Cancer Network 2010) and we did not have sufficient funds to attempt to recruit and transport a representative sample of these individuals to CreaTv in San Jose, California; further we had time constraints to make progress and finish the project in a suitable manner to satisfy multiple master’s students’

graduation timeline desires. Therefore we were additionally constrained (delimited) to the universe of individuals living with terminal breast cancer within the Greater Bay Area.

155,000 individuals is a very small sample pool and yet our sample pool was reduced further- encompassing a portion of this 155,000, because our goal was not to interview those living with breast cancer in the US, but to interview those living with *terminal* breast cancer in the Greater Bay Area. The Cancer Prevention Institute of California (2007) estimates that in 2005 there were only 4,442 cases of female invasive breast cancer in the Greater Bay Area (which includes Alameda, Contra Costa, Marin, Monterey, San Benito, San Francisco, San Mateo, Santa Clara, and Santa Cruz counties) and in 2003 about forty cases of in situ or invasive breast cancer were diagnosed among males in the Greater Bay Area (Cancer Prevention Institute of California 2007). We considered the Greater Bay Area region a reasonable monetary (funds for fuel) and time commitment (driving time to and from the studio and filming time) for our informants to be filmed in the San Jose CreaTv location.

The sum of 4,442 and forty results in the approximate raw figure of male and female individuals living with breast cancer in the Greater Bay Area as 4,482. (I acknowledge that the female data come from the year 2005 while the male data come from the year 2003. I choose to use the most recent data available for each sex).

And “[i]n 10% of breast cancer diagnoses, the cancer has already spread to distant organs in the body (*Imaginis 2007-2011*) ”; also known as metastasis causing the patient to have a terminal diagnosis. This narrows our pool further as that 10% of 4,442 total cases of breast cancer in the Greater Bay Area equals 444. 444 cases of metastatic breast cancer is an extremely small sample pool.

My research team and I had trouble accessing these metastatic individuals living within the Greater Bay Area as barriers to reaching them included asking difficult questions such as: where do you find these individuals? Many of them would be receiving Western treatment in chemotherapy clinics, medical offices and hospitals or in alternative settings. But walking into medical establishments and requesting access to terminal breast cancer patients poses privacy and legal issues that were too great for us to overcome due to monetary, time constraints, and the potential for the Institution Review Board to deny our approval. Thus, finding the individuals was one issue and accessing them was yet another.

Additionally, another factor was the time constraints imposed by the desire to complete the project in a timely manner to allow research members to earn their master's degrees in a reasonable time frame. Other delimiters included: once we found willing participants- how many of them would be willing to travel to CreaTv in San Jose, be willing to talk openly about their condition- share it with strangers while not receiving monetary compensation? It was difficult to cast a wide net to find metastatic breast cancer individuals and we worked hard and brainstormed on where to search for our informants.

I created a recruitment flyer and contacted breast cancer support groups, asking them to handout the flyers at their meetings, email it to their members, and post it at their establishments and on their websites. I posted requests in breast cancer online dialogue chambers and I also contacted churches and senior centers. And, lastly and most unconventionally I had volunteers post the flyers at grocery stores. I went through two time search phases in an attempt to reach individuals who may have been missed in the first search phase.

The recruitment flyer can be viewed on the following page and on the subsequent pages is the recruitment contact information.

Volunteers Wanted for a Documentary!

San Jose State University

*Beyond Pink – Living With Terminal Breast Cancer
Our Story*

Would you like to share your story of living with stage IV breast cancer to help others?

We are looking for volunteers with stage IV breast cancer to take part in a documentary on coping strategies.

As a participant in this research, you would need to attend one studio visit and be filmed while being interviewed.

To be eligible for this project, you need to be over 17 years old living with stage IV breast cancer. There will be no monetary compensation.

For more information about this study, or to volunteer, please contact:
Mary Koskovich 650-380-5958 Marykoskovich@gmail.com

Figure1. Flyer

Phase 1	Phase 2	Source	Response
9/7/11	10/22/11	breastcancer.org http://www.breastcancer.org/	posted onto dialogue chamber- 2 responses
9/7/11	10/22/11	breast cancer connections info@bccconnections.org	posted at facility
9/7/11		bay area breast cancer network (408) 261-1425	
9/7/11	10/22/11	Threads of Hope Breast Cancer Support (Fremont) triciamc@bralady.com	
9/7/11	10/22/11	Kaiser Permanente Cancer Support Group (Fremont) rebajom@aol.com	posted at facility
9/7/11	10/22/11	breast cancer survivor support	posted at facility
9/7/11	10/22/11	Bay Area Young Survivors bayareayoungsurvivors@yahoo.com	
9/7/11	10/22/11	American Cancer Society http://www.cancer.org/Aboutus/HowWeHelpYou/app/contact-us.aspx	
9/7/11	10/22/11	El Camino Hospital	
9/7/11	10/22/11	American Cancer Society Contra Costa County Unit	
9/7/11	10/22/11	Cancer Support: Chinese, Donaldina Cameron House, SF http://cameronhouse.org/cameronhouse@cameronhouse.org	
	10/22/11	Stanford Renewal & Recovery Breast Cancer Support Marcie Pais, MFT (Support) (650) 725-9456	hgautier@stanfordmed.org
		Washington Hospital (510) 608-1356	
		Kaiser Santa Clara Breast Cancer Support Group 408-851-4316	
		bay area breast cancer network 408 261-1425	
9/7/11	10/22/11	zero breast cancer info@zerobreastcancer.org http://www.zerobreastcancer.org/contact.html	

Phase 1	Phase 2	Source	Response
9/8/11		Shanti's LifeLines Breast Cancer Program (LifeLines) http://www.shanti.org/pages/about-lifelines.html 415-674-4780	
9/8/11	10/22/11	breast cancer fund http://www.breastcancerfund.org/info@breastcancerfund.org	
		Susan G Komen http://ww5.komen.org/ThankYou.aspx	posted into dialogue chamber- no response
		Susan Love http://www.susanlove.org/	
9/8/11	10/22/11	Y-ME http://www.y-me.org/ http://www.y-me.org/contact/	
9/8/11	10/22/11	Metastatic Breast Cancer Network http://mbcnetwork.org/mbcn@mbcnetwork.org	
9/8/11	10/22/11	Breast Cancer Action http://bcaction.org/info@bcaction.org	
9/26/11	10/22/11	bay area breast cancer and the environment research rhiatt@epi.ucsf.edu	
9/26/11		Cancer Resource Center UCSF CancerResourceCenter@ucsfmedctr.org http://cancer.ucsf.edu/howtohelp/ 415-353-7776	
9/26/11	10/22/11	http://www.sfsenior.com/kaitam@sfsenior.com	
9/26/11	10/22/11	almaden senior center info@almadenseniors.org	got an email - will post it
9/26/11		Yu-Ai Kai senior center staff@yuaikai.org	got an email - will post it
9/26/11		cypress senior center district1@sanjoseca.gov	
9/26/11		city of santa clara senior center custservsrcenter@santaclaraca.gov	

Phase 1	Phase 2	Source	Response
9/26/11		city of milpitas senior center abueno@ci.milpitas.ca.gov	The City has guidelines on what we can post publicly. Postings are reserved for local non-profit organizations, schools, and City-sponsored programs.
9/26/11		city of east palo alto community services mokelo@cityofepa.org	
	10/22/11	Fremont Breast Cancer Support Group smantz@aol.com http://www.kathywoodyard.com/html/support_bayarea.html	
	10/22/11	Post in grocery stores in San Francisco and Berkeley	

Figure 2. Sampling Outreach History

To following is a copy of the email I sent to most of the sites that I contacted for recruitment (and resembles the phone conversations I had while searching):

Hi-

My name is Mary- I have metastatic breast cancer and I'm trying to finish my master's degree. My master's degree involves creating a documentary on individuals with metastatic breast cancer. My research team and I would like to interview metastatic breast cancer individuals and hear them tell the stories of how they cope with a terminal illness on a day-to-day basis.

Would you consider hanging my flyer at your establishment

and/or

posting it on your website

and/or

handing it out at meetings to help me find individuals with metastatic breast cancer who would like to share their stories in our documentary? I would really appreciate it. I've attached the flyer.

Please call me at 650-380-5958 or email me at:

Marykoskovich@gmail.com

Thank you

Mary Koskovich

San Jose State University Graduate Student

Figure 3. Outreach Communication Sample

I may have received greater access to informants because of my status as a person with their same unique terminal condition. Therefore, I may not have received informants if I did not have the same diagnosis or I may have only gained access to fewer individuals if I

did not have cancer myself. It would be interesting to have someone without metastatic breast cancer attempt to gain informants (I acknowledge that this is a different study all together, but worthy of further exploration elucidating the different sampling responses based upon insider gathering versus outsider gathering).

My searches resulted in six participants: Michelle Moskalik, Wave Geber, Laura Philben, Janet Sollod, Lydia Mackovitch, and Birgitte Moyer-Vinding (not including myself). One individual died before we could interview her (Wave) and then another individual initially indicated that she wanted to be interviewed but when we attempted to schedule her specific studio date and time- she then declined. Laura did not want to give a reason for why she changed her mind and I did not feel that pressing her for an answer would neither be tasteful nor fruitful. We choose not to film Birgitte due to the combined issues of tight studio availability and the desire to complete the project sooner. We had a *first come first serve* policy and interviewed individuals as soon as they contacted us and we were able to schedule them for studio filming time slots.

The four individuals that we filmed heard about the project from different sources. Michelle heard about us through an email from Breast Cancer Connections. Several years ago she attended their in-person support group. She stopped attending the in-person support group but asked to remain on the mailing list. Thus receiving a recruitment flyer in an email, she responded to our request. Janet learned about our project through BAYS = Bay Area Young Survivors, through a post in their Yahoo group. Lydia heard about us through her Breast Cancer Connection's in-person support group. One of the therapists announced and

handed out a flyer then Lydia responded. I, of course, heard about the research because I am the primary interviewer.

As noted earlier in my discussion, Pelto and Pelto (1970) state that: “When we as anthropologists decide to qualify some of our observations of social behavior, we are faced with the problem of defining the universe of observation and devising ways of ensuring that observations fairly represent that universe (Pelto and Pelto 1978:127).” We received access to a very biased group because I only received responses from individuals who were attending in-person metastatic breast cancer support groups or had attended in-person support groups. This pool does not fairly represent the universe of metastatic breast cancer individuals on the planet, within the United States or even within the Greater Bay Area. Therefore my research team and I were unable to ensure that observations fairly represented the universe of metastatic breast cancer individuals.

When we began the conceptualization phase of the project our research team imagined interviewing a wide variety of individuals such as those who were: obese, racially diverse, without medical insurance, caring for young children and/or the elderly, unable to have children, males, and those diverse in their sexual orientation. In retrospect this was a lofty and diverse goal but still may not have ensured that observations fairly represented the universe of metastatic breast cancer individuals as that no data exists that indicates the specific percentage of metastatic breast cancer individuals with the characteristics of obesity, race, medical insurance, burdens of caring for the young and/or old, sexual orientation, and those unable to bare children as a consequence of their treatment. There is one characteristic that data exists for: there are approximately four male metastatic breast cancer individuals

living within the Greater Bay Area. I tried very hard to find male informants. I repeatedly posted in the male metastatic breast cancer dialogue forums on several sites, but I was unsuccessful- no males responded. I felt as if I was an interloper because I was posting within a dialogue chamber that was labeled “Males With Metastatic Breast Cancer”; though, no one made me feel unwelcome. Many individuals viewed my request, but no one responded to me.

Pelto and Pelto’s (1970) statement seems to underscore our situation: “Different sampling strategies in urban research reflect differences in researchers’ theoretical intentions as well variations in size and complexity of the research setting (129).” Our theoretical intention was to gain the depth and richness of a few terminal breast cancer stories. The size of our sampling pool had served to be a large barrier in attaining a robust response (along with many other factors). These other factors serve to make the research setting quite complex and are discussed in the next paragraph.

“Strict random sampling requires that every individual (or other unit of observation) in the population has an equal probability of being selected. Randomness in sampling is highly desirable for any quantified data that are to be analyzed by means of inferential statistics (Pelto and Pelto 1978:128).” In our research we did not use strict random sampling because many factors influenced our ability to do so: 1) participant’s willingness to be on film, 2) participant’s consent to a lack of anonymity, 3) a very small pool of people living in the US with metastatic breast cancer and an even smaller number of individuals living in the Greater Bay Area within driving distance of CreaTv in San Jose, 4) participants willingness to talk about, share, and be open with strangers about their terminal condition, and 5) random

sampling would have included individuals who were less than eighteen years old and owing to the time constraints of Institutional Review Board approval we opted to exclude this age group. This method of sampling was very much non-representative of the terminal breast cancer community and was quite biased as it selected for those who had the time to travel to San Jose's CreaTv, time and personal funding to sit for the two to three hour of interviewing, for those with the inclination to share their story on film, and an age group greater than seventeen years of age.

Along with our limitations, haphazard sampling created a sampling bias. Pelto and Pelto (1978) are indicating that statistics are influenced by the sample. Therefore, Pelto and Pelto are indicating that if one doesn't take care to specifically select a non-biased sample- then the statistics are not useful for generalization. But the other side of this coin is that if biases are understood and laid with the various limitations, then this information can be included in the final analysis in a contextualized way that leads to a greater understanding. I agree with Pelto and Pelto (1978) that our data cannot be used for generalization, but that was not the goal of the project. Instead the goal of our research was to take a very small number of individuals and ascertain their stories- to get depth and richness as opposed to breadth.

We could only have a few individuals tell their stories in a documentary, as that the typical length of a documentary limits the number of individuals' stories. There is merit in quantitative analysis and there is merit in qualitative analysis; our analysis is quite obviously the latter. This is an in-depth examination of a non-representative, self-selected sample of individuals and the project goal is to explore variations and similarities across that diversity.

Budget

Funds to support the documentary project were gathered through the Tower Foundation and IndieGoGo. The Tower Foundation directly manages all financial aspects of the San Jose State University donations and IndieGoGo is an Internet platform designed to assist individuals in raising and collecting funds for charitable causes. As various individuals learned of our project they donated money for its completion and dissemination. Those that donated to the IndieGoGo site did so to give a wedding gift as I got married during the project and requested donations for the project instead of wedding gifts.

To follow was our proposed budget that we created when we started the project:

Proposed Expenditures
Seven participants – audio break-in intro interview – coffee/tea, water, snack = \$42
Use of the CreaTv studio for filming - \$100/hour with two CreaTv assistants x seven interviewees x three hours each = \$2,100
Editing film – this will be done by the Student Team Members and some of the Faculty Supervisors = \$0
Dissemination of film = \$0 (through freely accessible venues such as YouTube, public access television and whatever other exhibition places)
Create DVDs = unknown
Transport seven participants to and from the studio (to be provided by interviewers) – fuel 0.54/mile x seven interviews x two (roundtrip) x fifty miles = \$2,646

Figure 4. Proposed Budget

Below is a chart with the current funds and actual expenditures:

	Tower Foundation \$5,000.00		IndieGoGo \$2,284.29	
Expenditures	Paid	Unpaid	Paid	Unpaid
Studio A Rental	\$400	\$1,000		
Flip Cameras				
Dusty Rose Blanket			\$34	
Snacks for Shoot		\$60		
DVD's		\$11		
DVC's		\$30		
Producing-CreaTv	\$45			
Final Cut Pro	\$90			
After Effects	\$90			
Studio Access	\$45			
Advance FCP		\$90		
Canvas Bags			\$29.84	
Screen Printing				
Fuel for Drivers				
Dissemination of the documentary at conferences & other events				

Figure 5. Actual Budget, December 2011

Initially we thought we might have seven participants, but instead we only had four informants and none of the participants needed a driver making our fuel cost zero.

Therefore, we didn't need to spend funds for this proposed expenditure, decreasing

anticipated costs. Yet, there were areas in the budget that we did not anticipate, for example Final Cut Pro, After Effects, canvas bags, etc. The amount of funds we will eventually spend upon completing the project remains to be seen, but we feel confident that we have raised enough funds to complete the project. If we come close to emptying the accounts through creating and disseminating the documentary, we have ideas on how to raise additional funds, such as showing the film at a museum, having interactive activities and a discussion on the film's topics afterwards along with a walk/jog-a-thon.

Materials and Methods

After sampling and gaining candidates, I provided the consent form via email and then pre-interviewed each individual on the telephone. My goal in doing so was to gather general demographics, preliminary breast cancer information, answer any questions they might have, get the informants to start thinking about what we'd be asking during the filming, explain the entire process, and hopefully cause them to begin to feel comfortable with me as their primary interviewer.

In appendix A are the documents outlining the candidates telephone interviews. These documents do not include all the topics we discussed on the phone because I wasn't able to type as fast as we were talking. Many candidates asked me for my terminal breast cancer story and were very interested in the treatments I had received and how I was responding to those treatments. I shared my story freely. You'll also notice that every informant did not answer all the questions as that sometimes we became sidetracked as they told me their stories.

In Appendix B are the open-ended interview instrument we used during our practice interviews and during our filmed interviews consisting of twenty-six questions and multiple probes. We emailed our informants this instrument before they were scheduled for their studio filming time so that they might become familiar with the questions before the filming started.

