

THE BREAST CANCER JOURNEY

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

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May 2012

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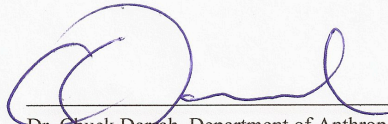
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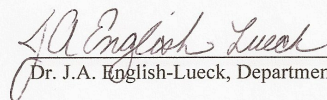
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By

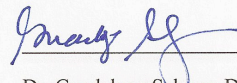
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 May 14, 2012

Dr. Chuck Darrah, Department of Anthropology Date

 May 14, 2012

Dr. J.A. English-Lueck, Department of Anthropology Date

 May 15, 2012

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Abstract

This project report addresses the process undergone to create *The Breast Cancer Journey*, a half-hour documentary that explores the diverse experiences of people living with metastatic breast cancer. The research group's objective in making this film is to generate an educational tool that disseminates information and generates a dialogue regarding the coping strategies and needs of terminal breast cancer patients. This tool will be beneficial to anthropology, nursing, and health care students, as well as people living with metastatic breast cancer, their medical community, and their friends and families. Our research group filmed interviews with four women living in the Greater Bay Area with metastatic breast cancer. The interviews were then analyzed, eliciting themes to create a documentary. This documentary identified various experiences regarding support systems, coping techniques, loss, the Pink Movement, and interactions with the medical community. The culmination of these experiences creates *The Breast Cancer Journey*, a variety of experiences, interactions and emotions that result from a metastatic diagnosis. By identifying and documenting this range of experiences, our research group created awareness and increased knowledge of the lives of people with metastatic breast cancer patients.

Acknowledgements

This project could not have been completed without the help and cooperation of many individuals. I would like to first show my gratitude to Mary, Michelle, Lydia, and Janet, whose stories and experiences made this documentary a possibility. The generosity of these women sharing their stories allowed *The Breast Cancer Journey* to be a moving representation of the lives of metastatic breast cancer patients. Secondly, I would like to thank the members of CreaTV, and our editor, Pablo, for their work in the production of this film. In addition to those who assisted in the production of this film, I would like to thank the organizations and individuals, including the Charles Davidson Foundation, Gayle Klunt and Jack Hoeflich, whose interest in the subject greatly assisted with the distribution and dissemination of the documentary. I also am greatly indebted to my friends and family who listened to my concerns and presented suggestions and assistance when needed. Finally, I would like to thank the students and professors from the Beyond Pink team; Mary, Cassie, Dr. Darrah, Dr. Jan, and Dr. Salazar. This project would have been impossible without your assistance and guidance. Thank you.

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Introduction

In February of 2011, I met with Professor English–Lueck to discuss the possibility of joining a student project regarding the needs of metastatic breast cancer patients. The goal of the project was to produce a documentary that highlighted the diverse needs, managing skills, and coping mechanisms of patients with metastatic breast cancer. The project was originally created by Mary Koskovich, who was diagnosed with stage IV breast cancer while completing her master's degree in applied anthropology at San Jose State University. Each member of the project collaborated, while at the same time, maintaining specific individual project goals. In addition to being the primary investigator, Mary created a project report from the interviews that we conducted, addressing the coping strategies of metastatic breast cancer patients. Cassie Carruth, another member working on the project, wanted to use the interviews and footage that we obtained to understand the role of nurses dealing with this population. As I had a background in visual anthropology and an interest in using documentary films as an educational tool, I was invited to join the project in the role of producer/director for the documentary. Together with the assistance of our committee members, the three of us interviewed four women with metastatic breast cancer, creating a documentary titled *The Breast Cancer Journey*.

In this project report I will discuss the goals, budget, sampling techniques, production, and dissemination process used to create this documentary, as well as the obstacles and challenges involved in the project. Additionally, I will offer possibilities for future work and dissemination of *The Breast Cancer Journey*.

Project Goals

The ultimate goal of my project was to create and disseminate a documentary that described the complex consequences of metastatic breast cancer in patients' lives. When we first began this project, Mary told me one of the reasons she felt the project was so important was that when she was given her metastatic diagnosis she found it difficult to find information that was not directed towards primary breast cancer patients. Greenman (2005:263) believes that, "schooling is just one of the places where education takes place." This documentary was created as an educational tool for those who have been diagnosed with metastatic breast cancer, the medical community that works with metastatic patients, the friends and family who want to support loved ones who have been diagnosed, as well as the general public whose perception of breast cancer is dominated by media and awareness campaigns directed at primary patients and prevention. Perhaps the subject of metastatic breast cancer lacks the public understanding of its primary diagnosis counterparts because of its disheartening and sad nature. Unfortunately, this has created a gap in information sharing, which affects those who have been touched by this diagnosis.

Anthropology is a word-driven discipline. It has tended to ignore the visual-pictorial world perhaps because of distrust of the ability of images to convey abstract ideas. When engaged in ethnography, the researcher must convert the complex experience of fieldwork to words and then transform those words into other phrases shifted through analytic methods and theories. This logocentric approach to understanding denies much of the multisensory experience of trying to know another culture. Recently, the anthropological community has witnessed the growing use of film

as an ethnographic tool. Paul Henley (2000) and Marcus Banks (2001) both advocate for the practice of ethnographic film as a visual method in social science research. Peter Crawford (1992) extensively examined visual anthropology and ethnographic film-making as tool for anthropological discourse. This resurgence of anthropology and film has created non-conventional ethnographic methodologies, which produce different types of anthropological knowledge.

The use of videos in anthropology provides an alternative way of understanding culture-perceptions. Sarah Pink believes that there is great promise for the use of film as a reflexive approach to qualitative research in anthropology. In her work, *Home Truths* (2004), she analyzes video footage recorded by leaving a camera rolling and allowing participants to go about their daily activities, thus allowing the observer to understand how subjects interact. Pink (2004:85) stipulates that this video tour method allows observers to draw conclusions about how participants present themselves. “The tapes are expressive of *my* view through the camera. Simultaneously they represent my informants’ own representations of their selves and homes (performed to myself and the camera).” Pink suggests that the video tour method is a collaborative way to gain anthropological knowledge.

Recently, visual anthropologists have begun to shy away from the colonists’, or outsiders’ production of ethnographic films and have begun to encourage community participation in the video process. We can see examples of this in digital storytelling, recording life histories, and participatory video projects. These examples rely on methods that emphasis empowerment of communities and individual; limiting biases and

expanding representation. Digital storytelling is form of community based participatory research that encourages participation in local issues. Participatory video, another form of storytelling, encourages the community to participate in process of creating a story. By telling a story through their own perspective, community members are empowered to retell and alter the story to reflect their political reality. In addition to creating a story, the community is also encouraged to learn about the video process, often training participants to use the equipment, concepts, and techniques, which enables the community to tell more stories. Barbash and Taylor (1959:86) consider collaboration between filmmakers and subjects a key component of recognition and representation. “If the film is about someone's subjective or emotional life, it will probably only be enriched by their active participation.” By documenting individuals’ personal experiences and memories, previously unheard voices can be added to public discourse.

The use of reflexivity in anthropological film work informed the participatory process of this project. One of the goals of this documentary was to allow members of the metastatic breast cancer community to share their stories themselves, instead of allowing their stories to be edited and reshaped by a director. *The Breast Cancer Journey* is composed almost entirely of on camera interviews, with only a brief narration to set the stage at the beginning of the film. This approach was taken to allow the participants to shape their story, and attempt to avoid the biases implied from staged acting or voiceover narration. Creating participatory B-roll footage continued to allow participants to shape their own story. Whenever possible, the documentary incorporated supplementary B-roll footage, that was taken by the participants themselves. This was done by giving the

participants flip cameras and asking them to film their daily lives as they lived with metastatic breast cancer. Our interviewees filmed or photographed themselves interacting with friends, family and their children. By using this footage, the documentary was not only more participatory, but also showed a more personal story for the audience to connect with. Focusing on these four women's stories as a source of authoritative knowledge, instead of an outsider's or director's perceptions, gave voice to a community of previously unheard perspectives and acted as tool for sharing information.

When Margaret Mead first published *Coming of Age in Samoa*, she revolutionized the world of anthropology by sharing the skills and knowledge of anthropologists with the lay audience. She continued to support this concept during a published conversation with Gregory Bateson (2002: 45). "The principal point is access, so that other people can look at your material and come to understand it and share it." I believe that film is one of the many tools that anthropologists can use to share information that they have gleaned within a larger community, instead of knowledge being monopolized by the world of academia. The ability of film to reach across a broad audience spanning from the academic to the layperson, allows it to be a powerful tool for the generation of knowledge. The creation of this documentary is but a small step in filling the void of information regarding the needs and experiences of the metastatic breast cancer community.

Ethnographic Film Theory and Ethical Issues

Film is not reality. This is an easy concept to understand when analyzing a narrative Hollywood film. As children we learn that onscreen violence is staged, that the characters we see are only actors, and that what happens on screen, whether extraordinary or mundane it is simply a fabrication created for our viewing experience. Why does this concept suddenly become murky when we enter the realm of documentary film? It is because documentaries straddle a precarious line. This line is one in which the fantasy of a fictional story meets the reality of physically recorded events. When fact and fiction collide, it is extremely important to understand an effective tool that keeps a balance present between these two opposing forces. The tool is ethics, and when an ethical approach is taken during the creation of a documentary, the film as well as the audience will benefit. Documentaries are a powerful tool, which make an audience feel a certain way on an emotional level. Any documentary film, even those that purport “reality” are still fabrications created for the purpose of fictional consumption. Ethical film making will not turn a documentary film into reality, rather it will provide the audience with the knowledge of a filmmaker’s bias, and by doing so keep the film from becoming an unethical representation of reality.

Ethnographic films and other social documentaries have a long history of breaching ethical boundaries. Robert Flaherty’s *Nanook of the North* (1922) is a classic example of this breach. In what would later be known as “salvage ethnography,” Flaherty’s fictional construction of Eskimo culture would permanently shape an entire

country's perception about a real people. Another example of ethical misuse is found in *The Axe Fight* by anthropologist Tim Asch (1975). Asch was later discredited when it came to light that the violence recorded on film was not a traditional ritual, but rather a fight over goods brought in by westerners. The controversy surrounding *The Axe Fight* demonstrates that ethical issues are always present in documentary film making, and it is the duty of the filmmaker to make ethical choices during the making of a film.

The Breast Cancer Journey was made with ethical considerations in mind.

Usually a film is made by one subject about another. This film is interesting in that one of its interview subjects, Mary, also happened to be one of the co-creators of the project. Because of this ethical dilemma, the filmmakers chose to edit footage of Mary discussing her role as co-creator in the film itself. This self-reflexive choice asks the audience to question Mary, and her role co-creating the documentary. This conscious ethical choice keeps the films' interpretation of the reality of metastatic breast cancer patients an ethical representation.

Despite their ethical breaches, *The Axe Fight* and *Nanook of the North*, attempted to share knowledge through a means of communication. Michel Foucault's discourse theory (1975) explains the formation and relations between different bodies of social knowledge. Foucault argues that the knowledge one acquires has immense power and control over ones' behavior. He uses the term *power/ knowledge* to signify that power is constituted through accepted forms of knowledge, scientific understanding, and truth; but there are many truths, each within a particular socio-historic discourse. Therefore,

communities, who engage in the same discourse, share the same unique language and social knowledge.

Heizmann (2009) proposes that knowledge is often created, shared and established by those who have the power and means of communication, controlling who we are by deciding what we discuss. Therefore changes of knowledge occur when a counter-discourse receives attention through communication, but the change requires the possession of the means of communication. It is here, within the realm of counter-discourse that informal information and knowledge practices occur. The relations between different discourses, and among people who share similar domains of activity encourage the development of new domain of power knowledge.

In the media, breast cancer is dominated by campaigns directed at raising awareness and support for primary breast cancer patients. The Pink Movement governs and shapes the public discourse of breast cancer by publicly advertizing their perception of the disease, preferring to focus on the experiences of primary patients. This social construction of knowledge has inadvertently detracted from the metastatic breast cancer patients. Built from the metastatic community who share a distinctive language and social discourse, *The Breast Cancer Journey* acts as a means to develop a new domain of knowledge, within this sphere of counter-discourse.

Breast Cancer Films

The topic of breast cancer becomes more prominent in public discourse and it is also becoming more popular in documentary and fictional films. The stories and dissemination of breast cancer films range from overly dramatic *Lifetime* productions to homemade videos. Before beginning work on *The Breast Cancer Journey*, I reviewed multiple movies regarding the subject of breast cancer. The following films demonstrate varying points of views and experiences with breast cancer.

The Breast Cancer Diaries (2006) use Ann Murray Paige's experiences with breast cancer to put a face to breast cancer statistics. The film is mostly composed of footage gathered from a home camera that she has set up in her bedroom to act as a diary. By using an on-site camera the participant can share her feelings and experiences as they occur instead of waiting to be interviewed in a studio. As a result of this technique the film displays a candid and honest look at one woman's experience with breast cancer. The concept of using women who are currently dealing with cancer is a powerful idea. It allows the audience to see what the subject is currently experiencing, instead of reflecting on the occurrence after the event has passed.

17 Short Films About Breasts...(2008) creates a series of narratives that focus on the central theme of breasts. Within the film, women share their personal stories and experiences with breast cancer, and aging. The director Cathryn Robertson, describes the documentary as "a profound *affirmation of life*." The film's organization of short stories allows the audience to understand multiple perspectives and experiences regarding the subject. The diverse sample of women, as well as diverse experiences,

provides the film with a multidimensional viewpoint and approach.

The cancer film, *I a Minute (2011)*, also strives to achieve this multidimensional approach. This movie features celebrity cancer survivors and cancer experts who readily share their opinions of risk factors, environmental causes, complementary medicine and “being a survivor.” This film creates a narrative from the view the survivor. Using celebrities who are now cancer free focuses the film's message on hope and the skills needed to ‘beat’ cancer. The use of celebrities in health awareness campaigns or documentaries popularizes the topic and draws a large audience through the recognition of a familiar face. *Five (2011)*, an anthology of five short films that follows five women during their experiences with breast cancer, brings celebrity health campaigns to a new level using celebrity actors and directors. Directed by Jennifer Aniston, Alicia Keys, Demi Moore, Patty Jenkins and Penelope Spheeris, the movie uses fictional stories of women with breast cancer to highlight their shared experience.

Based on the book, the film *Pink Ribbons Inc. (2011)* uses the medium of documentary as a tool to discuss the Pink Movement, instead of those with breast cancer. The documentary focuses on marketing campaigns that have turned surviving breast cancer into a corporate industry. The director Léa Pool highlights the phenomenon of “pinkwashing” philanthropy, suggesting that these acts have only provided PR cover to corporations that donate to the cause.

The breast cancer films discussed, demonstrate various views and understandings of the disease. The majority of these movies discuss the experiences of primary patients, with exception of *17 Short Films About Breasts...* that briefly mentions stage IV breast

cancer. Instead, the films tend to show the lives of primary patients disregarding those with a metastatic diagnosis. The medium of film is becoming a more popular to discuss breast cancer, but the darker side of metastatic cancer is still unrecognized.

Process

It is common knowledge among video editors that every minute of final footage requires about an hour of editing. This simple math equation stipulates that *The Breast Cancer Journey*, a thirty-minute documentary would take thirty hours of editing. However throughout this project I have found the one to thirty ratio applies only to professionally produced material and does not include the months of preparation needed to complete a documentary from start to finish.

PRE-PRODUCTION

Sampling

The Peltos (1978:136) state, “ it is commonly accepted that the larger the sample, the greater accuracy in predicting from the sample to the universe it represents.” For this project, a large sample size was impossible to achieve. The Cancer Prevention Institute of California (2007) estimates that in 2005 there were only 4,442 cases of female invasive or metastatic breast cancer in the Greater Bay Area. Recruiting from this relatively small population was further narrowed by the ability to access this community and find individuals willing to publicly share their experiences on film. Mary acted as a gatekeeper to the community of metastatic breast cancer patients. Her status as a person with stage IV breast cancer had introduced her to many breast cancer support groups and organizations. She created a recruitment flyer and contacted thirty-five breast cancer support groups and organizations, asking them to handout the flyers at their meetings, email it to their members, and post it at their establishments and on their websites. Through this recruitment method our research group was able to interview four women,

Michele Moskalik, Janet Sollod, Lydia Mackovitch, and Mary Koskovich. Our haphazard sampling method did not produce a diverse sample of the metastatic breast cancer community due to the limitations of a small sample population and the rigorous requirements of participation. However this small sample of participants did not prohibit our team from completing a documentary that shares the diverse nature of metastatic breast cancer.

The Interview Instrument

Heilder (2006:9) believes that, “ethnographic understanding emerges from the analysis, and an ethnography is only as good as the analysis. But an ethnographic film can only be as good as the understanding that precedes the filmmaking.” Our research group demonstrated our understanding of the subject through the creation of our open-ended interview instrument. These interview questions were tested and reassessed during multiple practice interviews, some of which were filmed and reviewed. The final interview instrument consisted of twenty-six questions and multiple probes found in Appendix 2.1. Our informants were able to view the open-ended interview instrument before the interview, so that they would be as comfortable as possible with the questions.

Budget

It is fair to speculate, that the completion of this project would not have occurred without the charitable donations of our donors. Initial funds for this project were gathered to the Tower Fund Foundation, and were generously donated by The Davidson Family Foundation and Gayle Kludt. Additional funds were procured through an IndieGoGo

account, designed to facilitate donations to charitable projects. Finally, a large portion of our funds was donated as wedding gifts to Mary, who was married during the process of this project. A total of, \$7,252 was raised to film, edit, and disseminate *The Breast Cancer Journey*. As of May 2012, less than half of these funds have been used. By not exceeding our budget, there are resources for further dissemination and circulation of this documentary, as well as the possibility of further expenditure for other student projects, such as Cassie Carruth's work with nursing students.

Below is a chart describing the expenditures for the project.