Immediately before we filmed each candidate in the studio we provided her with a paper copy of the consent form (which had been previously emailed), had each participant

read it again in the studio and then sign it. We informed each candidate that they could stop the filming at anytime for any reason. Additionally that if there was any footage they were uncomfortable with, it could be removed from consideration in the documentary. We would erase any copies we possessed. No interviewees made this request.

Sometime before, during or after we interviewed our informant- we gave them a Flip Video Camera to record B-roll footage for the documentary. We asked informants to film themselves while they went about their regularly daily activities so that we could insert these pieces into the film and have viewers get a feel for the informants daily life and personality. We asked for footage such as putting on a wig, taking medications, walking the dog, and basically any activity that informants felt would give us insight into their lives. We also asked for still photographs to add to the documentary.

I've discussed and displayed the materials that we used for the project now I'll explain the methods that were employed to construct questions and structure the probes.

The ability to navel-gaze stands at the forefront revealing anthropology's self possessed drive to divulge its own biases thereby questioning other's biases, setting anthropology apart from other disciplines, providing a deeper analysis. One of anthropology's strengths is also one of its weaknesses; in a world that commonly sees valid science as quantitative— qualitative analysis strives to gain a foothold for legitimacy.

Additionally, the anthropological emic/etic perspectives assisted us in allowing myself and the research team to give voice to and define meanings through the internal experiences of those living with a terminal breast cancer diagnosis while also allowing a toggling to the opposite extreme that provides the extrinsic concepts and meanings applied

from those outside the world of terminal breast cancer onto those having the actual experience. Since my research is ethnographic in nature, I will provide a detailed, in-depth, rich description of the everyday life coping practices and personal illness narratives of individuals living with terminal breast cancer while focusing on the tool of holism to understand the terminal breast cancer culture's system properties that cannot necessarily be accurately understood independently of one another. I will not only look at individual agency, I will also embed the discourse within the larger social structures because individual agency provides only a partial understanding.

The questions created to gather data from informants was critical. As Spradley so eloquently asserts: "The essential core of this [ethnography] activity aims to understand another way of life from the native point of view (1979:3)" and in keeping with this goal my interview questions must be carefully crafted to allow informants to reveal their native perspectives. Therefore, I must first set aside my belief in naïve realism, "[t]his almost universal belief holds that all people define the real world of objects, events, and living creatures in pretty much the same way (Spradley 1979:4)." I need to jettison the idea that all humans place the same meanings and definitions onto terminal breast cancer coping strategies and reject the notion that illness narratives will be very similar if not virtually the same within terminal breast cancer community members. Spradley stresses that "[e]thnography starts with a conscious attitude of complete ignorance. "I don't know how the people of Cushing, Wisconsin, understand their world. That remains to be discovered" (1979:4)." Accordingly, I began my research by stating: "I don't know how the people with

terminal breast cancer understand their world of coping strategies and how they experience their lives with a terminal diagnosis. That remains to be discovered.”

Theoretical Perspectives and Biases

I've briefly mentioned my personal experience with breast cancer and why it deserves status as an important topic, discussed sampling and the introductory details of the project, now I'll transition to describe the two theoretical perspectives used in two different books and biases: ... *And a Time to Die: How American Hospitals Shape the End of Life* (Kaufman 2005) and *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (Klawiter 2008); explain the ethnographer's assumptions, biases, and theoretical framework that shaped the conduct of research, the representation of the people studied, and the research findings; and describe some lessons that are relevant to my project.

After conducting two years (1997 and 1999-2000) of on-site research at three California community hospitals observing the course of over a hundred critically ill patients and interviewing them and their families in addition to speaking with doctors, nurses and hospital staff, Kaufman (2005) illustrates how the power of American medical institutions has shaped the experience of dying by creating a third option in ... *And a Time to Die: How American Hospitals Shape the End of Life*. Instead of being merely either dead or alive, one can experience "a prolonged hovering at the threshold between life and death (2005:4)" through the powerful hospital technologies implemented within intensive care units (ICUs) such as breathing machines to replace failing lungs, cardiopulmonary resuscitation (CPR) to restore heartbeats and respirations, powerful medications to maintain faltering blood pressures, and feeding tubes to replace the conscious act of chewing and swallowing to sustain life.

While Kaufman's (2005) theoretical perspective addresses death by design via life support technologies through the stories of twenty-seven patients who find themselves in ICUs or in other specialized hospital units, Klawiter (2008) chronicles the activism surrounding breast cancer juxtaposing the realities of death and dying from breast cancer and the political movements employed in the hopes of altering the grim statistics. Despite their efforts the political activists find themselves wanting and their patients continue to wait and hope expectantly: "...breast cancer remains the most common cancer diagnosed among U.S. women and the second-leading cause of cancer death (behind lung cancer). The United States continues to lead the world in breast cancer incidence and mortality (2008:2)."

Unlike Kaufman's (2005) research, Klawiter's (2008) work results from data gathered over four years starting in 1994 using a roving, multi-sited technique visiting a variety of settings: community cancer centers, advocacy organizations, public health departments, research study groups, fund-raising events, educational forums, political protests, street theater, public hearings, town hall meetings, early detection campaigns, political coalitions, breast cancer summits, and international conferences. She describes how breast cancer is discursively constructed as a curable disease, explains the creation of "an expansive disease continuum that includes all adult women (2008:xxviii)" because asymptomatic women come to be viewed as a new population of patients at-risk-of-getting-breast cancer, and illustrates the accomplishments of the breast cancer movement such as the reshaping of breast cancer culture from a regime of silence, shame and concealment to a regime of openness, baldness, beauty, power, and verve.

Unlike Klawiter (2008), Kaufman's assumptions, biases, and theoretical framework revolve around her belief that "bureaucracy, rhetoric, machines and procedures define American hospitals and structure time and death within their walls, creating a new reality—death brought into life (2005:1)." Kaufman's viewpoint obscures the fact that only "...32 percent of all deaths in the U.S. in 2007 occurred in the hospital (Trott 2009:1)" which tells us that the bulk of Americans, 77%, die outside of hospitals.

Additionally, Kaufman argues that new technologies have significantly changed the dying process in the United States. But are ICUs, breathing machines, and other technologies such as CPR significantly changing the dying process of Americans more so than any other technologies that have been used in the past or are presently in current use? When compared with the life support measures taken to stave off death from coronary vascular disease (CVD), the ICU's impact appears insignificant. "Within five years following the first myocardial infarction (heart attack) at age forty and older, thirty-three percent of men and forty-three percent of women will die (American Heart Association 2010:8)." Individuals with CVD are placed within the third option of not being merely either dead or alive as that the constant thought/threat of death looms nearby causing them to hover somewhere between life and death through measures such as surgical placement of coronary artery bypass grafts, mechanical installment of coronary stents, and implementation of angioplasty which physically widens a narrowed or obstructed blood vessel through the inflation of a balloon catheter inserted into the clogged vessel (American Heart Association 2010:8). Essentially, a majority of heart attack patients are on life-support via these new technologies for an extended period of time with a vast majority dying within five years of

the implementation of the life support measures. Kaufman's narrow focus within hospital ICUs obscures the significant impact of technologies affecting individuals outside the hospital walls. She does not acknowledge the greater impact of these out-of-hospital and out-of-ICU patient experiences and thus offers the reader a biased lens for viewing those hovering between life and death.

While the assumptions and biases that Kaufman (2005) possesses remain unrevealed within her work, Klawiter employs a completely different tactic—openly laying out the impartialities inhibiting her judgments as evidenced in the following passage from her work:

There “...is the well-known and widely accepted story of the U.S. breast cancer movement. It is a popular story; it is a true story; it is a compelling story; and it is easy to understand. Like all stories, however, it is also partial and incomplete—partial in that it is shaped by particular ways of seeing and asking questions; incomplete—partial in that it is shaped by particular ways of seeing and asking questions; incomplete in that it privileges one site of activity and one organization. In this book I tell a different story about breast cancer activism. My account is also, and necessarily, partial and incomplete. The difference—and I believe it is an important one—is that I recognize that my account is partial and incomplete and I incorporate that recognition into my understanding of social movements in general and my conceptualization of the breast cancer movement in particular (2008:xxii).”

Klawiter explores and reveals her assumptions to the reader in an open manner. Yet perhaps there are biases that she is unaware of or is unwilling to share that remain unexplored and undisclosed within her work.

While Kaufman's (2005) bias centers on her assertion that ICU technologies significantly impact living and dying, Klawiter's (2008) bias lies within her desire to counter the mainstream understanding of breast cancer activism by mapping the contours of breast cancer within an embedded matrix of opposition to the mainstream. This approach is equally

advantageous and troublesome as that a narrowly sliced analysis can be rich and deep but lacking in generalizability.

How do Kaufman's (2005) and Klawiter's (2008) assumptions, biases, and theoretical frames pertain to my project and what are the specific lessons I learned from analyzing their inclinations? I am a woman living with a terminal breast cancer diagnosis; therefore my easily identified bias is that my perspective is deeply and inextricably intertwined within a personally experienced microcosm of dying- of impending death. I see a majority of concepts from the theoretical frame that humans are all terminal and with my physical end quickly approaching many of my theoretical concepts are filtered through a standpoint that a rapidly ensuing darkening into nothingness will soon descend upon myself and others (owing to my lack of a clear belief in an after-life existence- which is yet another layer of my multiple biases).

The most salient lesson for me imparted through my analysis of the work of Kaufman (2005) and Klawiter (2008) is that I would benefit from laying out my bias's within full sight of those who will read my work and in so doing I am upfront, self analytical, and revealing, saving the reader from the extra task of mining for my bias's affording them the luxury of possibly analyzing my research from a less skeptical perspective.

It cannot be taken for granted that I am a forty-one year old mainly heterosexual female of half-Caucasian and half -Thai middle-class heritage acculturated within the US mainstream. I am married with no children, fortunately possessing high quality medical insurance and I have a sufficient amount of social capital to secure work as a paramedic while gaining a full-time tenured faculty position at a community college at the same time as

earning an undergraduate degree and then subsequently going on to pursue a master's degree in anthropology. Owing to my education as a paramedic I have the ability to understand medicine at a deeper level than a layperson affording me greater ease in navigating the complex web of cancer treatment and oftentimes allowing me to be more demanding than the usual patient. All these factors and more obscure and narrow my analysis and exploration of those living with terminal breast cancer diagnosis, their coping mechanisms, and the stories they have to tell; and carry the same advantages and disadvantages of Klawiter's (2008) narrow presentation of a counter narrative pushing against the dominant, omnipresent perspective of the prevailing mainstream narratives revealing a lesser told, novel, thin-sliced but deep point of view.

While Kaufman's (2005) centers on her assertion that ICU technologies significantly impact living and dying, my research centers on the coping techniques on those living with terminal breast cancer. Our research is similar because both our explorations involve those who are dying and those who are having their lives extended. Kaufman's (2005) informants are having their lives extended by ICU technologies where as my informants are having their lives extended by chemotherapy, anti-hormonals, alternative methods and other treatments. Unlike Kaufman my research does not focus on ICU's impact on death and dying (the third option), my research focuses on coping techniques of those who are dying. Klawiter (2008) chronicles the activism surrounding breast cancer juxtaposing the realities of death and dying from breast cancer and the political movements employed in the hopes of altering the grim statistics. My research does not heavily explore the political movement of metastatic breast, but it does discuss the Pink Movement and its role in helping

individuals with terminal breast cancer cope. The thread that binds each of these research projects is the exploration of death and dying.

Kaufman (2005) conducts two years of on-site research at three California community hospitals observing the course of over a hundred critically ill patients and interviewing them and their families in addition to speaking with doctors, nurses and hospital staff. Klawiter's (2008) work results from data gathered over four years starting in 1994 using a roving, multi-sited technique visiting a variety of settings: community cancer centers, advocacy organizations, public health departments, research study groups, fund-raising events, educational forums, political protests, street theater, public hearings, town hall meetings, early detection campaigns, political coalitions, breast cancer summits, and international conferences. I take twelve hours and forty-five minutes of raw video footage and analyze it. In comparing all three projects it is clear that mine is a endeavor of much smaller scale.

Despite the similarities of our research touching on death and dying, each of our projects does so in a very unique way. Kaufman is interested in the creation of the third option. Klawiter is exploring the political activism surrounding breast and how that relates to the breast cancer death rate and my research delves into the coping strategies used by individuals with terminal breast cancer.

Chapter 2 Analysis and Findings

I've discussed goals; sampling; budget; material and methods; theoretical perspectives and biases; and now I'll move to the data, analysis and results. Below is a table indicating the filming date, filming time, primary interviewer and back-up interviewer/s

Informant	Filming Date	Filming Time	Primary Interviewer	Back-up Interviewer
Mary Koskovich	October 21, 2011	2:00pm – 5:45pm	Dr. English- Lueck	Cassandra
Michelle Moskalik	November 11, 2011	12:30pm – 4:30pm	Dr. English- Lueck	Cassandra
Janet Sollod	November 28, 2011	6:30pm – 9:00pm	Mary Koskovich	Cassandra and Dr. English- Lueck
Lydia Mackovitch	November 30, 2011	6:00 – 8:30pm	Mary Koskovich	Cassandra and Dr. English- Lueck

“Coping has been define as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus and Folkman 1984) “Because coping involves shifting

processes as the relationship between the person and his or her environment changes, it may involve different forms of coping at different times (Corr et al 2002:107).” In the following chapter we will see how each informant copes with their death and dying process.

Day-to-Day Psychological Coping

In her interview on October 21, 2011 Mary Koskovich says:

“So my whole life crumbled when I got the diagnosis. It was extremely devastating and I feel like on a day-to-day basis I work really hard. I struggle to come to terms with it [the terminal diagnosis] and at some moments I feel like I’ve reached coming to terms with it. So, I’m in one of three states usually: denial, or acceptance (okay they said I have one to five years to live) um, the average person lives 22 to 24 months after diagnosis - of a terminal diagnosis. I happen to be at 29 months. So, maybe sometimes I like to think of it as its not a terminal diagnosis because we’re all terminal it’s a coping- like diabetes – that I’ll be able to be treated and then I’ll get to live. And then I think is it [the hope of living longer] some bullshit because they [people with a terminal breast cancer diagnosis] didn’t want to deal with the fact that they are probably gonna die. Who out there is living that long? Um, so I vacillate between three states: denial, no I’m really gonna die and its gonna be between one and five years and me saying I’m gonna take one day at a time - I can be treated and it can be treated like diabetes. They [the medical community] can hold it at bay. But if they could hold it at bay or cure it [metastatic breast cancer] would be cured - it would be being treated like its diabetes.”

Mary toggles between one of three states to psychologically deal with her terminal diagnosis on a day-to-day basis: denial, acceptance, and a quasi denial state. She does not discuss what she thinks about when she is in a state of denial. Mary only says that she uses denial as one of her ways of coping. In her acceptance state she faces her illness and prognosis head-on and she accepts that she has between 1 and 5 years to live. Additionally, Mary tries to use something I’ve named as: a *quasi denial* state in which she tries to convince herself that her illness can be managed in a similar fashion as diabetes. She wants to believe that she can live longer as the disease is treated in the same fashion as a long-term illness (as opposed to a terminal condition). But she is unable to convince herself of this idea because there aren’t many individuals with terminal breast cancer successfully living this way. Mary

toggles between three states to cope with her day-to-day feelings of having a terminal illness: denial, acceptance and quasi-denial.

Quasi denial differs from denial in that quasi denial involves rationalization. In this case the rationalization is that the terminal conditional can be treated as if it's a persistent illness, thus transforming a terminal condition into a chronic one. In denial there is no rationalization. There is only a denial of the entire state of being terminal- a refusal to look at it- a refusal to accept it.

In her interview on November 30, 2011 Lydia Mackovitch states:

“When I got diagnosed, um, metastatic –I actually.... I guess I'd been through some of that [fear and trying to cope] before. But my primary thought was: ‘I can't leave my son.’ ‘What's going to happen to my son?’ ‘I want to be there for him.’ Um, it hit me in...being diagnosed as someone without a child versus being diagnosed as a parent was for me a whole different experience. I don't even generally go to the place of worrying about myself dying - even though I don't want to die. My whole thought process is: ‘I don't want to leave my son.’ And so it's a really weird thing that it's [the terminal breast cancer diagnosis] hit me so differently.

Um, but in addition to that at some point once you're diagnosed as metastatic, I mean, it's the worst news you can get. And then it's like- ‘Well now what?’ – ‘Now let's go on and live life.’-because people live a lot longer now with this diagnosis. And so, you know, you have to go ahead and do stuff. So you live your life one day at a time. And there's not anything to fear any more in a way. And so, I have a lot of hope. I think they [the medical community] are coming up with new things [treatments] all the time. And so in a sense I'm not in that fearful place that I was originally. I'm more hopeful and I'm looking for more- ‘what can I do to stay here as long as possible?’