Budget			
Item	Description	Date	Cost
CreatTV Class	Class-Final Cut Pro	September 10, 2011	\$90.00
CreatTV Class	Class-Advanced FCP	October 15, 2011	\$90.00
CreaTV Class	Class-Producer	July 27, 2011	\$45.00
CreaTV Class	Class-Studio Access	July 23, 2011	\$45.00
Cheap Totes	Tote's for thank you gifts for participants	October 1, 2011	\$23.89
Set Design	Dusty Rose Blanket	October 2011	\$34.00
Studio A Rental-4 hrs. @\$100/hr	Mary Koskovich Interview	October 21, 2011	\$400.00
Studio A Rental-3 hrs. @\$100/hr	Michele Moskalik's (Discounted rate due to CreaTV double booking)	November 28, 2011	\$100.00
Studio A Rental-3 hrs. @\$100/hr	Lydia Mackovitch 's interview	November 30, 2011	\$300.00
Studio A Rental-3 hrs. @\$100/hr	Janet Sollod's Interview	December 2, 2011	\$300.00
SJSU Book Store	CD Sleeves DVD-R 25Pk	May 1, 2012	\$46.5

Office Max	CD/DVD Labels Embossed Note Cards	March 1, 2012	\$30.19
Best Buy	DVD-R	April 3, 2012	\$12.44
Peet's Coffee and Tea	Gift cards for composers	March 1, 2012	\$40.00
Editing	Pablo Woythaler 30hrs @ \$30/hr	April 15, 2012	\$900.00
AS Print Shop	Flyers for premiere	April 24, 2012	\$12.07
Total			\$2,469.09

Figure 1: Budget for the Beyond Pink Project

CreaTV Classes

In preparation for producing a documentary with CreaTV, I was required to take a number of courses offered through the organization. I began by taking the introductory *Orientation* class that provided an overview of services policies and examples of previous CreaTV projects. This course introduced me to the staff, volunteers, interns, and other students interested in producing public access programs. After this initial class was completed, I was able to move on to more advanced workshops such as *Studio and Control Room*. By taking *Studio and Control Room* I was able to learn practical skills, such as camera operation, audio controls, lighting setup, video switching audio board, Teleprompter and studio set-up. To become certified in this course, students are required to participate and work on an episode of *Our TV/Your TV* the following week. Successful completion of the *Studio and Control Room class* is required by any CreaTV member who would like to produce a show using CreaTV Studio A. The completion of this course

was essential to the project, because our interviews were filmed in the CreaTV studios using the cameras, lighting, and sound equipment reviewed in this course.

Finishing the *Studio and Control Room* course only allowed me to operate and work in the CreaTV studios in order to produce a video or show for CreaTV; I also needed to take *Producing at CreaTV*. This class, taught by Alison Stewart, discussed ways to plan a community access television show and examined topics such as preproduction, rundowns, underrating, legal issues, and postproduction options. The production class at CreaTV was fundamental to the completion of this documentary as it gave me the tools to successfully produce a documentary, and build a relationship with Allison Stewart, who later became an integral part of this project.

The first group of classes that I attended at CreaTV gave me the technical skills to produce raw footage, and work with CreaTV staff. However, to present the completed documentary I also needed to master the basic concepts of nonlinear editing. I attended two Final Cut Pro (FCP) classes (*Final Cut Pro* and *Advanced Final Cut Pro*) taught by Jen Vaughn. Final Cut Pro classes were chosen over the Adobe Premiere classes offered because FCP 7 is recognized as an industry standard, and is considered to be more intuitive, additionally CreaTV offers advanced classes in this program. These classes provided me with the skills of basic nonlinear editing, such as navigating menus, making cuts and dissolves, adding narration, adding music, and creating simple effects. The skills provided in these classes enabled me to create a thirty-minute documentary from the eight hours of raw footage that we taped.

PRODUCTION

Managing Interview Filming Sessions

Although I had taken hours of classes through CreaTV, I was unaware of the various facets of production and management that are required to produce a successful interview session. My basic understanding of the technical aspects such as camera, lighting, set design, and sound were sufficient when paired with the assistance of CreaTV staff. However, the classes I took did not mention the important skill of translation. I found that producers must be able to translate and communicate the needs of CreaTV staff, interviewers, and interviewees, in order to successfully produce a program.

For our first interview, I reserved the studio for a three-hour time slot. Our team had roughly two hours of interview questions, and planned on allowing for a short intermission, as well as thirty minutes before and after the interview to set and strike the room. I had e-mailed the CreaTV staff a week prior with my requests for lighting microphones and set pieces.

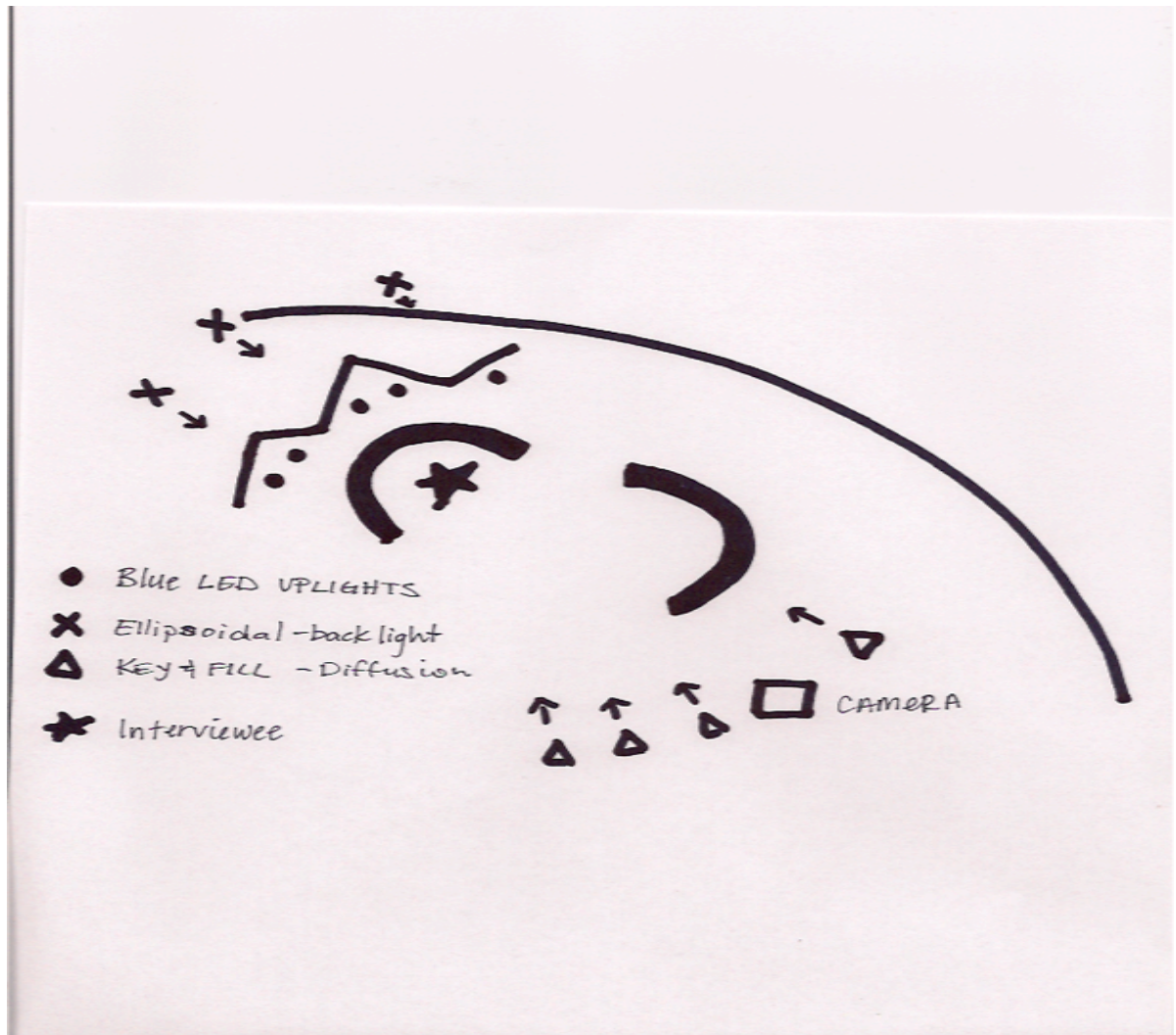


Figure 2: Beyond Pink Set Design, Lighting, and Sound Layout

Upon my arrival for the first interview, I found the studio to be set and the staff ready to begin, deeming the thirty minutes for set-up almost unnecessary. There were still some minor changes that needed to be adjusted on the set, such as assuring the staff at CreaTV that we did not want a pink backdrop, even though the interview was about breast cancer. After being shown multiple pink lighting gels, I was able to convince the staff that we wanted blue gels on our up lights. I also requested that we replace the folding plastic

chairs with cushioned armchairs from the lobby. The importance of this request was not understood until I explained that two of the woman we would be interviewing had metastatic cancer in their bones and sitting in a plastic chair for two hours might be uncomfortable, and would possibly compromise our interview.