One of the hardest things with my metastatic diagnosis...is again that guilt that I might not be there for my son. On the other hand I feel like for me one of the things that I'm luckiest about with this diagnosis is that I have my son. It's so hard with a metastatic diagnosis....one of the things you need to do is concentrate on the present moment...enjoy today and not worry about what's going to happen next month, next year, whatever...to live in the moment and no one is better at that- living in the moment- than children. And so having a child teach you how to live in the moment to pull you into that has for me has been huge I think in helping me cope with this.”...

... “I don’t tend to get angry about my disease. I don’t know who’d I’d be angry at. But, you know, some people do get angry you know they voice their anger. And I think its good to be able to hear that and, you know, be around that. But one of the other things for me that’s good with me being in the group [in person terminal breast cancer support group]. For some reason I’m so good- I’ve learned so well from my son- to live in the moment and it’s like, you know, you’ve got a treatment decision –the cancer stuff is right there in your face. And when you don’t it’s there it’s always there but you don’t think about it so much.

Well, I find I’ve gotten so good at, like, not really worrying about the cancer thing that I kinda just live life as if I don’t have this thing hanging over my head. And I find going to treatment, I’m sorry, going to my support group every week – hearing other people talk about it – having other people use the word terminal – ‘You’ve got a terminal illness’ - it, it re-grounds me. It [hearing other individuals calling the disease terminal] keeps me from getting so far into denial that I’m not realistic about what I need to do to fight this disease. So it’s important to be able to ignore the disease enough to live life and have a good time. And be hopeful and do all those things and it’s also important to not get so far on that track [of denial] - that you say ‘oh I’m not gonna go do the chemo treatment’. I really feel I need to do everything I can to keep myself healthy.”

... “I try to be in denial about the fact that I’m a patient”

... ”Now I’m in enough denial I expect I’ll get there” [– referring to becoming a grandparent].

... “if I can stay healthy enough for the next new thing and the next new thing [treatment]. Each thing works a little better, you know, as they [the medical community] are coming up with new things. Maybe I can reach further and further [live longer]. So I’m actually more hopeful now. But again I feel like I don’t take on - I don’t want to take on a lot of responsibility as far as a job - career – that kind of thing.”

Similar to Mary, Lydia toggles between one of three states to psychologically deal with her terminal diagnosis on a day-to-day basis: denial, acceptance, and a quasi denial state. Her child facilitates her denial. Lydia says that her child teaches her how to *be in the moment*. This is how she avoids continually thinking about her terminal diagnosis and dying every moment. She is caught up with her child while being right with him in his moment

from day-to-day. Lydia is aware and understands that she is in denial and admits that this is how she copes. Sharoff (2002) labels this: *No-Mind-No-Thing*. He indicates that Lydia's strategy is: "[t]he intent to quiet the mind by staying in the here and now, respond to what is immediately present, and not shift to the past or future."

However, Lydia finds that the in-person support groups that she attends help to "re-ground" her so that she doesn't go into such deep denial that she doesn't deal with the day in and day out things that she needs to do to treat her illness. Mostly Lydia toggles between two states to cope with her day-to-day feelings of having a terminal illness: denial and acceptance. For most of her week she uses denial by being in the moment with her son. Then once a week she has an in-person terminal breast cancer support group that "re-grounds" her and pulls her out of denial so that she doesn't go so far down the path of denial that she denies the reality of the fact that she has terminal cancer and needs to treat it to stay alive.

Lydia's quasi denial is a little different from how Mary describes her understanding of it. Lydia links each treatment together – one after another in her mind. All these links create longevity and additionally she hopes new treatments are discovered to make her links even longer. Lydia does not describe her quasi denial as a hope to treat her illness as if it were a chronic condition. This is what distinguishes her from Mary.

In her interview on November 11, 2011 Michelle Moskalik indicates:

"Okay I have very little time left. I want to focus on the things that make me happy. And only, you know, spending time with the people that I most want to spend time with and spending time with my chickens and the garden and not stressing about anything really. And my husband and mother have been great because they've really given me the opportunity to do that. I think I went from being really, really depressed to on the verge of death really

I was facing death immediately. To realizing - 'no I'm still alive today.' And 'wow I'm probably gonna be alive tomorrow'. Even though I have this horrible diagnosis and the doctors had given me six months from March. I can do whatever I want with these days.

Honestly the AML [acute myeloid leukemia] diagnosis set me free. And made me feel happier than I had before with the breast cancer recurrence, because again I was complacent. I was angry about it and I was in a really bad place with the breast cancer I just felt like I was stuck and, you know, I had an expiration date but it was far in the future and, you know, there were things I could do and I could travel and do some things but I didn't really know when the time was going to come or how I would feel and that kind of thing. With the AML it was just so crystal clear that—'no this is it. You're...it's coming [death] and it's coming quickly.' So, life has changed since March.

And I think I woke up one day and realized that I want every single day to be able to do something that makes me happy that makes others happy that fosters the deep relationships that I have with other people, that brings me closer to my family and my husband and my animals. And uh, I know that unfortunately I can't do the things I could do before – as my doctor puts it 'I'm very fragile'. But I don't really feel that fragile. I can't hike or spend time in crowds - the leukemia kills the good cells in your bone marrow...my immune system is very low.

...I've taken on an attitude where before I, you know, I was very upset about it. 'Why me? Why do I have to deal with it?' to 'I'm living every day the best that I can and the, you know, the fullest that I can and I'm including the people that I really love and care about in those days. And I have no regrets at this point'...

...cuz now it's [death] really in front of me- 'I'm going to die soon and so I need to not do the thing - I need to only focus and do the things that make me happy.'...

...It's okay if I'm negative about this [my diagnosis] sometimes because you can't stay positive. It's such a horrible diagnosis. You can't always be up and say 'I'm gonna be fine'. 'And I have hope and I know that everything's gonna be fine in the future and it's gonna get better'- because I know it isn't."

Unlike Mary or Lydia, Michelle deals psychologically with her terminal diagnosis on a day-to-day basis with acceptance. She doesn't toggle between coping skills- she only uses one. Initially she had been diagnosed with terminal breast cancer and then during her terminal breast cancer treatment had a routine blood test eventually leading to the diagnosis

of AML. Doctors told Michelle that her AML was caused by the first breast cancer treatment she had received, as that AML can be chemotherapy induced. Because of the AML diagnosis Michelle was unable to receive treatment for her terminal breast cancer, as that chemotherapy can't be given to a patient with very low white blood cell counts.

Additionally, Michelle was not a candidate for AML treatment. AML treatment/cure involves a bone marrow transplant; but in order to be a candidate for a bone marrow transplant a patient cannot have a terminal diagnosis. Therefore, unlike the other informants in the research, Michelle was unique because she was not a candidate for treatment and her estimated time of death was six months from March; meaning she should have died in September according to the doctor's estimate but she was alive during the filming in November. Basically, Michelle had outlived her *expiration date* by two months and this set her apart from the other informants who had not reached their *expiration dates* (everyone else's expiration date had a range). Additionally Michelle was not a candidate to receive treatment for either of her cancers. She did not have the option of delaying her death with treatments.

Perhaps with imminent death in her face, a state of acceptance is easier for Michelle to attain. Lydia, Mary and Janet were not told that they would die in six months from the time of their diagnosis. They were not told that there was zero chance for a cure. Lydia, Mary and Janet were given the standard metastatic breast cancer diagnosis doctor statement: "The average survival of women with metastatic breast cancer from the time of the first appearance of the metastasis is between two and three and a half years, according to most studies. But 25 to 35 percent of patients live five years, and about ten percent live more than

ten years. And one or two percent are cured. (Love 2002). Lydia, Mary and Janet have the ability to know that their *expiration date* could be further in the future by several years and if lucky maybe they could be one of the one to two percent who gets cured or lives a good five or ten years. Lydia, Mary and Janet; unlike Michelle, had the option of hope for a longer life involving many years not many months. During the interviews Mary had had terminal breast cancer for two years and 9 months, Lydia for four years and Janet for three years.

Michelle indicates that she was angry early on in her diagnosis, but there was no anger during these last eight months (tragically, Michelle died two weeks after she was filmed). Michelle copes by knowing that she has control over each and every day that she is given. She copes by spending time only doing the things that bring her joy: spending quality time with those she loves, bonding with her garden and chickens, and making those she cares for happy.

In her interview on November 28, 2011 Janet Sollod says:

And sometimes I think I'm gonna make it a year and then sometimes I think I can have a 5 year plan. At some point someone asked - it was a friend who knew I had cancer and asked something about 'where do you see yourself in 5 years?' And, I was like—'in a pine box'. 'Where do you think I'm gonna be in 5 years[?!?!]' 'Really[?!?!?!]' I was, like, 'I have metastatic cancer. 5 years is thinking positively.' But as time has passed I've been metastatic for 3 years. I have mets they pop up and they get removed and they pop up and they get removed. And I'm feeling I could have 10 years. I could even maybe have 20 years. But that's like really hard to let myself to allow myself to even think about. 20 years is almost frightening.

You know, I've stopped investing money or taking a 401K out cuz, like, I'm not gonna make it to 65, you know. I do think I'm gonna make it to 40. And that for me is like a big step. Um yeah, but I think 65 is like not - I had a friend send me, a friend who works at Genetech, who makes the drug Herceptin which is one of my vitamins and, um, she at some point sent me an article about some new drug they [the medical community] have coming through the pipeline and how excited they are and the initial studies show an increase in survival from 2 years to 2.5 years. 'Don't tell me that[!]' 'I don't

wanna know that I could have 2.5 years instead of 2 years[!]’ I was so upset and angry with her. I couldn’t even answer. I couldn’t respond. I was like, ‘Did you read that before you sent that to me[???!!!]’ ‘You’re telling me I only have 2 years that’s not what you send to a friend [?!]’ ‘And in those 2 years is your drug even going to come out?’ Everybody keeps saying there’s all these new drugs in the pipeline. ‘That’s great but when am I gonna get them?’ So that’s how I was about 3 years ago with my first metastatic diagnosis.

But now I’m a little bit more optimistic and I look at those drugs in the pipeline and two of them are actually going to come out in the next six months. And I actually think I will benefit from them. So that’s nice. But when other friends talk to me about stuff- ‘oh this new data maybe we can use the bark of the willow tree’ - I’m just making this up - ‘to treat my cancer.’ ‘I think well that’s nice why don’t you let me know when its FDA approved.’ ‘Cuz I don’t need to know about it before that.’ It’s really hard to look at a timeline and see if that’s gonna help me.”

And it’s [the cancer] become this chronic illness, which is annoying and yet currently manageable. And it has its ups and its downs. And it’s like maybe like having diabetes. I don’t know I don’t have diabetes. But it’s just a chronic illness that I manage and sometimes it gets out of control and sometimes it’s under control and things are good and I can think about other things and go on about my life.”... “At this point I don’t think I’m going to die tomorrow or next year or maybe not even for five years – maybe even ten years.”

Similar to Mary and Lydia, Janet toggles between one of three states to psychologically deal with her terminal diagnosis on a day-to-day basis: denial, acceptance, and a quasi denial state. She predominately lives in denial and when someone shatters that denial she becomes quite mad, for example she becomes very angry with a friend that sends her an article about a new treatment that can extend life from an average of two months to an average of two and a half months. Janet has reached three years of survival and to have her denial ripped from her by an article causes her to go into a rage. Unlike Lydia and Mary, Janet never indicates in a straightforward manner that she is using denial as a coping skill.

I'm uncertain if she is consciously aware that she is using denial as a coping skill. There are no statements from her that indicate her awareness.

Janet's acceptance is apparent in her statement about being in a "pine box" in answering a friend when asked where she'll be in five years; indicating that she'll be dead and buried in a coffin. Further she has stopped investing money and taking out retirement funds, clear actions that acknowledge that she doesn't believe she'll be alive in the future to use the earned money from investments or 401k's. This acceptance was not forced upon Janet, as in the case of her friend sending her the article. Janet consciously chooses this state of acceptance.

Similar to Mary and Lydia, Janet has a quasi denial in which she hopes that the metastatic breast cancer can be treated in the same manner as a chronic illness such as diabetes. Mary stands out in her *inability* to truly accept that cancer can be treated as a chronic condition, but Lydia and Janet do not indicate doubts. Lydia and Janet use this quasi denial successfully to cope psychologically on a day-to-day basis. Mary can't quite make herself believe it and have it stick. She can't quite accept it into her psyche to successfully use it as a coping skill as indicated by this statement: "*And then I think is it [treating metastatic breast cancer like it's a chronic condition, much like diabetes] some bullshit because they [individuals with metastatic breast cancer] didn't want to deal with the fact that they [individuals with metastatic breast cancer] are probably gonna die. Who out there is living that long?*" Lydia and Janet use their quasi denial in a way that Sharoff (2004:9) would describe as *Certainistic Thinking*: "...a major problem when there is not supporting empirical evidence for a belief but an individual nevertheless maintains that idea is correct.

With certainistic thinking, a closed feedback loop exists and there isn't a search for supporting data." I suspect that Lydia and Janet are not 100% certain of their ability to live longer and longer otherwise why would they toggle between one of three states? Dr Love (2010:584) confirms this hope we can have surrounding metastatic breast cancer, but she is clear that the medical community has not hit the mark yet: "At the time I'm writing this book, nothing we know of can offer a cure. However, as new therapies are continuously developed, we have reason to hope that, as with AIDS, we can one day convert metastatic disease."

When Janet toggles between the three states of coping she does so in a different manner than Mary and Lydia – she switches from moment to moment between the three states. Mary and Lydia use one of the three states for long durations, for example Lydia uses denial - being in the moment - with her son for a week and then attends in-person therapy session and takes on acceptance. In one sentence Janet says she sees herself in a pine box in five years and a few sentences later she says she could live ten or maybe even twenty years.

Despite the similarities between Lydia and Mary's coping mechanisms, there are differences. Lydia suspends time when she is in denial being in the moment with her son. She removes herself from the past and the future and only exists in the now. When Mary uses denial she goes into the past and uses its healthy characteristics to pretend that in the here and now she does not have cancer. She jogs, rock climbs, wears her wig and consciously decides just to be "Mary" for the day. She refuses to think about cancer, death or the future, but her denial does not extend to a complete and deep denial. If a friend inquires about how her chemotherapy session fared, she would not say she didn't have

chemotherapy and therefore didn't have cancer. Mary's coping is a "day without cancer" or "week without cancer" in which she pretends, consciously decides to NOT act or thinks as if she has cancer. Mary and Lydia decide not to focus on cancer and death but utilize different portions of the time line to achieve their goal. Therefore, Lydia suspends and Mary goes back in time into the past.

Sharoff (2004:1) explains: "There is no such a thing as a "bad" or harmful coping skill. There are only bad or harmful coping strategies. When patients with a psychological disorder come to therapy, a skill may appear dysfunctional but that can be because of how it is used. Utilized in a different way or different context and supplemented with other skills, that same ability can be very beneficial." Thus, if one agrees with Sharoff the informants coping skills of denial, acceptance, and quasi denial are not "bad." If these skill/s lead to distress or dysfunction in every day living then according to Sharoff, the strategies would be considered harmful. For example, if Lydia used denial so extensively that she stopped getting her cancer treatments her strategy would be considered "bad" or harmful. If it is utilized appropriately (in the right amounts) and with other skill such as acceptance and quasi acceptance it is beneficial. Toggling between the three coping skills is a successful strategy for Lydia, Janet and Mary.

Corr, et al 2002 state: "Because they are living people, like people in other stressful situations, they [individuals diagnosed with a terminal condition] employ or develop a number of different ways of coping. Some people when confronted with an object that blocks their forward journey in life speed up their personal engines and charge full speed ahead, crashing into and perhaps through the barrier. Other persons who encounter a roadblock back away and try to find some way around it. Others simply remain stationary, not moving forward, not seeking a way around. Still other people go off in some different direction, seeing the roadblock as something that cannot be

overcome and that demands that some other road be taken. So dying persons may cope by withdrawing, or by becoming angry, or by finding what has occurred in their lies up to now that might make death acceptable. One major point to be underlined again is that different people cope in different ways (113)”

All the informants use multiple techniques to cope with their diagnosis, although Michelle stands out in her more recent uni-skill utilization of acceptance. I would classify the quasi acceptance as charging *full speed ahead*. Mary (although not convincingly), Lydia and Janet are ignoring the prognosis (walking right over it) and marching to *I can live longer and longer!* Each participant through acceptance finds a way around the roadblock. Or you could interpret that situation as: the roadblock no longer exists; it disappears. There isn't a problem to deal with when the participants employ acceptance. The struggle to cope ceases. None of the informants remained stationary: Lydia, Janet and Mary used the toggle technique and Michelle successfully used acceptance.

The reason that that the informants utilized the toggling technique and acceptance is that “Page 52 – [t]hese patients can consider the possibility of their own death for a while but then have to put this consideration away in order to pursue life (Kubler-Ross 1969).” It can be difficult to pursue life if one is in acceptance and acceptance caused a lot of thinking about death. In order to go about life Janet, Lydia and Mary toggle away from acceptance to either denial or quasi acceptance when they need a break from thinking of cancer constantly.

Moos and Schaefer have identified nine major types of coping skills (1986:14-19):

Appraisal-focused coping

1. Logical analysis and mental preparation—Paying attention to one aspect of the crisis at a time, breaking a seemingly overwhelming problem into small,

potentially manageable bits, drawing on past experiences, and mentally rehearsed alternative actions and their probable consequences.