The staff on the shoot also made some valuable suggestions based on their years of experience. For example, I had initially requested one clip-on microphone for the interview subject to wear. After explaining how this project would be edited, a crew member suggested that we also mic-up the interviewers, allowing us to hear the interview questions. This suggestion was then used for all of the interviews and proved to be an essential audio marker during the editing process. In addition to making minor set adjustments, I was able to explain the nature of these interviews, the project background and how our team hoped to use the documentary. For the most part, the set design and crew remained the same for all of the interviews, with the exception of different colored gels to backlight the interviewees' hair (blue for dark hair, red for light hair) and an unexpected intern, whose limited technical abilities affected the audio focus and white balance of the camera.

In addition to managing the set, I found that it was important to explain the filming process to the women being interviewed and answer any questions that they might have. Before each of the women came in for their interview they were e-mailed an overview of the interview questions, consent forms, and an information guide to prepare for the interview. The interview guide covered subjects such as, what to wear, how to answer interview questions, and what to expect during the interview (Figure 2).

Thank you for volunteering your time and participating in our series of interviews.

Some things to consider when being interviewed:

What to Wear

- Please feel free to wear whatever you feel the most comfortable in, however some colors and patterns do not translate very well to film. Red, black, white, thin stripes and tight patterns often appear blurry on film, and should be avoided if possible. Shiny or metallic clothing can also be problematic when being filmed.
- During the interview we will ask you to wear either a wireless or small clip-on microphone, which will be attached to your collar. Unfortunately, these microphones easily pick-up the sound of necklaces, so please avoid wearing large necklaces.

Answering Questions

- We have attached a list of our proposed interview questions so that you can be familiar with the types of interview questions that we will be asking. If there are any questions that you do not feel comfortable with please let us know.
- When answering interview questions on film please try to answer in complete sentences, this format translates best for film.
For example, if the question is: "How old are you?" Please answer, "I am 52 years old." Instead of replying, "52."
- Please do not be worried about talking too much; we look forward to hearing your stories and life experiences.

The Interview

- The length of the interview will be around an hour and half, in addition to set-up time. We will take a few breaks during the interview and if you need to stop or take a break please let us know.
- Before you begin the interview we will ask you to sign a consent form, so that we can use your image, name and voice in our documentary.
- If you have any props that you feel would help explain your illness narrative please feel free to bring them and we will try to incorporate them into the interview. Your photos and pictures may also be used in the documentary if you wish. If you would like to contribute your photos we can either accept them in a digital format or original prints, which we will scan and return to you.

Thank you again for participating and sharing your story

Figure 3: Interview Preparation Document

None of the women interviewed were used to being on camera or being formally interviewed about their experiences with breast cancer, and therefore it was important to

make them as comfortable as possible in an unfamiliar setting. When the women arrived for their interviews we sat them down in the back lounge away from the cameras and set. In this more familiar setting, I would sit down with the women and go over any questions or concerns that they had regarding the interview, as well as have the interviewees sign multiple consent forms for CreaTV and the Department of Anthropology, located in Appendix D. In order to assure the confidence of our interviewees, I used this time to check if there were any interview questions they did not want asked, and to explain that we would not show any footage that they were uncomfortable with (none of the women made any of these requests). Since this documentary was designed to present these women's experiences as narratives instead of interviews, we also spent a few minutes practicing answering interview questions, by repeating the question in the answer. For the most part the interview questions were designed to elicit stories instead of “yes” and “no” answers. Reviewing a few practice questions before the interview helped the women to become more comfortable with the process. Throughout the pre-interview, the interviewees were introduced to the members of our team including the CreaTV crew.

Once the women were ready to begin their interviews, the crew adjusted the lighting and camera angles, as well as conducting a sound check. When the camera in the studio power on, they connected via a live feed on a high definition television screen in the room. This became a problem, as the women were self-conscious of how they looked and sounded on screen (easily solved by disabling camera to television feed). Still, it was necessary to reassure some of the women that they would not appear in the documentary as they did on the television screen because we would not be filming in high definition

and the final footage would be color corrected. During our second interview, Michelle brought her mother and husband for moral support; I was able to give them a more accurate idea of how she would appear on film by allowing them to look through the camera. As the interviews progressed both the interviewees and interviewers became more relaxed, allowing for more natural looking footage.

During the interviews I was unable to act as an interviewer because I was producing the segment. The role of producer/director could easily be compared to that of an interpreter. Wearing a microphone and headset during the interviews allowed me to hear and communicate with the crew in the control room, while at the same time observing and listening to the interviews in progress. This position allowed me to direct and correct the interviewee. For example, when the crew in the control room noticed that the audio levels were off because the interviewee's hair was touching the microphone, I would ask the interviewee to stop talking and then move her hair off the microphone. I quickly learned it was better for me to ask the interviewees to change something instead of the cameraman, as the cameramen simply repeated the control room crew's orders without pausing the interview and fixing the problem. This often left the interviewers and interviewees confused, and unclear as to how to fix the problem. Acting as interpreter between the crew and interview was also beneficial when there were technical errors, or if a tape needed to be changed, because I was familiar with the structure of the interview questions and could stop the interview at an appropriate time instead of during the middle of a heartfelt story.

Listening to the crew during the interviews made me privy to some of the hierarchy and power issues within the crew. For example, a more senior crewmember, expected the interview to be run as he saw fit, and at times this created conflict with another member. I often found myself hearing apologies by a crewmember for another's actions. Still, these conflicts of hierarchy and power can be viewed as a part of working within an occupational subculture and they did not affect the interviews.

Generally, the staff at CreaTV was interested and excited to be working on a project that they believed would help people. Several shared stories of friends or family who had cancer. After we had completed the second interview one pulled me aside to show me the nicotine patch he was wearing on his arm and told me that he had been moved by the women's stories and was now trying to give up smoking.

Organizing and Scheduling Interviews

Organizing and scheduling interviews and studio time proved to be one of the most difficult aspects of producing a documentary. Though booking ten hours of studio time over a two and half-month period appears to permit room for leeway, multiple factors and considerations needed addressing. First, the studio and crew needed to be available for a three-hour time span. CreaTV's Studio A, that our team was using for the interviews, is the largest and most popular studio, because students become familiar with it after completing the *Studio and Control Room* class and working on an *Our TV/ Your TV* episode. As a result of the large number of weekly and specialty shows produced in this studio, studio reservations are at a premium. In addition to booking available studio space, organizing studio time around the busy schedules of our team members also

needed to be considered. As the producer of the show, I was required to be present when any of our team members were in the studio. While our interviews did not require that all team members were present, each of our interview sessions had two interviewers, one lead interviewer and one secondary interviewer. Finally, and most importantly, studio time needed to revolve around the lives and availability of our interviewees. At times we were forced to reschedule or cancel an interview because one of our subjects was unwell, in the hospital, or receiving treatment.

To mitigate scheduling problems, our team created a Google Documents calendar of our availability. I also listed CreaTV's hours for studio shooting. In the end, I found the easiest scheduling process was to 1.) pick a date and time that worked for our team members, 2.) check to make sure that time slot was free in the studio, 3.) ask the interviewee if they were available during that time, and 4.) book and confirm the space with CreaTV. Unfortunately, this process was not always smooth. During our filming period we were forced to reschedule (due to miscommunications) double bookings at CreaTV or a change in schedule for either an interviewee or team member. Despite these obstacles our team was able to complete four sets of two hour interviews that provided the documentary footage.

Collecting B-role Footage, Narration, and Soundtracks

Creating a documentary requires more than just excellent interviews— B-roll footage, narration, and an appropriate soundtrack helped to create the tone and story arc of the film. It was important that the B-roll footage be participatory, allowing the women to shape their own personal stories. We asked each woman to either film their daily lives,

or submit photographs of themselves and family members to be used as supplementary footage throughout the documentary. Both Lydia and Mary took flip cameras home and shot footage with their families, friends, and daily activities. Janet submitted an array of travel photos that had been taken since her diagnosis. Michelle passed away before she was able to film any footage, but her husband generously gave us photographs of Michelle to use in the documentary. While editing the film, I found there were segments that needed to be covered with B-roll footage, either due to the quality of the footage or for awkward transitions that sometimes occurred. This footage was gathered from archive.org, an Internet library of uncopyrighted videos, photographs, papers, and music. Though the website is extensive, it was difficult to find footage that did not look dated, or have a watermark from its original producer. The most difficult footage to find was videos of the Pink Movement, because many of these events and fundraisers are copyrighted. After sifting through the archives of uncopyrighted footage, I was able to find enough footage for the introductory narration, as well as medical and Pink Movement activities. The B-roll footage from participants and from archive.org was incorporated into this documentary during the final stages of editing.

Creating a well-balanced documentary requires multiple components to work together. One of the most important, if not subtler, pieces is the music. The soundtrack to any documentary should reflect the tone in feelings of the film, without overshadowing the storyline. I was able to work with two musicians, Alex Nitta and Willie Rusert, to create a soundtrack that appropriately complemented the mood and tone of the documentary. I met with Alex and Willie to describe the background behind the

documentary. I was also able to show them some of the footage that we had filmed at CreaTV. My meeting with Alex and Willie occurred shortly after Mary passed away. Her death, as well as that of Michelle demonstrated the truly emotional nature of the film. Three weeks after our meeting I received three tracks from “Bump in the Night Studios.” The first song, *Mecca*, was perfect for the DVD title page as well as the ending credits. The second song, *Fog City*, was used during the introductory narration, and conveyed a poignant ambiance to begin the film. The third song involved a banjo and was far too upbeat and twangy to be incorporated in the film. The musicians offered to redo the song without the banjo but as we already had two tracks and I did not feel it necessary to have music throughout the entire film, I declined.