2. Cognitive redefinition—*Cognitive strategies by which an individual accepts the basic reality of the situation but restructures it to find something favorable.*

3. Cognitive avoidance or denial—*An array of skills aimed at denying or minimizing the seriousness of a crisis.*

Problem-focused coping

4. Seeking information and support—*Obtaining information about the crisis and alternate courses of action and their probable outcome.*

5. Taking problem-solving action—*Taking concrete action to deal directly with a crisis or its aftermath.*

6. Identifying alternative rewards—*Attempts to replace the losses involved in certain transitions and crisis by changing one's activities and creating new sources of satisfaction.*

Emotion-focused coping

7. Affective regulation—*Efforts to maintain hope and control one's emotions when dealing with a distressing situation.*

8. Emotional discharge—*Openly venting one's feelings...and using jokes and gallows humor to help allay constant strain.*

9. Resigned acceptance—*Coming to terms with a situation and accepting it as it is, deciding that the basic circumstances cannot be altered, and submitting to "certain" fate.*

Figure 6. Major Coping Skills

Some of these nine coping skills can be seen in the behaviors of the participants. In their quasi denial state Lydia, Mary, and Janet use the *Appraisal-focused Coping Logical Analysis and Mental Preparation* by focusing on one cancer treatment at a time thus dividing a seemingly overwhelming crisis (the entire cancer treatment) into smaller, controllable bits. Instead of looking at all the treatment options and each of their possible outcomes, Lydia, Mary and Janet take one treatment at a time and hope that each treatment will some how link together in prolonging life or they hope their condition will be able to be treated as a chronic condition being converted from a terminal condition to a persistent state.

Cognitive Redefinition can most vividly be seen in Michelle's acceptance of her imminent death, she accepts the basic reality of the situation. Yet, Michelle feels she has control of each and everyday she is given. This is her restructuring of the situation to find something favorable. Lydia, Mary and Janet's quasi denial can't be defined as *Cognitive Redefinition* as that in quasi denial the basic reality of the terminal situation is not accepted. In quasi denial there is a denial of the basic reality of imminent death and there is a restructuring of reality and the facts to comfort the individual. Lydia, Mary, and Janet restructure reality by deciding their terminal condition isn't really terminal at all but merely chronic.

All participants except for Michelle use *Cognitive Denial*. Mary and Lydia consciously choose to use denial as a tool to deal with their terminal illness. Again it is unclear whether Janet is consciously aware of her use of denial as a tool. I use the term quasi denial for Moos and Schaefer's *Cognitive Avoidance* (1986:14-19). For Janet and Mary this takes the form of converting their terminal illness into a chronic condition in which life is extended. For Lydia, she hopes to link each treatment together thus living longer and longer.

Moos and Schaefer's (1986:14-19) *Seeking Information and Support* can be seen in the next chapter of the paper. All participants find information and support through in-person metastatic breast cancer support groups. Michelle and Mary stopped attending the sessions, but Lydia and Janet are still currently participating. Mary is the only informant that mentions gathering information and seeking support through on-line forums.

In Moos and Schaefer's (1986:14-19) *Taking Problem-Solving Action* coping skill the crisis is the terminal diagnosis. The actions employed by the informants are varied from

taking their treatments (anti-hormonal pills, surgery, chemotherapy) to spending more time with friends and family because the problem is that the participants have been informed that they will die sooner than they had previously believed. In a section further on in the paper I discuss a phenomenon called Extreme Behaviors Post Diagnosis. These extreme behaviors can be seen as problem-solving actions as that instead of procrastinating, participants act on their long held desires and dreams.

Moos and Schaefer's (1986:14-19) *Crisis Aftermath* can be seen as the events that occur after the participants' deaths, the fallout that occurs for the participants' friends and family. It can be difficult to plan funeral/memorial services; dispose of personal items such as clothes, jewelry, and cars; and attained assets. Mary has paid for and planned her memorial service, completed a last will and testament, Do-Not-Resuscitate Orders, Advanced Health Care Directive (Combined Living Will and Durable Power of Attorney) (orders for medical personnel if one is being kept alive on a machine and has a terminal illness additionally assistance via an appointed health care agent who makes health care decision in the case of the patient being unconscious is provided) and prepared papers for her beneficiaries to easily access her assets. Lydia, Michelle and Janet did not prepare the legal documents. Although, Janet mentions asking her mother if she'd take her apartment and also asking a friend if s/he would take her cat.

Janet uses *Identifying Alternative Rewards* more often than any other participant. When she was bald, she amassed a beautiful hat and scarf collection. Instead of focusing on the loss of her hair she focused on the fun of finding and buying attractive hat and scarves. And unlike Michelle, Lydia and Mary, Janet does not mention her mastectomy as being a

negative loss. She viewed her mastectomy as an opportunity to get new, bigger, and better breasts. Lydia, Mary and Michelle indicate many losses (in the Chapter called Bucket of Pain – Cancer Thief): breasts, libido, chemotherapy side effects, hip stiffness, feeling attractive, (as many participants complained of losing their hair, eyelashes and eyebrows), ability to have children, long term future dreams and aspirations, energy and vitality, getting to be a grandparent, and of health (as many participants complained of nausea, vomiting, diarrhea, and pain). After Michelle loses her ability to hike, she focuses on spending time with family and friends, her chickens and garden. Lydia enjoys her son as if she were a grandparent instead of a parent. This reorientation means she has more shared fun time with her son than discipline time. Mary attempts to rock climb El Capitan, deepens her relationships with family and friends, gets married, and goes on to completing her master's degree by filming the documentary. In the chapter, Extreme Behaviors Post Diagnosis, each informant participants in extreme behaviors, for example Janet travels to New Zealand and heli-boards (has a helicopter drop her off on the top of a mountain so she can snowboard to the bottom). These extreme behaviors can be defined as *Alternative Rewards*.

All participants used *Affective regulation*. Michelle hopes that she can have each of her last days be fulfilling by spending time with those she values. Lydia, Mary and Janet hope that they can live longer and longer with the disease. Mary and Janet hope the condition can be treated as a long term chronic, but not as a deadly condition.

Janet and Lydia use *Emotional Discharge* during in-person metastatic breast cancer support groups, as openly venting one's feelings is a standard activity in these

groups. None of the participants mention using jokes and gallows humor to help allay constant strain, but we did not ask this question specifically of our informants.

Mary, Janet and Lydia used *Resigned Acceptance* differently than Michelle. Michelle was given six months to live and she was two months past her *expiration date*, on the other hand Mary has been diagnosed metastatic for two years and eight months. “The average survival of women with metastatic breast cancer from the time of the first appearance of the metastasis is between two and three and a half years, according to most studies. But 25 to 35 percent of patients live five years, and about ten percent live more than ten years. And 1 or 2 percent are cured. (Love 2000).” Because these statistics allow for hope (unlike Michelle because her diagnosis was considered incurable), Mary toggles between denial, acceptable, and quasi hope. Mary hopes to be one of 1 to 2 percent who are cured or one of the 10 percent who live more than ten years or one of the 25 to 35 percent who live five years. Janet and Lydia’s situations are similar to Mary’s except each participant has had their metastatic diagnosis for a different amount of time. Janet has been metastatic for two years and eight months and Lydia has been metastatic for four years.

In her book *On Death and Dying*, Kubler-Ross (1969:63) indicates there are five stages in the death and dying process: the first stage is denial and isolation, the second stage is anger, the third stage is bargaining, the fourth stage is depression and the fifth stage is acceptance. None of our participants indicated that they isolated themselves, but we did not specifically ask this question as our inquiry was designed in the anthropological style of

open-ended general questions. All participants at some point displayed denial except for Michelle.

Kubler-Ross's second stage of anger was expressed Janet, Michelle and Mary. Lydia says she has no anger because she wouldn't know who to be angry with. Janet becomes angry when a friend asks her where she'll be in five years. She answers angrily that she'll be in a pine box. Another friend sent her scientific article that has a new drug coming out for breast cancer that increases the average two-year life span to two and half years. Janet is enraged. She can't believe a friend would tell her she would only get an extra six months. Additionally the article indicates that metastatic individuals only live an average of two years. Janet is incensed with the truth of this statement. She does not want to hear that her *expiration date* has passed. Michelle states that when she got her diagnosis she was so angry that she picked up a cabinet or some other object and threw it. Mary does not explicitly say: "I'm angry", but she has trouble coping and struggles. She is frustrated by her inability to do the physical activities she used to be able to do. She is frustrated that she doesn't feel as vital and vigorous as she once did before the diagnosis.

Lydia's desire to take treatment and then live longer and then take another treatment and live even longer, linking these treatments together to live a long life, could be interpreted as Kubler-Ross's (1969) second stage of bargaining. Michelle does not display any bargaining in her interview. Again, we did not specifically ask the participants if they participated in bargaining as our interviews were in the anthropological style of open-ended interview questions. Mary and Janet's desire to have the metastatic breast cancer become a chronic illness could be interpreted as Kubler-Ross's (1969) second stage of bargaining.

Some might argue that this isn't bargaining at all, but just a form of denial. Bargaining entails "entering into some sort of an agreement which may postpone the inevitable happening: If God has decided to take us from this earth and he did not respond to my angry pleas, he may be more favorable if I ask nicely (1969:93)". There is no clear entering into an agreement stated by any of our participants. The hope for a longer life is the postponement of the inevitable from happening.

Kubler-Ross's (1969) fourth stage of depression is only seen in Michelle. She clearly states that she has experienced depression. Lydia, Mary and Janet never state that they have experienced depression. This does not mean that they did not experience depression. Again, we did not specifically ask the participants if they experienced depression as our interviews were in the anthropological style of open-ended interview questions.

All participants expressed Kubler-Ross's (1969) second stage of acceptance. Michelle did not toggle she expressed clear and consistent acceptance. Mary, Janet and Lydia toggled between denial, acceptance and quasi denial, not staying in one state.

Corr et al (2002:114) in response to Kubler-Ross's stages

"In fact, since the publication of Kubler-Ross's book in 1969, there has been no independent confirmation of the validity or reliability of her model, and Kubler-Ross has advanced no further evidence on its behalf. On the contrary, some of the most knowledgeable and sophisticated clinicians who work with the dying have made known their view that the model is inadequate, superficial and misleading (for example, Feigenburg, 1980; Pattison 1977; Schneidman, 1980; Weisman 1972). Wide-spread acclaim in the popular arena contrasts with sharp criticism in the scholarly world and suggests that different factors may be at work in these competing assessments of Kubler-Ross's model (Klass, 1982; Klass and Hutch 1985)." Kuber-Ross's work has been found to be quite popular with the lay public but lacks scientific rigor. She pioneered the research in death and dying and should receive credit for this difficult and groundbreaking task."

On one hand it is clear that Kubler-Ross's work is controversial, many in the field question her work's strength and trustworthiness and on the other hand it can't be denied that she paved the way for all the research that came after her by bravely requesting access to patients dying in the hospital. In an ethnographic fashion, Kubler-Ross listened as they told their stories she recorded and then later transcribed the data.

Corr, et al (2002:109) indicate: "The needs of dying persons are both complex and highly personal. In part, they are shaped by social, cultural, and religious influences, as well as by family practices and personal experiences. As a result, each individual will cope with his or her own dying in his or her own way." We see in our participants the use of a variety in the ways that they cope with their condition. Lydia's in the moment denial with her son differs from Mary's straight out denial, which is different from Mary's quasi denial that stretches to the past for her to remember how fit and vigorous she was. She puts on her wig and does the activities such as biking and running like she used to. Lydia uses the present moment and Mary uses the past to achieve their quasi denial state.

In-Person Breast Cancer Support Groups

Each informant has attended in-person metastatic breast cancer support groups. Janet and Lydia currently attend sessions; and Mary and Michelle attended sessions in the past.

Janet states:

“How do I cope with my diagnosis? - some days differently than others. I rely on a support group that I’m part of which is a bunch of young women with also metastatic breast cancer and um, it’s a really wonderful group of women. And they help me, yeah, just to help me get through and um – I don’t know – um, I look at them and what they go through and what I’ve gone through is nothing compared to what they have to do [treatments]. You know some of them have brain mets and some of them have bone mets and lung mets and I only have liver mets.” ... “we all support each other and its really good group um, my family has been just amazing: helpful but scared I mean its really frightening to be told you have metastatic cancer of any kind.”

Mary indicates:

“I did attend a support group several times and um, I guess even though I know I’m terminal I got stuck in the terminal breast cancer group because if you get stuck in the early breast cancer group that scares those people - they don’t want to think about having a terminal diagnosis or it [the cancer] coming back. So I understand being put in that group.

I got very involved with online support groups...What was great was that I was able to come in contact with people that had - from all over the world - that had the same, um, problem as me and were encouraging...a lot of support.”

Lydia says:

“I do belong to a metastatic support group and that has been really helpful to be able to talk.” ... “And I also went ...there’s a support group in Palo Alto. I got involved in that. They have a buddy program. Where you are paired with somebody with similar issues and they help do research when you have to make a [treatment] decision and all kinds of things. I’ve been a part of that organization both as a client and then as a buddy to others who have been diagnosed.” ...So that’s been a great source [of support]”

... “So I belong to a metastatic breast cancer support group and um...it’s that I find its really helpful for me...for several reasons, um, I mean

some of it, I mean yeah, it's a place you can have whatever emotions you- whatever you want to say - whatever you want to feel - you don't have to kinda put on a good face or what have you- which I find with my family and friends I don't want them to be too upset and down about it [the terminal diagnosis] so I am more positive and uplifting with them. I put a positive face on it. I don't feel like I'm pushing it but I at the same time it feels better to me to have them be positive. And so I wanna...I kinda am...I stress the positives when I talk to them [my family and friends].

But it's good to be in a group where people can say the negative things. People can feel whatever they're feeling and it's okay to do all that. But what I really love - what everybody's stories are...what everyone's doing.

Part of it I don't have time to go out and search the Internet and read everything about ...I probably go crazy if I did. But when you hear about what actual people are doing, you know...oh this person went and got something re-biopsied or, you know, this person is on some new medication, oh, these are the side effects they get."... "We learned coping mechanisms from each other. Avastin can cause nosebleeds. And so someone said to you 'what I do is take a Q-tip and put Vaseline on the inside of my nose. And then I don't have that problem.' And so we all started doing it and we all got that benefit."

As for Michelle, she never indicated during her interview that she had attended in-person support group sessions. I spoke with her husband, after she had died, about how Michelle discovered the creation of our documentary and he told me that Michelle used to attend in-person support group sessions. Unfortunately, I did not happen to ask Michelle's husband if Michelle found the sessions helpful or other details. Mary did not seem ready to be in an in-person terminal breast cancer support group perhaps this indicates that she acknowledged and accepted her terminal diagnosis and perhaps she was not ready for this acceptance. Lydia and Janet are enthusiastic about their in-person support groups. Janet finds comfort in seeing that there are those who have worse diagnoses than hers. She can rationalize that she's not as bad off as that there are others who are doing far worse than herself. Both Janet and Lydia find comfort in being around others with the same diagnosis; gaining solace from walking the same path and sharing similar experiences with them. Lydia

mentions the relief from being able to let down her positive facade; she can be unhappy, angry or say whatever she wants when she is in the group. She doesn't have to pretend to be feeling hopeful about her condition. Additionally, Lydia finds other women's stories and their tricks-of-the-trade useful. She'd suffered from nosebleeds while taking a particular medication until another group member taking the same drug told her a secret for getting rid of nosebleeds.

In-person support groups serve not only as a place of comfort; to be around those who are suffering in similar ways, providing camaraderie and quelling loneliness; they help to contextualize the terminal breast cancer experience within a larger frame: some individuals have brain metastasis, some have liver metastasis, and still others may have it all over their bodies: brain, lungs, liver and bones. The sessions can be used to gather information about new treatments, side effects, effective counter-measures against adverse reactions, a safe haven to vent non-positive feelings, and a place to give and receive with those who are in a similar life circumstance.

Extreme Behaviors Post Terminal Diagnosis

I've discussed the psychological coping on a day-to-day basis and the in-person support groups, I'm now going to move to another thread which runs through each informant: extreme behaviors. Michelle states:

"I'm gonna die sooner. I haven't done enough with my life. I need to travel. I really need to get to know the people I have in my life now and build deeper relationships with them. And so that's what I did. I was working part time as a consultant, which gave me the flexibility to do a lot of traveling. I went to Europe. I went to Italy and France and Prague and just had these great trips. And I did small trips to Las Vegas or Disneyland, Napa and Boston and Chicago. We just traveled all over and didn't really think about, you know, 'Should I be doing this?' – 'Should I be focusing on my career?' The career became secondary. And it really became – 'I need to focus on what makes me really happy and doing the things I felt like.' 'If my life is being shortened I need to go do the things that I feel like I've missed out on and I don't want to miss out on any of those things.' So, that's what really changed."

Michelle deepens her relationships and travels the world while making her career secondary.