Although we wanted the majority of the film to be comprised of on-camera interviews, allowing the participants to share their personal stories, I felt it was necessary to include a prologue in the form of narration, based on the themes from the documentary. The narration used in this documentary falls under Heilder’s (2006) dimension of “added information,” providing context beyond what was contained in the visual images. Dr. English–Lueck recorded the narration during a one-hour session at CreaTV. This session required far less preparation and set-up than the on-camera interviews, as we only required one standing microphone and one sound manager. The audio from this recording was overlaid with B-roll footage, creating an opening that set the tone for *The Breast Cancer Journey*.

POST-PRODUCTION

Editing and Analyzing Footage

As anthropologists we are taught that the more data that is gathered, the better. While this may be true, reducing hours of notes—or in this case eight hours of raw footage, into a concise and eloquent package—is often a challenge. Unlike writing a paper, creating a video from interview footage poses the challenge of producing a story using only someone else's quotes. Richard L. Bare (1971:142) believes that, “the mark of good editing is to put the many takes and scenes of the motion picture together in such a manner that the smooth flow of the dramatic action is not interrupted, and the audiences’ attention is not diverted to the editing itself.” The unseen work of editing requires those involved to understand the subject, audience, and the technical skills to produce a final product.

In *The Ethnographic Interview*, James Spradley (1979) conveys the importance of analyzing ethnographic interviews as a way to understand what concepts mean to your informant and how to explain a cultural meaning system in its own terms. To begin understanding how we could use our interviewees’ quotes to create a story, our team reviewed the video footage to determine general themes that spanned all four interviews. I would later use these notes as a roadmap for creating the documentary, I felt it was important to summarize and timecode the interviews. This later became an invaluable tool as I could use these timecodes to find quotes from the hours of raw footage. The themes that we elected to use in the documentary were fleshed out and incorporated into a story arc chart located in Appendix D. This story arc was divided by themes that later

became the eight chapter tiles for the documentary; The Breast Cancer Journey, Before Cancer After Cancer, Cancer as a Chronic Condition, Navigating the Medical Community, Public Relations: Managing Friends and Family, Support Networks, The Pink Movement, and Revelations from the Journey. Within each of these chapters I presented the interviewees' different experiences with metastatic breast cancer.

All of our interviewees eloquently told their personal stories; as a result, the interviews incorporated in the documentary were clear and concise. However, it was difficult to decide whose stories should be incorporated and whose should be left out. There were often incidents where I was forced to choose the interviewee's story whose footage was most relevant and lacked technical errors. According to Ascher and Pincus (1999:146), "even on a straightforward documentary or corporate video, the way sound is handled in terms of minimizing noise and maximizing the intelligent stability of voices is a big part in success of the project." Sound and audio errors were the most common throughout the footage, often resulting in the removal of valuable footage. For instance, Lydia told a wonderful story during her interview that had to be cut. During a Thanksgiving dinner she wanted to share the news of a good scan with her family and friends. There were children at the dinner and she did not want to say that the scan was for breast cancer, so instead she said that she had some bad cells that had shrunk. Her four-year-old son corrected her yelling across the dinner table, "cancer, it's cancer!" She used this story an example of how familiar her son was with her condition. Unfortunately, the sound engineer during her interview was not watching her audio levels as closely as needed: the audio levels were too high or "hot," creating a peaking effect. There is no

way to remedy this problem as the error had occurred during the original recording. This example, along with other technical errors, forced me to disregard what would have been valuable interview footage.

The process of deciding which footage should be included in and what should be excluded from the short documentary required me to review my notes and re-watch all of the footage multiple times. Though this is a time-consuming process, the most difficult part was watching these women describe their journey that would ultimately end in death. This became more difficult and more emotionally draining, as members of our project passed away. I found it easier watching Janet, our interview subject who was most in denial of her condition, or Lydia whose life revolved around her son. Even though I had only met Michelle once, her story was more upsetting because she passed away shortly after her interview. Mary's interview was always the last one I watched. After her death in January, her interview footage became the most painful to review as a result of her work on the project and our friendship. I had hopes that re-watching the footage multiple times would desensitize me to the nature of the interviews. This never happened, and instead I became keenly aware of how much emotional distress the documentary's audience would be able to handle. According to Bare (1979:152), “The audience will not be *moved* by picture unless the actors feel strongly emotions of the screenplay they are performing.” This documentary did not involve actors or screenplay, therefore all emotions were genuine and became a window into the lives of our participants. It is important to realize that even though this is a sad and dark subject, the women who we interviewed were “living their lives”. Their lives consisted of more than this disease; their

lives included family, goals, laughter, and love. These components were just as much a part of their lives as metastatic cancer, if not more so, these aspects were important for the audience to see, as they showed our interviewees as people and not just a disease.

During the second phase of the editing process, I hired Pablo Woythaler, an editor from Stanford Video, to assist me with the more technical aspects of Final Cut Pro. Though I have taken enough Final Cut Pro classes to understand the basics of editing, Pablo's speed and knowledge of the program was invaluable. My editing skills were far inferior, but the courses that I taken taught me the language that was needed to explain what I wanted. Together we sorted through the finalized footage, creating transitions between quotes and overlying B-roll footage. We approached this project with different skills and knowledge sets; this sometimes resulted in differing ideas of how the documentary should look. There were often quotes for stories that I wanted to include because of their anthropological or narrative merit, but were unfit because of their aesthetic elements. Through constant compromising, we each learned the other's idea of a perfect clip and found or created the interview footage necessary to complete this documentary.

DISTRIBUTION

Disseminating Information

As I previously mentioned, this documentary was created with the intention of being used as an educational tool to share information with metastatic breast cancer patients, their friends and family, their medical community, as well as the general public. Eastman (1974:73) states that, "Writers on documentary film agree on one attribute of

that form of motion picture: it is truly a document—recorded evidence or information.” To share this recorded evidence with a large and diverse audience requires the documentary to be available to as many people and organizations as possible. As producer of this documentary, I maintain intellectual property rights, but I do not believe in limiting the people who view this documentary to be beneficial to the project. Instead, wide distribution of this product facilitates the sharing of knowledge and use as an educational tool.

Participant Première

Our team is greatly indebted to women who participated in this documentary, their friends and families, as well as the donors who made this project possible. It was important to our team that these individuals be one of the first groups to view the finished product. This was accomplished by inviting them to the premiere of the documentary hosted by the Department of Anthropology held on April 28, 2012. I created and mailed invitations to the appropriate parties inviting them to a private showing of the documentary, light refreshments, and a brief discussion (see Appendix E for invitation). We received a wonderful turnout, all parties attended with the exception of the Davidson family and Janet, who had to work. At the premiere each party was presented with a copy of the documentary and a card thanking them, or their loved one, for their time and efforts with the project.

Student and Faculty Showing

In addition, showing the friends and family involved in the project, our team felt it was important for students (especially anthropology, nursing, and health care students) at

San Jose State University see the film. Our team organized a student premiere of the film on May 1, 2012. I gathered a list of possible student clubs, organizations and classes that might find this documentary pertinent to their studies for future work located in Appendix C. These groups received a cover letter and flyer regarding the student showing of *The Breast Cancer Journey* (Figure 4).