She focuses intently on what she believes will make her happy. Janet indicates:

"I'm trying to think of what was happening in my life when I was first diagnosed. And to me it's such a line. I call it BC (before cancer) and AC (after cancer)"... "there's such a big line between before cancer and after cancer, and I think so much has changed for me in my outlook since cancer um- I appreciate so much time with my family and friends. And I did that before cancer too. But since cancer I've taken more time off of work in order to spend time with family and friends and to travel and to do slightly crazy things that I wouldn't have normally done. Like rock climbing in Thailand, heli-boarding- in which - is snowboarding out of a helicopter in, um, New Zealand. I've done some crazy things since being diagnosed because I feel like - hey the opportunities come up – I'm gonna do it rather than waiting. And I've taken a lot more time off work more than I've ever had before or ever would have thought of before. There's been a big shift."

Similar to Michelle, Janet puts her career as a pediatrician on the back burner. And similar to Michelle, Janet spends more time with family and friends, and travels; but Janet adds *crazy sports* to her repertoire. She rock climbs in Southeast Asia and has a helicopter drop her off at a high mountain peak in New Zealand so she could snow board to its bottom.

Lydia takes a different avenue because she has a son and pursues what Dr. English-Lueck dubs “*extreme parenting*.” She wants to parent her son in the way that a grandparent might where there’s an abundance of pleasure without as much of the discipline: “I kinda try with my son to be both a parent but also enjoy it the way you sometimes see grandparents enjoy their grandchildren. You know, they really have fun and do that. And I try and kinda remind myself to do that a little more.”

Mary attempts to rock climb El Capitan, deepens her relationships with family and friends, gets married, and goes on to completing her master’s degree by filming the documentary.

Extreme behaviors are a thread running through all informants. Each participant felt the need to change after receiving the terminal diagnosis and each was similar in their desire to spend more quality time with friends and family. Yet each is also unique: Michelle chose to travel the world; Janet and Mary engaged in *crazy sports*; and Lydia takes on extreme parenting. I have heard of this extreme behavior referred to as the “*bucket list*” on www.breast.org Stage IV Breast Cancer Dialogue Chamber. Some members of this chamber make lists of all the things they have wanted to do, such as scuba dive the Great Barrier Reef, parachute from an airplane, and travel to see Niagara Falls, etc. Then the participants proceed to tick items off the bucket list, one by one.

Bucket of Pain – The Cancer Thief

Perhaps these informants would never have engaged in their extreme post-diagnosis behaviors if they had not been given a terminal prognosis; the terminal cancer may have given them the license to do things they may never have gotten to do or chosen to do in their lifetimes. If cancer can give, what can it take away? Mary states:

“Basically at 35 I went into complete menopause from the treatments. And that was hell.”... “not only were my boobs being altered I had to really think about: ‘Is estrogen really about making me a woman? - part of my sexuality? Can I still feel sexy?’ ...Frankly my sex drive is not what it was ... I have to work psychologically to tell myself- ‘I’m still sexy. I’m as sexy as I think I am.’”

... “So I just feel like the cancer takes away from me so much all the time that I have to remember... for me it’s like a bucket. And it’s a bucket of pain that surrounds cancer. And each droplet goes into the bucket. But those droplets are like rain and they don’t know that they are going into the same bucket. So I have to manage that [the cumulative pain] otherwise I find that I’m resistant to everything- like, I wanna just go - ‘fuck it’ - ‘I don’t wanna have any more treatment.’ You know- ‘I’m done with this.’ ‘This is total bullshit.’ So I have to sit there and on a day-to-day basis – you know, me having larger breasts is not connected to the chemo that I’m having at this moment. Um, so- it’s managing it [the cumulative pain] all the time.”

Lydia indicates:

“I have the, you know, the old lady stiff hips...When I’m on chemotherapy, um, you know, when I was primary, and that was fourteen and a half year ago, um, it [the treatments] was really harsh and I, you know, weeks during the weeks I had was sick from chemo. I mean I was on the sofa and just reading books and that’s pretty much what I did- just hung out. Um, when I was in the clinical trial with Gemzar/Avastin and Taxol I was doing everything. I was the primary caregiver for my son and we’d go to the park and we’d do all kinds of things. I mean I had, um, I was taking Decadron for the nausea and that worked really well. It also gave me lots of energy. However, it makes it really hard to fall asleep

...The thing that really got me was later after I’d been on Taxol for awhile- on the three [drugs] - um, I started losing eyebrows and eyelashes that was when I think I felt I started to look sick as opposed to - it’s really strange - you could look like a really healthy person bald. I mean most people who

see a woman who's bald probably has cancer. But when you lose your eyebrows and eyelashes - you don't look the same

...I think one of the big things when I've been going through chemo is, um, it really makes it hard for me to do work, uh, I just don't have the energy to do everything...

At times when I felt from chemo - I thought 'this might be the best I ever feel for the rest of my life' because I don't know what's happening. I don't know what my future is...

I'm not working now but I find, like, even doing things like my bills or, you know, papers just get piled up and what have you. It's hard to get through all that. Ah, so that's definitely there's some things that do not get done...

One of the hardest things with my diagnosis, my metastatic diagnosis, is, you know, is again that that, uh, guilt or whatever of, you know, that I might not be there for my son...

When I had my mastectomy, um, I remember, you know, it was emotional, you know, it's like this part of me [my breast], you know, that I've had all my life - is going to be taken away. And I remember more it was, um, you know, a mourning process or whatever- you know, I remember the morning of my surgery, you know, saying goodbye. Um, you know, I think probably in the beginning I had a little bit of feeling of, you know, gosh, it's, you know, being intimate with your husband or whatever you feel kinda awkward you don't look good, you know, I remember wearing a camisole or something just because you don't feel as beautiful, you know, or whatever...

And so I ah, I remember when I had my ovaries removed- that was a bigger deal for me. It's not - it's weird cuz it's not externally visible but you're taking away your hormones - you're taking away your ability to have a baby...in a way that was kinda hard to deal with. But I mean actually that was more defining I think to me as a woman - straight, you know- in some ways, but uh, I don't know I guess I sorta feel I'm more akin to like a grandmother or something because I don't have all these hormones raging through me and I have the hips get stiff and things like that...

It changes, you know, having the metastatic diagnosis it does change your long-term view of things. Um, you know, I had at some point wanted to go, uh, I have a master's degree and I wanted to go get a PhD, you know, uh and it just kinda says 'well that's I'm just not- I'm not gonna do that' ...I had to let go of that part of me...

The biggest thing when I was first diagnosed, metastatic that is, um, I mean, I didn't know how long I had to live, it's a, you know, you're whole- everything shrinks down. Um, I had this young child who- my son was nineteen months old and I'm constantly pushing him in the carriage and stuff. And, um, I ah, one of the places we used to go we had a music class, uh, and it was right next to a senior center. And so I'm always there with him in the stroller and there are all these grandparent-aged, you know, people. And the

first couple months when I'm in shock and everything - I just had tears streaming down my face as I'm pushing this stroller along because I'm thinking 'I'm never gonna be a grandmother. I'll never be even that grandparent age. I'm not getting there, you know.' And that was, like, a really hard thing...

And I'm a very open person- I would just tell everybody. You feel like 'well I don't want to ruin their day'- you know with this news and it's kinda of a weird thing. Um, I do find, you know, when I'm talking to with people or in a group it's in the back of my head I remember that I'm different from them that I have this thing hanging over my head. Um, I'd prefer people to know then I don't have to think that to myself..."

Janet says:

"There's also the fertility issue which has been a big issue for me. ...Before cancer I was 32 and I thought I had lots of time to have kids and meet the right person. And, you know, I wasn't in a rush, um, and I just thought that that would happen for me. Um, and then I was diagnosed. And the very first thing I thought was 'oh my God my eggs'- because if I have chemo 'its gonna fry my eggs'- maybe I mean I didn't want to risk that [having her eggs damaged by the chemo] so, um, so I had eggs frozen and um, some fertilized, um, I had a friend. And I had some not fertilized cuz I still thought I might meet someone who might wanna, you know, be a father for my child, etc. So, um and that's been another big, long saga. Um, which is now sadly ended. And I can't have children. That's a huge lose. I'm a pediatrician and I always thought I would have children. And to not have that to not be able to have that was one of the biggest losses that cancer took from me...

...so basically in the end I decided to go for the surgery and the bigger more painful recovery [instead of radiation to the liver]...

...and I get Faslodex which is another kind of anti-estrogen. It's also the largest shot in the butt that you have ever seen. It's brutal. It's awful. I've had a lot of treatments, surgeries, and my first shot of Faslodex - I nearly fainted. It was so painful...

...I've had a range of side effects ranging from just horrible diarrhea to, uh, skin cracked and peeling...I have vomited from chemo only about three times - which is pretty good...

...I was really sick at that point - throwing up...that was a pretty low point after my second chemo. Second chemo hit me like a baseball bat...turns out that was the worst...I needed my babysitters, I was sick. Um, and, uh, yah, that was the worst time. After that I became really fearful of that [vomiting] happening again. And so after my third chemo I took all these nausea medicines and it was actually better than the second one [chemo treatment] but I was just so afraid. I was terrified...

...still tired but no nausea [describing the next phase of chemo]. And you lose your taste buds and I remember at one point making myself chocolate chip cookies, which are my favorite thing in the whole world. And they tasted funny. They weren't right and I kept giving them to people. 'Try this. Is it wrong? What's wrong with my cookies?' And they're like - 'There's nothing wrong with your cookies. You just can't taste them.' And that was really sad...

...I had one horrifying experience looking for a doctor. I was looking for an oncologist and there was the guru. And everyone said 'you must go to this doctor.' And a friend of a friend goes to her and helped me get an appointment some how. This was someone who I could not get an appointment with by calling on my own. And somebody who knew this doctor got me an appointment. I knew that I was an extra appointment. I was an add-on...And, I was possibly in a slightly weakened state because I had already started chemo. And I had just had my first chemo about two days before.

And so I go to this doctor where I know that she's busy and I know that she's overbooked and I know I'm an extra patient. And they put me in this little gown in this little room for four hours. I sat there for four hours [!] Luckily I had brought a Cliff Bar with or I would have probably fainted. I didn't go to the bathroom because I thought if I left to go to the bathroom I'd miss her. By the time she came in I, like, I was nearly passed out. I couldn't - I don't even know what she said. It didn't matter. I would never treat a patient like that - ever. Nobody came in and said 'it'll be another minute'. 'It's gonna be an hour- why don't you go take a break.' Nobody came in my room. I was in the room by myself for four hours...

...I haven't felt at all disfigured. I have a mess of scars. But I had the plastic surgery with my mastectomies. So I call it my free boob job and I came out bigger and nicer than when I went in. At this point, breasts are just decorations. Um, because, um, because of breast cancer I've lost my fertility, um, and but I haven't lost my sense of, um, of being a woman...

...Since cancer I've been a lot more, um, I guess uh bold in the way I dress. I think I've gotten more fashionable and more willing to wear something sassy or try something bright and bold. Um, so cancer's maybe enhanced my sense of fashion. No, not my sense of fashion but my ability to coordinate - and I also discovered because of cancer hats and scarves - because I was really cold. Um, and I didn't like wigs, so I wore hats and I've amassed an awesome hat collection and I think it's an accessory that everyone should have. And I love my hats and people compliment me on my hats all the time. It's fabulous - and these hats and scarves. And also earring became really important when you're bald and when you have short hair - and, um so that's helped me a lot. I know that a lot of women feel that having the mastectomy or losing their fertility, um, has taken away their sense of being a woman or being female. And I'm lucky I haven't lost that sense.

I have lost my fertility and ability to have my own child. And that's been really hard. Um, but it doesn't, I think make me less of a female - less of a woman. Um, it just - me unable to have a future or leave a something behind. That's not the right word...have a legacy. Is more of what a child was to me and also for when I go I [die] as I had hired a surrogate and I had, um, frozen embryos that I tried to use to have a baby...

Michelle states:

... "I also had my ovaries removed and was thrust into immediate menopause which was fun - lots of hot flashes and everything that goes along with that." ... "Instead of as before [during the primary diagnosis] where I had, you know, the belief that I'm fine I'm cured the future is bright everything's the same as it was. My focus completely shifted to 'I'm not fine' it's great that I'm stable, but this isn't going to go away. This is chronic. This [the cancer] is going to kill me someday. And that was sad." ...

"When I'd previously been very active - it was just such a blow that I couldn't do a lot of things that I was doing before. That was hard"

... "The one thing that I didn't anticipate was, you know, you see these people who have cancer on television and they have a bald head and I can tell that they are sick. But they don't tell you - you lose your eyelashes and your eyebrows and you look like a turtle - at least that's how I felt about myself. And so, there was a time during the reoccurrence where I felt just unattractive and not healthy and really wanted to get back to, um, feeling better about myself."

... "I know that unfortunately I can't do a lot of the things I used to do before. The way my doctors puts it 'I'm very fragile' ...I can't really hike any more and I can't spend a lot of time in crowds because...since March, you know, I've lived with constant doctors and hospitalizations and things like that

...and the cancer diagnosis and the mastectomies I really felt mangled. I felt like, you know, I'd really been, um, I'd really been just mangled. And 'what kind of a woman was I where I had no breasts and no way to have children?'

And when I was launched into menopause. I really had no libido. That was very hard...there was a time where I felt very unattractive - no libido. It was gone and it was just very sad...when I was going to chemo and when I lost my hair - it was devastating...my hair like with many women it's their, you know, their security blanket. It's their way of showing 'I'm a woman' ...It's funny you think that 'It's not that big a deal', 'I mean, people look good with bald hair - you know, with a bald head.' Ah- 'You should just embrace it.' And say 'Okay I have cancer - get over it.' But you don't do that. You know you really, at least I did, I really kind of, dwelled on it...

Whereas Mary labels the way cancer takes away from the individuals with metastatic breast cancer as a *bucket of pain* with droplets labeled “physical pain,” “job loss,” “lack of sleep,” etc being collected into a bucket that is owned by each terminal patient- each loss being collected into a personal pain bucket- Dr. English-Lueck dubs this phenomenon as the *cancer thief*, where the cancer comes and steals from each patient: hair, vitality, future goals, etc. Regardless of its name or metaphor, each informant suffered severely from cancer losses. All informants had their ovaries removed at a very young age and were thrust into immediate, uncomfortable, and unnatural surgically induced menopause. Mary ties this loss to her decreased and missed sex drive and her decreased feelings of sexiness. Michelle and Lydia disliked the hot flashes. And all participants except for Janet grieved the loss of their libidos.

Mary has to cope on a day-to-day to basis to accept her new, uncharacteristically large breasts for her frame and Lydia felt a great sense of loss when she had her mastectomy- she said goodbye to her breast before the surgery. And after the surgery, Lydia felt uncomfortable and covered herself with a camisole during a romantic moment to try to feel beautiful. Michelle indicates that she felt *mangled* after her mastectomies. Janet stands out in that she indicates she received new, better, improvement, and larger breasts. She is positive about the loss of her old breasts and enthusiastic about receiving her newly reconstructed saline implanted breasts. She indicates that they are “just ornaments anyway”, therefore losing them wasn’t significant for her as that her replacement set are bigger and nicer. A thread of similarity that ran through each informant was a sense of loss in feeling attractive, except for Janet who never indicates feeling unattractive; in fact she indicates the

opposite. Both Lydia and Michelle mention how the loss of eyebrows was unsightly and attention grabbing. Every participant voiced suffering in some ways or in many ways of feeling unattractive except for Janet. And, every participant felt a sense of loss of health, vigor and vitality.

The cancer thief not only steals a sense of attractiveness, it steals time. It steals time used at doctor's visits, infusions, on other treatments, time used to recover from treatments, and time used in sleeplessness as a side effect from treatments. It not only takes away time, it takes away the ability to have children. Every informant indicated a deep sense of loss of not being unable to bear children after the terminal cancer diagnosis and treatment. Most poignant was Janet's attempt after harvesting thirteen of her own eggs to unsuccessfully have a baby through fertilizations and implantations in a surrogate mother.

Cancer stole the aspirations and dreams of all the informants in one form or another. Both Lydia and Mary mentioned abandoning the goal of attaining a PhD. All the informants either stopped their careers or decreased the amount of time they spent at work they enjoyed. The dreams and aspirations of retiring, being a grandparent, having children, feeling vibrant, or just growing old are abandoned. The cancer bucket collects the droplets of the pain of keeping a secret, the pain of being different, the physical pain of nausea, shots, the lack of taste buds, diarrhea, cracked skin, and of bald heads.

The Pink Movement's Role in Coping

The Pink Movement is often conceptualized as a major source of support for those with breast cancer. However, interviewee responses, as well as published critiques of the movement, indicate that it is a mixed message for those with a metastatic diagnosis (Ley 1972, Sulik 2011, King 2006, Ferguson et al 2000).

Lydia indicates:

"I have heard about the Pink Movement. It's actually something that's been discussed in my metastatic support group. And, um, several people I know really hate the whole thing because it's - it's this - it's the same thing of 'It's the survivor', 'It's looking for a cure', it's - it's just feels like this thing for primary breast cancer. Um, it doesn't address the hardship of those of us that have terminal cancer. It is just - but I think what a lot of people have a problem with is maybe it's more commercial. It's, ya know, and it's very - every time you see these things it's very light and fluffy - 'Hey we're doing so great' and 'Things are wonderful' and - and it just doesn't feel like it portrays in anyway the metastatic situation.