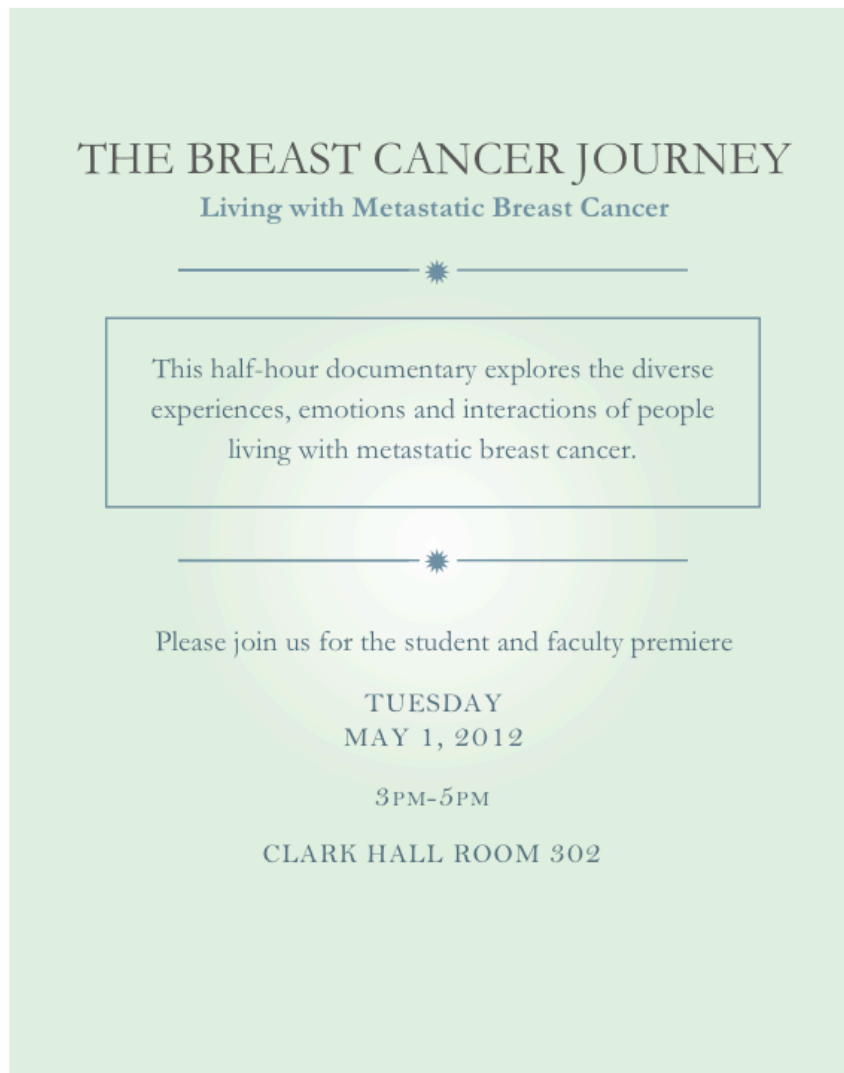


Figure 4: Student and Faculty Flyer

Ten students from the anthropology nursing programs, as well as various faculty members attended this premier. After viewing the film our team answered questions and held a brief discussion. We then asked students to write down their ideas for future uses of this documentary, as well as any comments or suggestions that they might have. Below is a selection of their comments from Appendix A.

“The reactions to the PINK movement were very interesting and somewhat unexpected. I would be interested in learning more of their thoughts about it and perhaps a comparison to others in early stages of breast cancer to see how helpful/supportive the PINK movement is [to] those with different breast cancer diagnoses.”

“Very informative and useful to anyone, especially to broach their understanding of the distinct challenges of this type of cancer.”

“It was as great video. I didn’t even realize how small the population for Metastatic breast cancer is. This is a great way to spread awareness and expose the hardships not often seen.”

Organizations and Community Distribution

A vital step in the of this film dissemination, as well as the dissemination of knowledge from this film, was sharing this film with organizations or people who come in contact with the metastatic breast cancer community. The film been presented to a number of organizations with the hopes that they will be able to facilitate role of gatekeeper to medical, student, and breast cancer communities. The documentary was given to Dr. VJ Periyakoil who works in the Hospice and Palliative Medicine centers at Stanford and the Palo Alto Veteran’s Association, to be considered for possible use in

future projects, such as the ISAGE project. On May 17, 2012, the documentary was shown to the oncology group at Stanford's Cancer Center. Additionally, the film was reviewed by Susan Zepeda from The Foundation for a Healthy Kentucky and shown by Jack Kramer at Enloe Medical Center's Cancer Department in Chico, California. The film will also be shown in Twin Lakes College's *Oncology and Massage* class and Professor Salazar's *Medical Anthropology* class, taught at San Jose State University. As a result of our work with CreaTV, the documentary will be aired steadily throughout the months of April and May and throughout the year 2012. Finally, in April 2012 the documentary was shown at the Southwestern Anthropological Association's annual conference.

Public Dissemination

In addition to classes, organizations, and institutions, it is important that this documentary be available to anyone searching for information about metastatic breast cancer. By the end of May 2012, *The Breast Cancer Journey* will be available for public viewing online at terminallypink.org and on the Terminally Pink YouTube channel.

As a reaction to her metastatic diagnosis, Mary conducted as much research about metastatic breast cancer as possible. Many patients take on the same role when they receive diagnosis and many of these patients turn to the Internet for answers.

Historically, patients have been taught to trust doctors with their lives, but with the advent of global communications, especially the Internet, patients now have the ability to gain health care knowledge from some place other than their doctor's office. As Ziebland (2004) explains in her article, *The Importance of Being Expert: The Quest for*

Cancer Information, Internet support sites are used for support, information, understanding a diagnosis and to make sense of an experience. The Internet has become a medium to fill in gaps left by medical professionals and create new experts of a condition. By uploading the film to the Internet for public viewing, knowledge regarding the experiences and needs of metastatic breast cancer patients can be found and shared by the general public.

Future Use

Student Ideas and Input

Our research team believed that we could gain valuable ideas for future dissemination of this project from students and faculty working and studying in the fields of anthropology, health care, and nursing. During the student and faculty premiere of *The Breast Cancer Journey* we asked the audience how they could see this film applied. Listed below is a series of excerpts from Appendix A suggesting future use for this project.

The Breast Cancer Journey would be an excellent coping/support tool for those with metastatic breast cancer at Stanford's Cancer Center. Also useful for educational purposes for all staff at Stanford that help these patients- doctors, nurses, staff. Also good to show researchers who may be able to push for more research at Stanford (clinical research and bench research).

Nurses will have clients with different health issues and illnesses: one could have breast cancer or metastatic cancer. As shown on the video, knowing there are support groups available for them will be good to include in the plan of care. Also, having a view of the 'journey' these clients/population goes through could help with opening topics for communication and support system.

As a nursing student, I felt this video was a very good resource because it addressed the psychosocial aspect of metastatic breast cancer, which isn't discussed too often. It would be a great resource for other patients with the same diagnosis. The

medical aspect is talked about a lot, but learning how to cope with is sometimes overlooked. The video can serve as a guide for health professionals in establishing communication that is therapeutic and supportive.

Dissemination through the Internet

The Internet has become a strong source of support and information sharing for those diagnosed with metastatic breast cancer. There is an array of online support groups and chat forums for people to turn to for information and guidance. The terminallypink.org website has the potential to be a robust resource for information sharing. In addition to hosting *The Breast Cancer Journey*, the website (which will be completed by the end of May 2012) has the potential to act as archive of information and has the ability to permit viewers to comment on and suggest further uses for the documentary. The prospective uses and dissemination of *The Breast Cancer Journey* are endless, as the information is shared and new networks of distribution are discovered and additional connections are made.

Timeline of Activities			
Activity	Date	Description	People Involved
San Jose State Human Subjects– Institutional Review Board Protocol Narrative	March and April 2011	A Human Subjects– Institutional Review Board Protocol was completed and accepted, allowing our team clearance to begin interviewing people for our project.	Mary Koskovich (Primary Investigator) Cassie Carruth Dr. Jan English-Luec Dr. Chuck Darrah Dr. Christa Amoroux Jessica Donohue
Gaining resources	2011	Acquiring funding to complete the documentary	Ann Kotas Mary Koskovitch

			Chuck Darrah
Interview instrument	Completed July 28, 2011	The final interview instrument was created after months of refinement. Questions were created, refined, filmed, and then reviewed to understand how well the questions and answers translated to film.	Mary Koskovich Cassie Carruth Jessica Donohue
Recruiting participants	September 7, 2011 to October 22, 2011	Mary created a recruitment flyer and contacted breast cancer support groups, asking them to handout the flyers at their meetings, e-mail it to their members, and post it at their establishments and on their websites.	Mary Koskovich
CreaTV Orientation Class	July 18, 2011	This class was an overview of CreaTV San Jose's policies and procedures. This course reviewed the basics of CreaTV, including how to navigate the organization and their community and educational channels.	Jessica Donohue
CreaTV Studio Access and Control class	August 20, 2011	A requirement for anyone wishing to use or produce in CreaTV's studio A. This course provided a general understanding of crewing a studio production. Throughout this course students learn how to use the camera audio and lighting equipment found in studio A.	Jessica Donohue
CreaTV production class	July 27, 2011	A requirement for anyone wishing to produce for CreaTV. The course overview the steps required to plan and produce a public access show, legal issues, and pre and postproduction planning.	Jessica Donohue
CreaTV Final Cut Pro	September 10, 2011	This editing class reviewed the basic concept of non-	Jessica Donohue

		linear editing, including making cuts, dissolves, adding narration, music, special effects in navigating menus.	
CreaTV advanced Final Cut Pro	November 19, 2011	This class requires certification in Final Cut Pro, and provides students with a more thorough understanding of nonlinear editing.	Jessica Donohue
Our TV your TV class	September 24, 2011	To receive certification in the studio and control room class, students must participate in an episode of our TV, your TV. This class acts as a practical exam of studio skills.	Jessica Donohue
CreaTV project proposal	October 2011	Before receiving studio time I CreaTV, a producer must complete a project proposal form. This proposal includes a planned start date, Project title, description, and basic project information.	Jessica Donohue
Things to consider when being interviewed document	August 2, 2011	This document was designed to prepare our interviewees for being on camera. The document included information on what to wear, how to answer questions, and general interview information.	Jessica Donohue
Open-ended Pre-Interview Phone Instrument	August 28, 2011	The open-ended pre-interview was used to gather general demographics, preliminary breast cancer information, answer any questions they might have.	Mary Koskovich
Mary Koskovich's interview	October 21, 2011	Mary was interviewed in CreaTV, San Jose, in studio A show for two hours.	Jessica Donohue Mary Koskovich Cassie Carruth Dr. Jan English-Lueck
Michele Moskalik's interview	November 11,	Michelle was interviewed at CreaTV, San Jose, in studio A	Jessica Donohue Cassie Carruth Dr.