But on the other hand, I feel like, you know, one of the most important things for women, ah, is that they're aware of breast cancer - if they feel a lump in their breast - they should go and get treated. I feel like any amount of money going towards research even if it's a small fraction of the money, you know, if they're getting more advertising than the money going to - any amount of money going towards [research] - is a benefit. So, I feel like the PRs a benefit. The money is a benefit. Um, as a metastatic person, I feel like that the movement doesn't really involve us [metastatic individuals] so much. It kinda glosses over us a bit."

Janet says:

"Um, so the Pink Movement is about breast cancer awareness. And before I had breast cancer - it made me aware. Um, once I had breast cancer I'm almost embarrassed, um that's not quite the right word, but I'm not offended cuz I think that the Pink Movement means well. But, I don't feel like it's supportive for people who have breast cancer. I feel like it's about awareness and prevention and 'Let's prevent this disease' - which is great. And, um, but I don't find it supportive.

They do these big walks and, um, I remember my first year of having breast cancer and having people were like 'Oh you should go do this', you

know, 'three day walk or that 5K run or something' and 'being a survivor or in treatment or whatever'. I didn't want to go out there among all these people who don't have breast cancer who – it just doesn't – it didn't feel supportive or good...

...but when you go to the grocery store and there's pink spatulas – it's like: really[?!] I don't want a pink spatula [!] And don't think that my purchasing a spatula is gonna really do anything for myself or anyone with breast cancer or even really promote awareness of breast cancer. But I do know that little girls in the age range from about two to about eight really like pink and so maybe they can have pink spatulas to play with in their little play kitchens."

Michelle states:

"So initially, you know, I thought that it was great. I thought 'Wow look at all the support just pouring out of the community and all the money that's being donated to research for breast cancer and the awareness that it's bringing', um, you know, for - cuz it's such a huge disease and it's affecting so many people – I – I really do admire the Pink Movement and I think it's great that they have it out there. And are, um you know - spreading the word and raising money and doing the research.

Um, after my initial diagnosis when I recurred I felt different. I felt it was more over-commercialized. And, uh, less of a, you know, 'Let's beat cancer' and more of a 'Rah rah rah' around the – the early – the people who had been detected early and were surviving and not so much thinking about the, you know, ladies with mets who were fighting a terminal diagnosis. You know, it seemed like breast cancer was now the 'it' cancer to have, because you'd probably be cured. It wasn't like lung cancer – that people don't talk about because, ah, you know, it's – it's a scary horrible dark disease that, ah, no one wants and, you know, when they get it people just hush and say 'well she has lung cancer unfortunately and she's gonna go'. But with the breast cancer it just seems to be so light and airy and just over-commercialized now. And it's sad because there is this other side to breast cancer it's more like the lung cancer – that's scary and dark and people don't really wanna, you know, think about it because it's, you know, it's a sadder story. I think that people want the happy ending and that's not always the case with breast cancer.

Mary indicates:

"My involvement with the Pink Movement is an active hatred- No[!] [laughter] um, sometimes during October which it is – 'This Is Breast Cancer Awareness Month[!]'. I can get a little angry at the pink ribbons. And a lot of people say, 'Well, you know, why would you get angry at the Pink

Movement?' 'They're there to help.' Well, I've read a lot for the master's project in regards to the Pink Movement and I'll give an example: there's Hoover vacuum cleaner and it's easy to say, 'Oh buy this pink vacuum cleaner bag or this pink, you know, rug accessory that goes with our vacuum cleaner'. Lo and behold only to find that the amount of dollars going to curing breast cancer or research is, you know, let's say you donated \$300 and a penny went there.

Well, there's been many books written about the topic of the Pink Movement and they call it Pink Washing. Which is similar to Green Washing where corporations, um, say 'hey donate to this' but they're consuming a lot of the money the consumer is thinking they're donating to research. So, a very clever ad came out that where – uh, was from the counter Pink Movement. And they had the vacuum cleaner and then they had - basically the vacuum cleaner was sucking up dollar bills and it explained how much went to what location. So, in a lot of regards I think the Pink Movement is good because it brings awareness. There's people - breast cancer is the second leading cause of [cancer] death in all women in the United States second only to lung cancer. Um, so I think it's good that people are aware what I don't think is good is that people believe that they are contributing and they're doing it honestly and the corporations are the ones that are winning out.

So, my encounters with the Pink Movement and my interactions with the Pink movement are pretty varied. Um. Sometimes I'll see a billboard and there'll be these bald chicks marching along and they're gonna do their walk-a-thon and this might seem a little bit odd for me to say in that I got breast cancer when I was 35. But it's extremely rare for a woman at that age to get breast cancer. It's extremely common for women that are in their 50's and 60's to get breast cancer on the average. So when I see all these, like, beautiful bald women it's hard for me to believe that they have breast cancer. And they're all happy about it too. Like, the last time I checked that wasn't the happiest thing to have on the planet. So they're all smiling and they make it all great as if everybody's being cured and the death rate for breast cancer has only increased. So, we're not curing it. So, I think that particular message about the Pink Movement – my reaction to that – is pretty much – uh, - I think it's a lie.

The other problem I have with the Pink Movement message is it blames the victim 'Here detect it' 'If you detect it early, you know, you might be able to live'. Well, why not cure it? You know, because what if I didn't detect it early? Mine was detected early but it still came back. So, I don't like that particular message and the scare tactics: '1 in 8 women in their lifetime will get breast cancer'. So it makes – it pathologizes all women.

The other thing is that men get breast cancer. I don't think they're happy to wear pink...And, so I feel like it pushes those people to the margins. Um, although lately I've seen a little bit of diversity in the Pink Movement in

that - they don't put men on their billboards – but I do see that they put women that are older – of course, they're hot [very good-looking]. Like everybody in the Pink Movement is hot [?!] You know, last time I checked everybody isn't hot. So, um, that irritates me a little bit about the Pink Movement.

I would like them to move away from the message that it's 1 in 8. I'd like them to move away from the message that somehow or another 'It's your fault' and 'If you don't detect it early – shame on you.'”

The common thread running through the informants' statements about the Pink Movement is that they felt the Pink Movement had not helped them as a person with metastatic breast cancer. The participants felt that the Pink Movement was targeted at and designed for those with early breast cancer. Lydia said it didn't address the hardship of those with metastatic cancer. Janet just simply stated that the Pink Movement was not supportive for her and Michelle said that the Pink Movement was just not thinking about a person like her. Michelle felt that people want a happy ending, a happy story – the story of terminal breast cancer is not a happy story and certainly not a happy ending. She felt that terminal patient were the dark secret of breast cancer – nobody wants to think about us and certainly nobody talks about us. Similarly, Mary felt that the Pink Movement didn't relate to her as that they don't mention the people that die or can't be cured.

Commercialization was a heavy theme running through all the informants' interviews. Lydia dislikes the insubstantial fluffiness that comes with commercialization finding it difficult to relate to how the movement portrays the situation as somehow wonderful while she had received a heavy blow – a terminal diagnosis. Janet was incredulous that pink spatulas were being marketed to children and Michelle disliked the cheerleader – get-up-and-go and be happy - quality of the Pink Movement. Mary most

dislikes what Jack Hoefflich deems the “Barbie-ization” phenomenon. Jack describes Barbie-ization as the attempt to have any object resemble the Barbie Doll. The object would attempt to be unrealistically: beautiful, sexy, fairytale-ish, Caucasian, young, happy, fashionable, glamorous, superficial, pure, and a representation of the perfect American woman. Mary summarizes her abhorrence with the Pink Movement’s Barbie-ization by questioning how it is that everyone on the breast cancer billboards could be so incredibly sexy and she is bothered that along with commercialization only a small fraction of consumer money spent on Pink Movement items went to funding research without the consumer’s awareness.

Aside from marginalizing terminal individuals, its commercialization and Barbie-ization, the Pink Movement possess a positive aspect – it creates awareness of breast cancer, raises money to find a cure, and tries to prevent the disease. The participants articulated appreciation for this of the Pink Movement.

It’s debatable if the Pink Movement’s beneficial aspects are greater than it’s harms effects. The Pink Movement would have us believe that everyone that gets breast cancer survives by doing a walk-a-thon; is brave, bald & beautiful; full of spunk and verve; is heterosexual; is a female, and has great health insurance. The Pink Movement highlights ‘get a mammogram’ and blames the victim. Exploring beyond the Pink Movement gives a deeper and greater breadth to the analysis of the situation.

Identity Descriptors

Identity – revealed in the language of self-description – is at issue for women with metastatic diagnosis. In this section, I'll focus on the phrasing surrounding terminal breast cancer.

Mary states:

“Do I call myself a victim, a survivor, a patient? Um, how it affects my identity – it's such a difficult question. I don't feel comfortable saying I have cancer - I don't like it. Um, it makes me feel like – Mary = Cancer. Um, I used to say I'm person that has been diagnosed with cancer and then it felt a little bit, like, more distanced.

I don't like survivor. Um, I'm not sure why I don't like survivor. It feels like I've been stranded on some island and - and I survived starving to death. It just didn't feel right.

Patient because I'm a paramedic being a patient never offended me. Um, now a lot of people find the word victim to be quite inflammatory. In fact, there was a very long, uh, angry - on www.breastcancer.org chatroom/dialogue chamber - where somebody was very adamant about not wanting to be called a victim. Um, and in some ways I feel like it is an accurate statement. Um, it [getting diagnosed with cancer] could happen to anybody. Um, so in some ways I feel, like, victimized but then I don't want to identify as 'Mary's a victim' because at a certain point I have to live every day and I don't want to carry that on my back.

Um, I'm not sure what would be a decent thing to call it. Um, I don't know if there's some perfect way to call it. Um, maybe pink person, maybe beyond pink person. But I just don't like the word cancer and I don't want to have it.

...But, um, I feel like I'm so much more than a person that has cancer. Um, I'm a woman. Um, I'm a paramedic. Um, I run a paramedic school. I'm an anthropologist. I'm an athlete. There's all these things – I'm a rock climber. Um, but I'm also - cancer affects my life in such every single little cell of my body. Every single interaction that I feel like it is part of my identity too but I kinda don't wanna – I don't want it to be.

Lydia indicates:

“Um, well I think, uh I guess if I talk to people I say I have cancer. I don't tend to talk – I uh, I probably wouldn't say so much that I'm a cancer patient cuz again I try to be in denial about the fact that I'm a patient. Um,

so, but uh its funny – the term survivor, you know that comes us a lot. I’ve had people notice if I was wearing a head scarf or something – ‘oh are you a survivor?’. For ten years I felt like I was a survivor after having my primary but since I became metastatic that term doesn’t feel right to me. Survivor to be sounds like it’s something that’s done. And I’m just still in the mode of dealing with it all the time. Um, it kinda – survivor makes it sound like, you know, I’ve won and the caner’s lost or something. And its just it’s really not like that any more to me once I’ve become metastatic just it’s not ending - you just keep going.

Um, I don’t know, it it it to me the term survivor always makes me think that’s something for a person who’s a primary diagnosis not for metastatic. Um, as far as you know the term ‘terminal’ I like to use that to make myself be realistic, you know, sorta of a – ‘yeah this is serious stuff’. ‘You’re terminal’. But I generally don’t like using that term.

Um, what I usually say to people when I’m telling them, you know, about my disease I say I have metastatic breast cancer and what that means is I will be in treatment for the rest of my life. And I always say it that way because like I could say I’ll be in treatment till I die. But emphasizing my dying and it leaves them thinking about me dying. And my focus is really on living. And the fact that – it not - a lot of people are confused so like ‘oh you’re in chemotherapy – how long?’ It’s like – ‘I will be in treatment for the rest of my life’. ‘Sometimes it’s an easy treatment and just a hormonal pill – sometimes it’s chemotherapy. Some chemotherapies are harder than others. But I will always be in some sort of treatment.’ But when I say for the rest of my life. It helps them know this is a long battle for me. It’s not just a short period of time but it also lets them realize I’m living a life and continuing on.

Janet says:

“It’s really hard to know what to call myself or how to label my own cancer or how to call my friend’s and label their cancer. Um, I say I have breast cancer even though I may currently, like, currently have no evidence of disease. Um, but I still feel like I have breast cancer. I’m still under treatment. I’m still under surveillance. I don’t feel like a survivor, although sometimes the word survivor feels okay to say. But it really depends on the day and how my last scan went, how my last tumor markers were. How I feel about saying survivor versus I have breast cancer? I don’t say patient.

Some people use the word terminal I don’t like that word because I don’t think I’m dying right now. Some people say Stage IV that’s a nice, I guess, euphemism if someone knows what Stage IV means - um, then they’ll know.

I say metastatic. Um, that’s the word I use the most – ‘I have metastatic breast cancer’. I guess that explains what I have. Maybe I’m a

clinical person and like to use the clinical term. Um, but there are definitely some words or somethings that are more offensive. But hard to say to whom what is going to be offensive.

Um, at one point I was at the beginning of my cancer treatment and uh, I was bald. And I was at a party and I told a woman there that I had breast cancer and I said 'I have breast cancer'. And she got mad at me. And she said well you should say 'you're a survivor of breast cancer'. And I was like 'who are you to tell me what to say that I have or don't have. I'm not done with treatment yet'. I guess everyday that I survive- I'm surviving. But that survivor is not the right word. And I can't say that I had breast cancer because it is not in the past tense. I currently have it and I'm currently undergoing treatment. I was so upset with her. And she was mad at me for saying that I had breast cancer because it was hard for her to hear that. And that was – I didn't understand. I guess maybe it's too much for some people to know and maybe I shared too much and, um, I don't share it with everyone."

Michelle indicates:

"I have a pretty strong – I have pretty strong feelings about how the world, you know, views, you know, the vernacular that is used for survivors and, you know, breast cancer patients. Uh, I think victim is the wrong word. I think, uh, I think the media focuses again with the Pink Movement on the people who are detected early and ultimately are, uh, cured or at least, you know, have a good result with the breast cancer and they don't focus on that much on the metastatic, uh, community.

So, I really, really don't want to be thought of as anything other than I'm a normal person. I'm doing the best I can. I have cancer. It's a huge part of my life now because it's a terminal diagnosis. And, it is – it is draining my life and this is the way that it is. I don't want to be thought of as someone who battled cancer and lost as if I'm some how less than someone else or was weaker than the disease. The way I feel we're – everyone's gonna die. This is just that way, you know, that I'm gonna go out is, um, I have cancer and it will likely kill me. But everyone will, you know, unfortunately will experience it [death] in one way, or another and I don't think there's, ah, um, any less respect or any less, um, dignity in dying one way or another.

You know, I've done all the right things – I think, in dealing with my cancer and dealing with the medical profession and getting the right treatment. And working things out from a personal perspective and dealing with things from my family and my friends, and, you know, and nurturing those relationships and I just don't feel like I'm battling a war. I feel like I'm doing what I'm supposed to be doing and when it ultimately kills me I don't feel like um, I've lost."

Michelle feels the strongest of all the informants about the terms surrounding terminal breast cancer. Victim is unacceptable to her as that she believes the Pink Movement uses this term on early breast cancer individuals. “Battling cancer” - indicates to her that she lost a war and somehow she did not possess- have the adequate resources to come out victorious. Michelle wasn’t given weapons to battle the cancer therefore; she feels that “battling cancer” is an inappropriate term. A battle implies that you are willing to become a combatant, take up arms, and seek out the enemy. But the disease is more akin to enduring, tolerating, and making the best of a horrible situation. Michelle doesn’t want to feel at the end as if she *lost* and the term “battling cancer” implies that she was somehow given tools and was inadequate in deploying them. It implies that she did something wrong.

Mary doesn’t like the term survivor because it makes her visualize being stranded on a deserted island and fighting from starving to death. Again the idea of fighting (similar to the term “battling”) comes to mind, but in a fight tools are needed for victory. No tools are provided in this fight. But again the disease is more akin to suffering through, bearing, and doing the best that you can in a terrible situation. She doesn’t mind the clinical term patient and can see how “victim” could be a fitting word but resists using it because it brings up the imagery of helplessness.

Lydia dislikes the term patient because it destroys her coping mechanism of denial and similar to Mary does not see survivor as a fitting term. Lydia feels that survivor is a term that early breast cancer individuals use because they are done with treatment and have survived their bout with cancer, but that metastatic patients must live every day with the burden of cancer. To announce that they are survivors some how seems inaccurate to her.

She uses the term *terminal* to bring herself into reality about her condition - to make herself face the seriousness of it. Generally speaking *terminal* is not a term she uses on a day-to-day basis but instead, prefers the term *metastatic*. Lydia wants herself and others to focus on the fact that she is alive today and is busy with the business of living.

Similar to Mary, Janet struggles with the terminology surrounding terminal breast cancer as that she acknowledges that many individuals feel offended by different terms. She does not prefer the term *patient* and dislikes *terminal* because she is alive now, and similar to Lydia, would like to focus on the living aspect. Janet states that *Stage IV* is euphuism for *terminal* and settles on the term *metastatic*. Although, I would argue that *metastatic* is euphuism for *terminal* as much as *Stage IV* is euphuism for *terminal*.

Terms surrounding terminal breast cancer are fraught with contention. The word *patient* may be too clinical for some individuals and *I have cancer* can be too realistic or lack in subtlety for others. A common thread was that most informants did not prefer *survivor*. It's a phrase that conjures up inaccurate imagery of being stranded on a deserted island or being involved in a battle. To these informants having terminal breast cancer is a condition that happened to them and they do what they do on a day-to-day basis (take their treatments) because that is what they are supposed to do. They want to live. If there were some way to fight the cancer, these women would fight it. But there's no magic gun that you can aim at the cancer to kill it when you are terminal therefore, there is no battle or war. And as Michelle put it so eloquently: "[There's no] *less respect or any less, um, dignity in dying one way or another... and when it ultimately kills me I don't feel like um, I've lost.*"

Chapter 3 Concluding Thoughts

Sampling was problematic as only 144,000 individuals live in the US with metastatic breast cancer. We did not have funds to have those individuals travel to the CreaTv in San Jose, CA and be filmed. 444 metastatic breast cancer individuals live in the Greater Bay Area, yet we were only able to attain a sample size of seven. These seven individuals were mostly young. We only had one person of ethnicity who is half Thai and half Caucasian, myself. There were no: males, individuals with no insurance, individuals with obesity, and no individuals with sexual diversity. Therefore we greatly lacked in diversity. We had numerous barrier in our search for diverse individuals: 1) participant's willingness to be on film, 2) participant's consent to a lack of anonymity, 3) a very small pool of people living in the US with metastatic breast cancer and an even smaller number of individuals living in the Greater Bay Area within driving distance of CreaTv in San Jose, 4) participants willingness to talk about, share, and be open with strangers about their terminal condition, and 5) random sampling would have included individuals who were less than eighteen years old and owing to the time constraints of Institutional Review Board approval we opted to exclude this age group.

In retrospect some ways to overcome the small response would be to travel to support groups and in person make the request in a face-to-face manner. Perhaps this technique would result in the same number of respondents or it could have generated greater results. Additionally, requesting access to hospital, cancer treatment centers, hospice centers, and alternative treatment centers may have yielded more respondents, as the face-to-face technique would also be utilized.

Aside from sampling being problematic, the open-ended interview instrument produced open-ended questions where the informant could meander on their own pathways, going from here to there with little direction. This is an ethnographic technique in the emic style and it has benefits and difficulties. On one hand we receive a very insider perspective that is rich, detailed and personal. On the other hand we do not receive answers to specific questions, for example Kubler-Ross (1969) has five stages to her death and dying theory. We did not ask each participant if they had gone through the five stages for that was not the theoretical framework when the interview questions were developed. Additionally Moos and Schaefer have identified nine major types of coping skills, we did not ask each participant if they had specifically used any of the nine major coping skills. We instead asked the informants: “After you got your terminal diagnosis, what did you do to deal with it? Day-to-day? Month-to-month? Can you tell me of a time that really illustrates how *you* cope?” Only as the interviews unfolded did I realize that these frameworks were embedded, albeit indirectly, in the narratives.

Aside from sampling and an open-ended interview instrument, two interviewers were less experienced: Cassandra and I. Dr. English-Lueck has performed interviews as part of her life’s work as an anthropologist. Cassandra and I have just started our careers in anthropology and are near completion of our master’s degrees with little interview experience. I can’t predict with certainty but can only question whether an experienced anthropologist would have gotten more detailed answers from the informants. Additionally, Mary has terminal metastatic breast cancer and she did not interview Michelle. Would

Michelle have answered the questions differently if Mary was in the studio or perhaps would she have answered the differently if Mary had asked the questions?

Aside from sampling, open-ended interview instrument, two less experienced interviewers, the interviews were attained from informants in different stages of their disease process. Terminal breast cancer patients tend to be in one of three states: *NED* (no evidence of disease – the scanner can not detect cancer in the body – cancer exist in the body but not detectable by the scanner because the scanner is not technologically advanced enough to see the cancer), *progressing* (defined as the tumors are growing larger and/or the number of tumors have increased since the last scan), and *stable* (defined as the tumors are the same number and size as the last scan). Michelle and Mary were *progressing*. Lydia and Janet were *NED*. How would Michelle have answered the questions if she were *stable* or *NED*? How would Lydia have answered the questions if she were *stable* or *progressing*? These are unknown variables. If we had a larger sample size perhaps we may have seen trends in answers to interview questions that aligned with disease states.

In concluding this project report I am reminded of Unni Wikan's *The Story of My Eye/I or Two*, in which she states: (2000:255)

“Two features of the story line cry out to me as I read: the minimalist, staccato language and—the silences. I am struck that my story is a story of event, of happenings, rather than of digested emotional experiences; there is little florid language; the text is bare to the bone, thin. After rereading, I start revising. Fill in some content here, an explanation there. Contextualize! is the mantra of the anthropologist. And I contextualize, until I realize, that I am changing the tone and nerve of the text. The story of my Eye/I, was written in August 1996, becomes the story of my Eye and my illness, as viewed from the vantage point of January 1999. Thick description, yes. But thick of what?”

I realize that the story was written is authentic in a way that can only be undone by thick description from the present. My “context” now is not what it was then. True, I realize that I have omitted telling you things that might change your ideas of me and my illness. For example, there are few references to my nearest and dearest; my husband is unmentioned, except for his being away; my mother, likewise, no mention; only my son features, in a couple of brief references—when the truth is that my husband was quite beside himself and eventually broke off his engagement in the States to be with me; my mother was desperate to come and look after me; and my son did all in his power to help me.

But my experience was of being utterly alone in a trauma that shook me out of my life. The structure of my story, as originally told, captures this. So I go back and undo all the changes I had made. Back to basics. Let the events stand, unembellished, unexplained; the problem with “context,” I realize, as I heap explanation after explanation, is that it easily points in many directions at once. Yes, I would like you to know the terrible state of the Norwegian general hospital care, and why it was therefore urgent for me to move home, against medical advice, unless I spell it out to you. But then, why should I tell you? When my story is about me and my Eye.

There are stories within my stories. One is about the Norwegian welfare state. As I told the audience when I finally gave my lecture to the staff at the Health Ministry: next time I would like to speak on “How to get well in a sick-house” (skkehus). But at the time when I was living the trauma of my Eye/I, and writing it to you, it did not strike me that a critique of the Norwegian welfare state should be embedded. I had far more crucial things think about; my compelling concerns were others. And the omissions I made, the silences that now cry out to me with deep-felt sorry and pain, will remain covered. Only to me they talk—which is why I could hardly bring myself to reread my story.

Unni Wikan’s (2002:212) discussion regarding the writing and rewriting her account of having a detached retina, *The Story of an Eye/I (or Two)*, indicates that approaching a story at two different time frames, one while she was currently experiencing the illness and another 2.5 years after the illness, yields two different stories. She barely mentions people who played large roles in her life during her first account of the illness (her son, husband, and mother) because in the experience she felt alone emotionally. Her emotional reality was one of loneliness but the external reality was one filled with help and people who were

emotionally close to her. She is telling the story from an internal emotionally truthful perspective. This might not be the full story; it is one of many stories that could be told. This is why she leaves out telling the story of the condition of the Norwegian welfare state.

Wikan's (2002:212) account has me pondering the stories of our informants. Informants had traveled a particular amount of time within their terminal cancer journeys. Would Mary's story be different if she were six years into her journey instead of two years and eight months? Would Michelle's story be different if she hadn't passed her *expiration date* by two months? What would have happened if we asked informants how much each person in their life helped them?

As Wikan (2002:212) indicates all stories are true and there are stories within stories. We received one story from our informants because of when we asked them to talk to us and each of them copes at different times in different ways. "The needs of dying persons are both complex and highly personal. Corr et al's (2002:109) statement is apt: "In part, they [death and dying ideologies] are shaped by social, cultural, and religious influences, as well as by family practices and personal experiences."

In conclusion this project seeks to increase community awareness of the heterogeneous nature of the experiences of those living with terminal breast cancer, their coping strategies, and needs in regards to their illness. My research team and I: (1) identified the varied terminal breast cancer communities; (2) identified a sample of terminal breast cancer individuals; (3) interviewed four of these individuals on film; and (4) analyzed the interview materials. The last two goals: (5) The generalizations and lessons learned will be presented, discussed, and elaborated by the participants and researchers and aired on

public access TV stations; (6) Disseminate information as an educational tool to individuals with terminal breast cancer, those with an early breast cancer diagnosis, their social support systems and their treatment providers, and the general public; will be completed after the raw footage has been edited and the b-footage inserted thus creating a documentary that we can disseminate.

In this project report I discussed the project's goals; sampling, budget; material and methods. The project was conceived using particular theoretical perspectives and biases. Those changed through time to incorporate the emerging narratives. In the second chapter I discussed the coping mechanisms revealed in the interviews, such as day-to-day psychological coping, in-person breast cancer support groups, extreme behaviors post terminal diagnosis, metaphors, the Pink Movement's role, identities and linguistic descriptors were also discussed. Is someone with a metastatic diagnosis a cancer patient, person with cancer, survivor, person living with cancer, victim? Finally I reflected on areas in need of improvement in future projects.

We operated under some methodological constraints that could have unfolded differently. We could only have a few individuals tell their stories in a documentary, as that the typical length of a documentary limits the number of individuals' stories. There is merit in quantitative analysis and there is merit in qualitative analysis; our analysis is quite obviously the latter. This is an in-depth examination of a non-representative, self-selected sample of individuals and the project goal is to explore variations and similarities across that diversity.

In our research we did not use strict random sampling because many factors influenced our ability to do so: 1) participant's willingness to be on film, 2) participant's consent to a lack of anonymity, 3) a very small pool of people living in the US with metastatic breast cancer and an even smaller number of individuals living in the Greater Bay Area within driving distance of CreaTv in San Jose, 4) participants willingness to talk about, share, and be open with strangers about their terminal condition, and 5) random sampling would have included individuals who were less than eighteen years old and owing to the time constraints of Institutional Review Board approval, and the small number involved, we opted to exclude this age group. This method of sampling was very much non-representative of the terminal breast cancer community and was quite biased as it selected for those who had the time to travel to San Jose's CreaTv, time and personal funding to sit for the two to three hour of interviewing, for those with the inclination to share their story on film, and an age group greater than seventeen years of age.

Funding was not a limitation, at least at the end. We were able to gather funds from two sources: The Tower Foundation and IndieGoGo. By current projections, we not need more funds than we possess.

The following materials and methods were provided early or in the appendix in this project report: Open-ended Pre-Interview Phone Instrument for the seven potential candidates, the Recruitment Flyer, the Recruitment Contact List, the twenty six question Open-ended Interview Instrument, as discussed, the open-ended structure produced rich, but not generalizable narratives.

Finally, the theoretical frameworks used were at times provocative, and at other times, limiting. While Kaufman's (2005) bias centers on her assertion that ICU technologies significantly impact living and dying, Klawiter's (2008) bias lies within her desire to counter the mainstream understanding of breast cancer activism by mapping the contours of breast cancer within an embedded matrix of opposition to the mainstream. This approach is equally advantageous and troublesome as that a narrowly sliced analysis can be rich and deep but lacking in generalizability.

How do Kaufman's (2005) and Klawiter's (2008) assumptions, biases, and theoretical frames pertain to my project and what are the specific lessons I learned from analyzing their inclinations? I am a woman living with a terminal breast cancer diagnosis; therefore my easily identified bias is that my perspective is deeply and inextricably intertwined within a personally experienced microcosm of dying- of impending death. I see a majority of concepts from the theoretical frame that humans are all terminal and with my physical end quickly approaching many of my theoretical concepts are filtered through a standpoint that a rapidly ensuing darkening into nothingness will soon descend upon myself and others (owing to my lack of a clear belief in an after-life existence- which is yet another layer of my multiple biases).

The most salient lesson for me imparted through my analysis of the work of Kaufman (2005) and Klawiter (2008) is that I would benefit from laying out my bias's within full sight of those who will read my work and in so doing I am upfront, self analytical, and revealing, saving the reader from the extra task of mining for my bias's affording them the luxury of possibly analyzing my research from a less skeptical perspective.

It cannot be taken for granted that I am a forty-one year old mainly heterosexual female of half Caucasian and half Thai middle class heritage acculturated within the US mainstream who is married with no children fortunately possessing high quality medical insurance and having a sufficient amount of social capital to secure work as a paramedic while gaining a full-time tenured faculty position at a community college at the same time as earning an undergraduate degree and then subsequently going on to pursue a master's degree in anthropology. Owing to my education as a paramedic I have the ability to understand medicine at a deeper level than a layperson affording me greater ease in navigating the complex web of cancer treatment and oftentimes allowing me to be more demanding than the usual patient. All these factors and more obscure and narrow my analysis and exploration of those living with terminal breast cancer diagnosis, their coping mechanisms, and the stories they have to tell; and carry the same advantages and disadvantages of Klawiter's (2008) narrow presentation of a counter narrative pushing against the dominant, omnipresent perspective of the prevailing mainstream narratives revealing a lesser told, novel, thin-sliced but deep point of view.

In day-to-day coping what stands out are the likeness seen in Lydia, Janet and Mary's strategies. Each of these informants' toggles between three states: denial, acceptance and quasi denial. Michelle is alone, as she does not toggle between states. She is in the state of acceptance.

In-person support groups serve not only as a place of comfort; to be around those who are suffering in similar ways, providing camaraderie and quelling loneliness; they help to contextualize the terminal breast cancer experience within a larger frame: some individuals

have brain metastasis, some have liver metastasis, and still others may have it all over their bodies: brain, lungs, liver and bones. The sessions can be used to gathered information about new treatments, side effects, effective counter-measures against adverse reactions, a safe-haven to vent non-positive feelings, and a place to give and receive with those who are in a similar life circumstance. All informants used in-person support groups at some point during their illness. Janet and Lydia continue to attend in-person support groups. Michelle and Mary stopped attending at an unknown time period in the past. While Kaufman's (2005) bias centers on her assertion that ICU technologies significantly impact living and dying, the same can be said the technologies used on cancer patients: chemotherapy, radiation, surgery, and medications.

Extreme behaviors are a thread running through all informants. Each participant felt the need to change after receiving the terminal diagnosis and each was similar in their desire to spend more quality time with friends and family. But each is also unique: Michelle chose to travel the world; Janet and Mary engaged in *crazy sports*; and Lydia takes on extreme parenting. I have heard of this extreme behavior referred to as the "*bucket list*" on www.breast.org Stage IV breast cancer dialogue chamber. Some members of this chamber make lists of all the things they have wanted to do, such as scuba dive the Great Barrier Reef, parachute from an airplane, and go see Niagara Falls, etc. Then the participants proceed to tick items off the bucket list, one by one.

Cancer stole the aspirations and dreams of all the informants in one form or another. Both Lydia and Mary mentioned abandoning the goals of attaining PhDs. And all the informants either stopped their careers or decreased the amount of time they spent at work

they enjoyed. The dreams and aspirations of retiring, being a grandparent, having children, feeling vibrant, or just growing old are abandoned. The cancer bucket collects the droplets of the pain of keeping a secret, the pain of being different, the physical pain of nausea, shots, the lack of taste buds, diarrhea, cracked skin, and of bald heads.

For terminal breast cancer individuals it's debatable if the Pink Movement's benefits are greater than it's harms. The Pink Movement would have us believe that everyone that gets breast cancer survives by doing a walk-a-thon; is brave, bald & beautiful; full of spunk and verve; is heterosexual; is a female, and has great health insurance. Exploring beyond the Pink Movement gives a deeper and greater breadth to the analysis of the situation. The Pink Movement highlights 'get a mammogram' and blames the victim. There should be more to their message, such as 7% of women diagnosed with breast cancer in the US are metastatic.

Terms surrounding terminal breast cancer are fraught with contention. The word *patient* may be too clinical for some individuals and *I have cancer* can be too realistic or lack in subtlety for others. A common thread was that most informants did not prefer *survivor*. It's a phrase that conjures up inaccurate imagery of being stranded on a deserted island or being involved in a battle. To these informants having terminal breast cancer is a condition that happened to them and they do what they do on a day-to-day basis (take their treatments) because that is what they are supposed to do. They want to live. If there were some way to fight the cancer, these women would fight it. But there's no magic gun that you can aim at cancer to kill it when- you are terminal therefore, there is no battle or war. And as Michelle put it so eloquently: "[There's no] *less respect or any less, um, dignity in dying one way or another... and when it [the cancer] ultimately kills me I don't feel like um, I've lost.*"

Glaser and Strauss (1968) explain dying trajectories “*in terms of two principal variables: duration and shape. Some trajectories involve up-and-down history—remission, relapse, remission, and so on---often in a rather unpredictable way. Other dying trajectories make relatively steady progress toward death. In some cases, the dying trajectory may be completed in a very brief, almost instantaneous, span of time; in other cases, it may be slow, extending over a period of weeks, months, or even years.*”

We don't know Mary, Lydia or Janet's dying trajectory. The number of episodes of *NED*, *progressing* and *stable* will determine their death trajectories. Michelle's trajectory was very brief because of her AML diagnosis. She lived two month past her six-month *expiration date*. I liken Glaser and Strauss's (1968) definition of death trajectories to roller coaster rides. Some roller coaster rides are short while others are medium and some being long. The uphill parts of the ride represent disease *progression* while the flat parts represent *stable* and the *NEDs* are represented by the downhill. All rollercoaster rides (lives) involve different amounts and lengths of uphills, flats and downhills, but all coaster rides end (death).