	2011	for two hours.	Jan English-Lueck
Janet Sollod's interview	November 28, 2011	Janet was interviewed at CreaTV, San Jose, in studio A for two hours.	Jessica Donohue Cassie Carruth Dr. Jan English-Lueck
Lydia Mackovitch 's interview	November 30, 2011	Lydia was interviewed at CreaTV, San Jose, in studio A for two hours.	Mary Koskovich Jessica Donohue Cassie Carruth Dr. Jan English-Lueck
Mary's culminating experience	December 2011	Dr. Jan English–Lueck interviewed Mary about her experiences creating this documentary. These interviews were filmed in a San Jose State University conference room, as we did not have adequate time to book a studio at CreaTV.	Mary Koskovich Cassie Carruth Jessica Donohue Dr. Jan English-Lueck
Analyzing and coding footage for documentary themes	December 13, 2011	All of the interview footage was reviewed to identify general themes for potential use in the documentary.	Mary Koskovich Cassie Carruth Jessica Donohue Dr. Jan English-Lueck
Documentary outline	January 2012	From the themes gathered in our initial analysis of the footage I created a documentary outline, which was reviewed and discussed with Cassie Carruth and Dr. Jan English-Lueck.	Jessica Donohue Cassie Carruth Dr. Jan English-Lueck
Pre-editing of the interview footage	January-February 2012	After re-watching the interview footage, I was able use Final Cut Pro to compile shorter interviews of all the women (one hour each). These shorter interviews were then refined to 30 minutes or less.	Jessica Donohue
Meeting with composers	January 24, 2012	I met with musicians Alex Nitta and Willie Rusert, to discuss the general themes, moods and topics in the	Jessica Donohue Alex Nitta Willie Rusert

		documentary. We discussed possible ideas for the documentary soundtrack.	
Narration recording	March 2, 2012	A brief two minute introductory narrative was recorded at CreaTV studio A.	Jessica Donohue Dr. Jan English-Lueck
Editing the interview footage	February -March 2012	With the help of a professional editor, the two hours of pre-edited footage was constructed	Jessica Donohue Pablo Woythaler
Collecting and organizing B-roll footage	December 2011-March 2012	B-roll footage was gathered and submitted by the interviewees and their families. Additional B roll footage was retrieved from archive.org.	Jessica Donohue
Finalizing credits and acknowledgments	March 2012	All team members reviewed credits and acknowledgments for the participants and funders before being added to the final documentary.	Jessica Donohue
CreaTV submission	April 9, 2012	The documentary was first aired by CreaTV San Jose.	Jessica Donohue
SWAA submission	April 6, 2012	<i>The Breast Cancer Journey</i> , was submitted, accepted, and screened at the 2012 Southwestern Annual Anthropological convention.	Jessica Donohue
Invitations for Family and friends private premiere	April 14, 2012	Invitations were created and posted to the participants and donors, inviting them to join us for a premier of the documentary.	Jessica Donohue
Family and friends private premiere	April 28, 2012	Interviewees, their family and friends, as well as donors to the project attended a viewing of <i>The Breast Cancer Journey</i>	Jessica Donohue
Student and faculty flyer	April 4, 2012	A group of San Jose state clubs, student organizations, and classes were invited to attend a showing of <i>The Breast Cancer Journey</i> .	Jessica Donohue
Student and faculty	May 1, 2012	Students from the	Jessica Donohue

premiere		Anthropology and nursing department attended a showing of the documentary, followed by a brief discussion.	
terminallypink.org website	In progress	This website will be a place to share information and start a dialogue concerning the various aspects of managing a metastatic breast cancer diagnosis. As well as hosting the documentary.	Jessica Donohue

Figure 5: Timeline of Activities

Illness Narratives, Film Narratives

As demonstrated earlier in this report, the subject of breast cancer is not new to the medium of film. However, *The Breast Cancer Journey* takes a distinctive approach to the subject and benefits from the merits of the anthropological discipline. The process of creating product, theoretical foundation, and appreciation of the audience differs greatly between the anthropological in film disciplines. Balikci (1988:42) suggests the use of anthropological methods to create this documentary opposed to those of film allows for the implications of the anthropological message: “it invites the audience to perceive an exotic culture as a distinct and original whole to be studied on its own terms.” In the case of *The Breast Cancer Journey* the exotic culture can be found closer to home—the community of metastatic breast cancer patients.

In many cases, the product of anthropological research results in a paper, while the filmmaker’s final product appears in the medium of film. In *Ethnographic Film*, Heilder (2006:8) outlines many of the distinctions between film and ethnography. Apart from the product, the process by which a paper or film is reached differs greatly between the anthropologist and the filmmaker. The filmmaker starts the process with the concept and the script. Footage is then shot and edited, thus producing a film. In comparison, the anthropologist often begins with research plans and a set of theoretical problems. This is followed by the anthropologist asking questions, making observations, and gathering data that is then analyzed and written-up producing a report. Guindi (2004) believes that it is vitally important for the anthropologists to be present during the collection of data, in the case of documentaries, data collection occurs to the lens of the camera. “ When

anthropologists distance themselves from the instrument of research (camera or editing flatbed), they become dependent on the technical eye to do with the eye-as-mind should be doing (63).” Anthropologists acting as filmmakers allows for their involvement in the data collection process as well as the creation of a product, participation in the entire process.

In the *Illness Narratives*, Kleinman suggests that there is a gap of information sharing as physicians are taught to believe that disease is more important than illness. He suggests the following remedy:

“To change this deplorable situation, it is necessary to make the patient’s and the family’s narrative of the illness experience more central in the educational process. Only then will physicians gain appropriate attitudes, knowledge, and skills to enable them to undertake a mini-ethnography of the misery of chronic disorder or support patients in their terminal days are negotiated with the values of families from other ethnic groups.(255)”

While this proposal is an ideal way to create culturally sensitive medical practices, the expectations of these actions may not be plausible for all medical practitioners. It is here, within this disparity of information, the role and tools of anthropologists excel as they become a cultural brokers. By understanding the roles of stakeholders, their agendas, and the authoritative knowledge generated, anthropologists have the ability to create medical ethnographies that represent a community and assist their healthcare providers. *The Breast Cancer Journey* represents the community of terminal breast cancer patients and can be used as a tool for stakeholders from the medical community, breast cancer patients, friends and family, in the general public to gain authoritative knowledge of the subject.

Both anthropologists and filmmakers have the ability to contribute to a larger dialogue of knowledge sharing. However, anthropologists are trained with the ability to act as cultural brokers, encouraging participants to use emic typology to describe their experiences, and identify an audience by their roles as stakeholders in a community. The methodological approaches of film do have an advantage during the dissemination process. The accessibility of film has the potential to facilitate the sharing of knowledge by reaching a larger and more diverse audience. The accessibility of film partnered with anthropological approaches, creates a holistic approach to documentaries that improves knowledge sharing by identifying the position of stakeholders and representing a population from an emic perspective. *The Breast Cancer Journey* accomplishes this holistic approach. Its reliance on anthropological methods provided a foundation for the participants to share their experiences with metastatic breast cancer, while the film's accessible form enabled information to be shared with a considerable and diverse audience.

Conclusion

Like many patients, when Mary was diagnosed she looked for tools and resources to help her understand the implications of her illness. Though there are resources for metastatic patients, the majority of breast cancer discourse concentrates on the primary community. As the women in the documentary explain, a metastatic diagnosis defines you differently within the breast cancer community. Metastatic patients go to different support groups, have different interactions with the medical community, are excluded from the Pink Movement, and have the difficult task of managing relationships with friends and family. *The Breast Cancer Journey* was created to diminish the gap of authoritative knowledge concerning the diverse needs and experiences of metastatic breast cancer patients by building a discourse that includes a varied group of stakeholders.

The process of creating this project benefited from the combination of anthropological methods and the dissemination capacity of documentary film. The holistic anthropological approach enabled stakeholders and their agendas to be accommodated, while also encouraging the informants to have participatory roles in the project. Unlike this report, a wide audience, including the medical community, students, metastatic breast cancer patients and their friends and family, will see the documentary. The ability of film to be powerful mode of information sharing is further developed by the growing role of on-line communications. The Internet is becoming a place for informal education to flourish. By using the Internet to make the documentary available

to the public, the authoritative knowledge of *The Breast Cancer Journey* can be used as a resource for people like Mary, looking for a resource to help them understand their metastatic diagnosis.

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Appendices

Appendix A: Student Responses to Breast Cancer Journey Screening

Comments:

It was as great video. I didn't even realize how small the population for Metastatic breast cancer is. This is a great way to spread awareness and expose the hardships not often seen. (5)

Do you know of any other attempts to create documentaries like this? For other terminal or chronic illnesses? (1)

Very informative and useful to anyone, especially to broach their understanding of the distinct challenges of this type of cancer (3)

Excellent film! Patient's IDs, outlook, and their various interactions with friends, family, support networks are reflected through the whole movie. Filming is also excellent! The film really gave me more understanding to patients' situations, and I'm impressed by all the themes generalized in the film. (4)

The reactions to the PINK movement were very interesting and somewhat unexpected. I would be interested in learning more of their thoughts about it and perhaps a comparison to others in early stages of breast cancer to see how helpful/supportive the PINK movement is [to] those with different breast cancer diagnoses. (7)

Could use some more B roll footage with some narration to set up some of the different themes. It might be a way to slip in some light analysis between interview sections and add some variation to the film.