My ride has had one stable period, one NED period and several progressing periods. I feel like I've had a crazy ride so far. I don't how many more *stables* or *NED* or *progressions* that I'll get and for how long. No one really knows. I'd like to get off this particular roller coaster, but when I entered I was told that I'd ride till I died.

Doctors can give patients averages, ranges, and expiration dates, but no one knows with certainty when another person will die. Therefore, in a sense we are all *terminal*. One way to view this is: from the moment we are born we are in the process of dying. We share this commonality with each other and all other living organisms on the planet and the death trajectories will span in diversity. Some groups will have similarities while others will be very different.

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Beyond Pink Interview of Janet Sollod

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APPENDIX A: Summary of Telephone Interviews

1) Birgitte Moyer-Vinding

**Open-ended Pre-Interview Phone Instrument
Beyond Pink:
Living With Terminal Breast Cancer**

Introduction

I'd like to ask you some general questions to get to know you.

1) So, tell me about yourself

Probes:

- a. How old are you? **73**
- b. Where do you live? **Portola Valley, California (94028)**
- c. Where did you grow up? **In Denmark**
- d. What do you do for a living? **I am retired now. Was chair of the Music Department at Notre Dame de Namur University for 24 years (on the faculty there for 28 years)**
- e. Do you have any children? **3 adult children**
- f. How would you characterize your race and ethnicity? **White Caucasian**
- g. How would you characterize your sexual orientation? **Heterosexual**
- h. How would you characterize your socioeconomic status? **Upper middle class**
- i. Do you have medical insurance? If yes, what is the name of your medical insurance carrier? **Medicare primary, Anthem Blue Cross secondary**
- j. How did you find out that you had breast cancer? **Routine mammogram**

k. How old were you when you were first diagnosed? **66**

2) Michelle Moskalik

**Open-ended Pre-Interview Phone Instrument
Beyond Pink:
Living With Terminal Breast Cancer**

Introduction

I'd like to ask you some general questions to get to know you.

1) So, tell me about yourself

Probes:

- a. How old are you? **42 now**
- b. Where do you live? **San Jose**
- c. Where did you grow up? **CA – Sonoma county**
- d. What do you do for a living? **Retired from being a lawyer (March 2011)**
- e. Do you have any children? **No children**
- f. How would you characterize your race and ethnicity? **Caucasian**
- g. How would you characterize your sexual orientation? **Heterosexual**
- h. How would you characterize your socioeconomic status? **Upper middle class**
- i. Do you have medical insurance? If yes, what is the name of your medical insurance carrier? **Yes- Blue Shield (its ok). Aetna for 1st bout (it was horrible – billing issue- mediport placed – told it was covered & it wasn't. \$4,000 out of her pocket because of a typo!)**

j. How did you find out that you had breast cancer? **Michelle found it on her own (MD said you are too young...then 3 years later it got bigger).**

k. How old were you when you were first diagnosed? **33**

NOTES:

Leukemia induced by chemo from the breast cancer - AML

Initial breast cancer in both breasts

BRA CA gene

Estrogen positive

Progesterone positive

Her 2- negative

3) Wave Geber

**Open-ended Pre-Interview Phone Instrument
Beyond Pink:
Living With Terminal Breast Cancer**

Introduction

I'd like to ask you some general questions to get to know you.

1) So, tell me about yourself

Probes:

- a. How old are you? **55 (but 40 at 1st diagnosis. 48 metastatic)**
- b. Where do you live? **Berkeley**
- c. Where did you grow up? **New York**
- d. What do you do for a living? **Consulting/counselor once a week running a program for teenage mothers (also on disability)**
- e. Do you have any children? **no**
- f. How would you characterize your race and ethnicity? **Caucasian. Jewish**
- g. How would you characterize your sexual orientation? **bisexual**
- h. How would you characterize your socioeconomic status? **\$50,000 previously- on disability now – don't know how to characterize my socioeconomic status**
- i. Do you have medical insurance? If yes, what is the name of your medical insurance carrier? **PPO \$959/month. Dec 1st- medicare**
- j. How did you find out that you had breast cancer? **was 35 went to have a breast reduction- found calcification- got biopsy over a couple of years. started ultrasounds and mammogram**
- k. How old were you when you were first diagnosed? **40**

Notes:

1996 original stage 1 diagnosis, lumpectomy. 11 nodes negative. lobular cancer. 32 radiation treatments. She was 40 years old at the time. She did not want to go into menopause.

Neck pain 8 yrs later, liver then skin, bone marrow
metastatic since 2004

Stage IV treatments: tamoxifen, femara, ovaries out, tried a couple of things that didn't

work: aromasin, low dose estrogen (felt great- wasn't so agitated, less uptight, slept better), one chemo- zeloda x 1yr, radiation to cervical and lower spine, cyberknife C2, stopped all treatment just this month. Had blood transfusion- cancer taking up bone marrow. UCSF- hospital is where she was treated.

4) Laura Philben

**Open-ended Pre-Interview Phone Instrument
Beyond Pink:
Living With Terminal Breast Cancer**

Introduction

I'd like to ask you some general questions to get to know you.

1) So, tell me about yourself

Probes:

- a. How old are you now? **65**
- b. Where do you live? **Danville**
- c. Where did you grow up?
- d. What do you do for a living? **retired (retired when she was 1st diagnosed)**
- e. Do you have any children? **no**
- f. How would you characterize your race and ethnicity? **Caucasian**
- g. How would you characterize your sexual orientation? **heterosexual**
- h. How would you characterize your socioeconomic status? **live in Danville- not sure how to quantify socioeconomic status.**

i. Do you have medical insurance? If yes, what is the name of your medical insurance carrier? **Kaiser and she loves it. Didn't spend any money on the chemo! - no dime out of her pocket**

j. How did you find out that you had breast cancer? **1st time felt a lump on breast (IIC). Metastatic- had gallbladder out and there was ascites. The surgeon was astute- he thought it was suspicious and sent liquid to pathology.**

k. how old were when you were diagnosed? **49 (1st time) 59 (second time)**

l. are you married- **yes to a man**

Notes: decided to learn how to play tennis, play the piano, take up art- when diagnosed. Has had metastatic breast cancer for six years.

5) Lydia Mackovitch

**Open-ended Pre-Interview Phone Instrument
Beyond Pink:
Living With Terminal Breast Cancer**

Introduction

I'd like to ask you some general questions to get to know you.

1) So, tell me about yourself

Probes:

a. How old are you ? **43 old now and was diagnosed when I was 29 years old with the primary stage IIb invasive ductal- ER & PR + (mastectomy, chemo, tamoxifen).**

Finished tamoxifen and had a baby at 37 years of age. - prolapsed uterus after 1.5 years after having baby. This prompted an ultrasound to assure that a tumor wasn't pushing on ovaries. Then she got a PET due to her history of cancer. Ovaries were fine- liver showed cancer. Metastatic diagnosis at 39 years of age. Went back on tamoxifen which didn't work - clinical trials- gemzar, avastin, taxol did this for 2 years all the while taking care of the 2-4 year old son. Got to NED after 2 year from metastatic diagnosis.

Then started getting really bad headaches possibly due to decadron. Went on arimidex for 18 months- then routine scan showed the cancer was came back in the liver. There were 5 lesions- smaller than before (Feb 2011). Now on gemzar and avastin

b. Where do you live? **Sunnyvale**

c. Where did you grow up?

d. What do you do for a living? **software engineer- mainly retired now**

e. Do you have any children? **one child**

f. How would you characterize your race and ethnicity? **Caucasian**

g. How would you characterize your sexual orientation? **heterosexual**

h. How would you characterize your socioeconomic status? **very well off**

i. Do you have medical insurance? If yes, what is the name of your medical insurance carrier? **through husband's work- united. It's been fabulous. I have had different insurances throughout the experience.**

j. How did you find out that you had breast cancer? **just been to OB GYN for routine**

exam- did a breast exam -nothing there. 2 weeks later- she placed her hand on her chest- and felt a lump by accident.

k. How old were you when you were first diagnosed? **29 years old**

6) Janet Sollod

**Open-ended Pre-Interview Phone Instrument
Beyond Pink:
Living With Terminal Breast Cancer**

Introduction

I'd like to ask you some general questions to get to know you.

1) So, tell me about yourself

Probes:

- a. How old are you? **36**
- b. Where do you live?
- c. Where did you grow up?
- d. What do you do for a living? **Pediatrician**
 - e. Do you have any children? **No**
 - f. How would you characterize your race and ethnicity? **Caucasian**
 - g. How would you characterize your sexual orientation? **Heterosexual**
 - h. How would you characterize your socioeconomic status?
- i. Do you have medical insurance? If yes, what is the name of your medical insurance

carrier?

j. How did you find out that you had breast cancer? **Noticed my breast was lumpy (primary diagnosis). Found out metastasis from a routine scan.**

k. How old were you when you were first diagnosed? **2009 - 34 years old original stage III - 1 year check up.**

NOTES:

Original- lymph node enlarged 1.5 years before diagnosis. Did not worry- let's just keep an eye on it. and she watched and didn't think about it for 1 year. Then put on a tank top one day- and her breast looked abnormal -could see a shadow lump - 10am area - a bunch of lumps. She's a pediatrician. 1st treatment: Chemo, mastectomy, didn't have to have radiation. Then was on tamoxifen and herceptin. 6 months or less than a year- had the PET scan that found liver spots (1st metastasis). Then a little local reoccurrence. Had liver surgery April 2008. Then more chemo. She had a single accessible liver metastasis. She was told: "You could be tumor free". Then she was clean for a whole year. Then she noticed a local recurrence at the edge of mastectomy area and had that removed. Then she had radiation (mini radiation- around local metastasis). Then she was clean till a scan in Dec 2010. There were new liver metastasis in a totally different location. There were several spots seen, but only one light up on PET scan. The surgeons went in and explored- and removed cancer- other spots weren't cancer. The surgeons weren't sure if they got clean margins. She's had one scan since then- everything lights up on a PET after a surgery. The area where she had surgery light up- unsure if its more tumor or not. She's going to have

another scan next month. Currently she's on Lupron, Faslodex and Herceptin. She has a great quality of life: rock climbs, works, dates - in menopause for 2 years - constantly worries - can't have children.

7) Mary Koskovich

Open-ended Pre-Interview Phone Instrument
Beyond Pink:
Living With Terminal Breast Cancer

Introduction

I'd like to ask you some general questions to get to know you.

1) So, tell me about yourself

Probes:

- a. How old are you? **41**
- b. Where do you live? **I live half time in the Bay Area and half time in Yosemite**
- c. Where did you grow up? **Bakersfield, CA**
- d. What do you do for a living? **Director & primary instructor of paramedic school**
- e. Do you have any children? **No**
- f. How would you characterize your race and ethnicity? **½ Asian & ½ Caucasian**
- g. How would you characterize your sexual orientation? **Mostly heterosexual**
- h. How would you characterize your socioeconomic status? **Middle class**
- i. Do you have medical insurance? If yes, what is the name of your medical insurance

carrier? **Kaiser**

j. How did you find out that you had breast cancer? **I had a non-painful, swollen lymph node in my armpit**

k. How old were you when you were first diagnosed? **35**

APPENDIX B: Open-ended Interview Instrument

Open-ended Interview Instrument Beyond Pink: Living With Terminal Breast Cancer

Introduction

I'm going to be asking you many questions about your illness, so I can understand your experience. At any point during this interview if you are tired or need a break- please let me know- so we can pause.

1) I want you to think about your experience with breast cancer holistically. Can you think back before you were diagnosed: What did you know about breast cancer before you were diagnosed with breast cancer?

Probes:

- What was your 1st experience with breast cancer?
- What experiences made you 1st aware of breast cancer?
- Do you have family members, friends or other individuals that had or have breast cancer?

2) How were you given the news of your terminal diagnosis?

3) When you were initially diagnosed what was going on in your life?

- How did work react?

- How did your family/friends react?
- How did treatment change what you did day-to-day?

4) How did cancer change your life?

- Your romantic life?
- Home-life, passions, aspirations/hopes/dreams?
- How did it change your relationship with your faith or spirituality?

5) What was your initial stage of diagnosis? How was it determined?

6) In what part/s of your body was the cancer initially located? Where is the cancer located now?

7) What treatments have you received?

Probes:

- surgery
- radiation
- chemotherapy
- oral medications
- clinical trials
- alternative: diet, acupuncture, massage
- other

8) How did you decide what course of treatment to follow? Who helped you make those

decisions?

9) What was/is your treatment like?

Probes:

- Tell me about the 1st time you were treated.
- Who did you see?
- What did it feel like?
- What were you thinking?
- Who were you with?

10) Who helps you understand what you are going through in the course of your treatment?

Think about

Probes:

- nurses, doctors
- other people with breast cancer
- practitioners of faith
- people in complimentary medicine
- other individuals that you've encountered because of your illness: insurance employees, lawyers, etc

Probes: You have talked about [fill in the blank with what the person has been talking about]...

Tell me of a time when you interacted with this person that was positive and when it

was negative.

11) Where did you get help after diagnosis to cope with your illness?

Probes:

- family
- friends
- physical support group
- online
- alternative outlets
- religious organizations
- medical community
- Can you tell me of a specific time that is important to you when you got help coping?

12) After you got your terminal diagnosis, what did you do to deal with it? Day-to-day?

Month-to-month? Can you tell me of a time that really illustrates how *you* cope?

Probe: How does the way you coped with an early diagnosis differ from the way you deal with your terminal diagnosis?

13) Were you ever “No Evidence of Disease” (NED)? If so, how long? Have you experienced stability in your disease? If so, please describe it? Have you experienced progression in your disease? Please explain it. What were you experiencing during these times?

14) How responsive is your care provider to your needs and concerns?

Probes:

What information was given to you regarding your illness?

Was there any information that should have been provided at an earlier time?

15) Over the course of your disease did you have changes in the people that provided your care?

We've talked about your experience with health care providers. Now, we're going to switch gears to talk more about your personal experience with the disease.

Within the cancer community there are differences of opinion about the way people relate to their disease...

16) How do you describe yourself in relation to the disease? Some people use the terms: "cancer patient", "person with cancer", "survivor", "person living with cancer", "victim". What do you think of these terms?

- How do others describe you? Doctors, family, friends, etc
- How do you feel about that terminology?

17) How does cancer change the way you think about yourself or the way you see yourself?

Probes:

- Which affects you the most: terminal diagnosis, treatment & side effects, knowing you have cancer?

- Some people say that breast cancer changes how they feel as a woman. What is your experience?
- Breast cancer changes how some people feel as a mother or as a potential mother. What is your experience?
- Breast cancer changes how some people feel as a romantic partner or as a potential romantic partner. What is your experience?
- Breast cancer changes how people present themselves. For example, some people prefer to wear a wig if they are bald or some people change what they wear to hide a breast surgery. What has been your experience?

Probes:

- How do you feel or think that other people see you differently?

19) Take a moment and think about the Pink Movement. What does the Pink Movement mean to you? What has been your experience with the Pink Movement?

Probes:

Tell me of a time in a conversation or during an activity that the Pink Movement effected how you thought of yourself.

Have you ever done an Avon walk or something similar?

What do you think of the October Breast Cancer Awareness Month?

We've talked about your experience with health care providers and your personal experience with the disease. Now, we're going to talk more about the shape and course of your life.

20) I want you to think about your future. The future ideas you had before you were diagnosed and your future as it's now unfolding. Can you compare where you thought you'd be in the future before your diagnosis to the future you are now expecting?

Probes:

- What were your aspirations before your initial diagnosis?
 - family, career, personal goals and passions
- How have they changed?
- What are your aspirations since your initial diagnosis?

21) People tell us that they think two things when receiving a terminal diagnosis: "I'm going to beat this", or "I'm going to die."

- How did you react?
- What role have others (family, friends, doctors) played in this experience?
 - How have they reacted?

22) The bulk of political effort and medical treatment is based on the premise that breast cancer is curable. For example, people with breast cancer often hear the phrase '*don't give up hope.*' How do you react to this attitude?

Can you tell of a time that you strongly reacted, positively or negatively, to the hope associated with the promise of a cure?

- What has been your experience?
- Have your thoughts changed over time?

Given that a terminal diagnosis is associated with death- we're going to ask you several questions related to end-of-life decisions.

23) What arrangements have you made for your continuing care? Or end-of-life care?

Probe:

- hospice, in-home care, family care-givers
- Have you made a Living Will or Do Not Resuscitate order?

24) What arrangements have you made regarding saying goodbye?

- probes: funeral, memorial service, last visits
- How have your family and friends been involved?
- What previous experiences have influenced your decisions?

25) Is there anything else you would like to tell me?

26) Thank you for sharing your experience with us.