Watching this for a second time was helpful in two ways: (i) I felt a legacy of them and their lives remained, so that something very important about them stayed behind: they weren't 'terminal'; (ii) I was more able to listen to their actual words, not just feel overwhelmingly sad. Nevertheless the film did not sanitize the extreme challenge of not making personal identity equate with disease/dying. (9)

Very inspiring and heart-wrenching documentary. Very informative, even for a nurse who has worked with breast cancer patients. (2)

Just finding out the population with metastatic is small, especially in the area, creating this definitely exposes this group and made people more aware of the illness. (8)

Future Applications:

Can see potential benefit/application for families dealing with this for the first time (3)

The Breast Cancer Journey would be an excellent coping/support tool for those with metastatic breast cancer at Stanford's Cancer Center. Also useful for educational purposes for all staff at Stanford that help these patients- doctors, nurses, staff. Also good to show researchers who may be able to push for more research at Stanford (clinical research and bench research) (7)

Nurses and families: both on the 'front lines' and with their own cancer mediated challenges to moderate. (9)

Nurses will have clients with different health issues and illnesses: one could have breast cancer or metastatic cancer. As shown on the video, knowing there are support groups available for them will be good to include in the plan of care. Also, having a view of the 'journey' these clients/population goes through could help with opening topics for communication and support system. (6)

As a nursing student, I felt this video was a very good resource because it addressed the psychosocial aspect of metastatic breast cancer, which isn't discussed too often. It would be a great resource for other patients with the same diagnosis. The medical aspect is talked about a lot, but learning how to cope with is sometimes overlooked. The video can serve as a guide for health professionals in establishing communication that is therapeutic and supportive. (5)

A tool/resource for cancer clinics/breast cancer educators to have available for their metastatic patients. (2)

Can be shown to people from the Susan B. Komen Foundation, have an impact on the Pink campaign. (1)

It can be recommended to be watched by hospital workers, nurses, doctors, support networks. (4)

Appendix B: Open-ended Interview Instrument

Beyond Pink: Living With Terminal Breast Cancer

Introduction

I'd like to ask you some general questions to get to know you. Then, 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) So, tell me about yourself? (We'll send these questions to the interviewees b4 the interview)

Probes:

- a. How old are you?
- b. Where do you live?
- c. Where did you grow up?
- d. What do you do for a living?
- e. Do you have any children?
- f. How would you characterize your race and ethnicity?
- g. How would you characterize your sexual orientation?
- 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?
- k. How old were you when you were first diagnosed?

2) 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

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

4) 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?

5) 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?

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

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

8) What treatments have you received?

Probes:

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

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

10) 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 was you with?

11) 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 (blah blah blah)....

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

12) 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?

13) 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?

14) 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?

15) 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?

16) 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.....

17) 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?

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

Probes:

- Which effects 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?

19) 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?

20) 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 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.

21) *I want you to think about your future. The future ideas you had before you were diagnosed and your future as its 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?

22) 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?

23) 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 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.

24) 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?

25) What arrangements have you made regarding saying goodbye?

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

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

27) Thank you for sharing your experience with us.

Appendix C: Student Clubs, Organizations and Classes

SJSU Clubs and Groups

AMSA Pre-Med Club	Michael Sneary	Advisor	Michael.Sneary@sjsu.edu
	Daniel Smith	President	quarkhopper@gmail.com
Anthropology and Behavioral Science Club	Roberto Gonzalez	Advisor	Roberto.Gonzalez@sjsu.edu
	Esmirna Ruiz	President	e_ruizz@hotmail.com
California Nursing Students' Association	Colleen O'Leary-Kelley	Advisor	colear@son.sjsu.edu
	Sara Worrell	President	worrell.sara@gmail.com
Filipino Nursing Student Association	Katherine Abriam-Yago	Advisor	Katherine.Abriam-Yago@sjsu.edu
	Daniel Francisco	President	Daniel_Francisco29@yahoo.com
Future Professionals in Health and Aging	Brian Grossman	Advisor	Brian.Grossman@sjsu.edu
	Debbie Lopez	President	heart4seniors@hotmail.com
The Global Health Association	Laurie Morgan	Advisor	laurie.morgan@sjsu.edu
	Dwayne Alexander Abella	President	dwayne.abella@gmail.com
Health Science 104 Service Learning Club at San Jose State University	Robert Rinck	Advisor	obluvtbeach@yahoo.com
	Beheshta Kakar	President	kakar.beheshta@gmail.com
Health Science Convocation	Edward Mamary	Advisor	edward.mamary@sjsu.edu
	Jennifer Sausal	President	jennie511@yahoo.com
Health Science Undergraduate Student Association	Brian Grossman	Advisor	Brian.Grossman@sjsu.edu
	Vu Phillip	President	pmv11789@yahoo.com
Nursing Club Class of 2012	Colleen O'Leary-Kelley	Advisor	colear@son.sjsu.edu
	Courtney Batchelder	President	courtney.batchelder@gmail.com
Nursing Club	Arlene Spilker	Advisor	arlene.spilker@sjsu.edu

Class of 2013			
	Sheren Dangca	President	sherendangca@sbcglobal.net
Nursing Club Class of 2013 Spring	Arlene Spilker	Advisor	arlene.spilker@sjsu.edu
	Paige Le	President	paige.t.le@gmail.com
Peer Health Education Program	Melinda Chu- Yang	Advisor	melinda.chu-yang@sjsu.edu
	Mufaro Zakers	President	phew.stress@gmail.com
The Public Health Nursing Club	Paula Edwards	Advisor	edwardspaula1@gmail.com
	Richard Becker	President	rbecker24@hotmail.com
The Valley Foundation School of Nursing Class of Spring 2014.		Advisor	

SJSU Departments

The Valley Foundation School of Nursing	Jayne M. Cohen	<i>Dept Chair, Nursing Director, School of Nursing</i>	Jayne.Cohen@sjsu.edu
	Dr. Sue Malloy	Undergraduate Advisor	SMalloy@son.sjsu.edu
	Daryl Canham	Graduate Advisor	Daryl.Canham@sjsu.edu
Division of Health Professions	Barbara Conry	Director of Health Professions	bjconry@casa.sjsu.edu
	Caroline Fee	Associate Director of Health Professions	cfee@casa.sjsu.edu
Department of Health Science	Dr. Kathleen Roe	Professor & Department Chair	kathleen.roe@sjsu.edu
	Dr. Edward Mamary	Professor & Director of MPH Program	edward.mamary@sjsu.edu

Outside SJSU-People of Interest

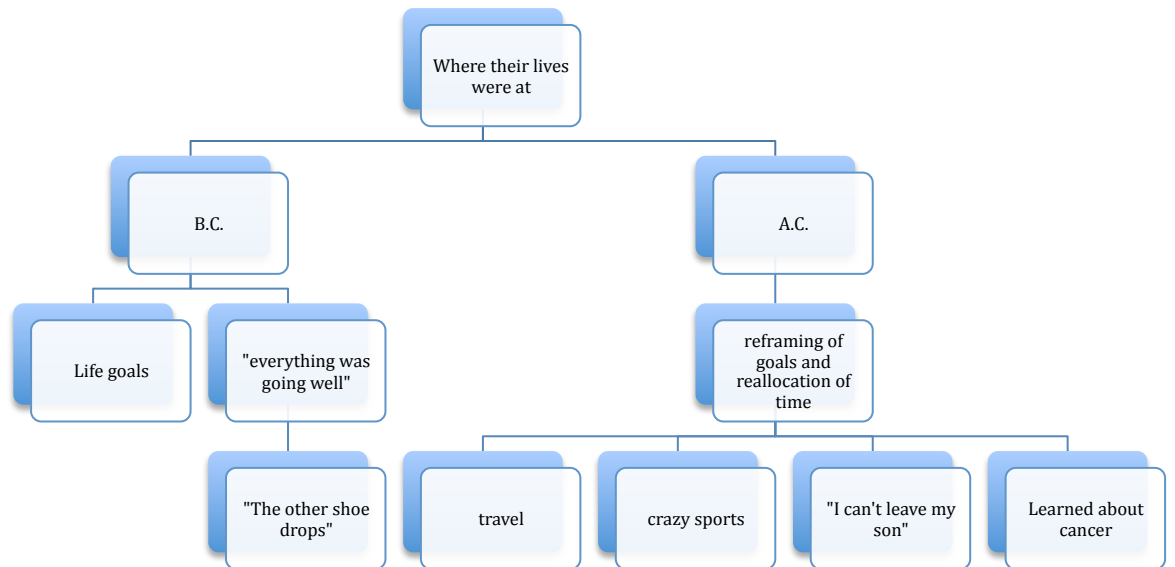
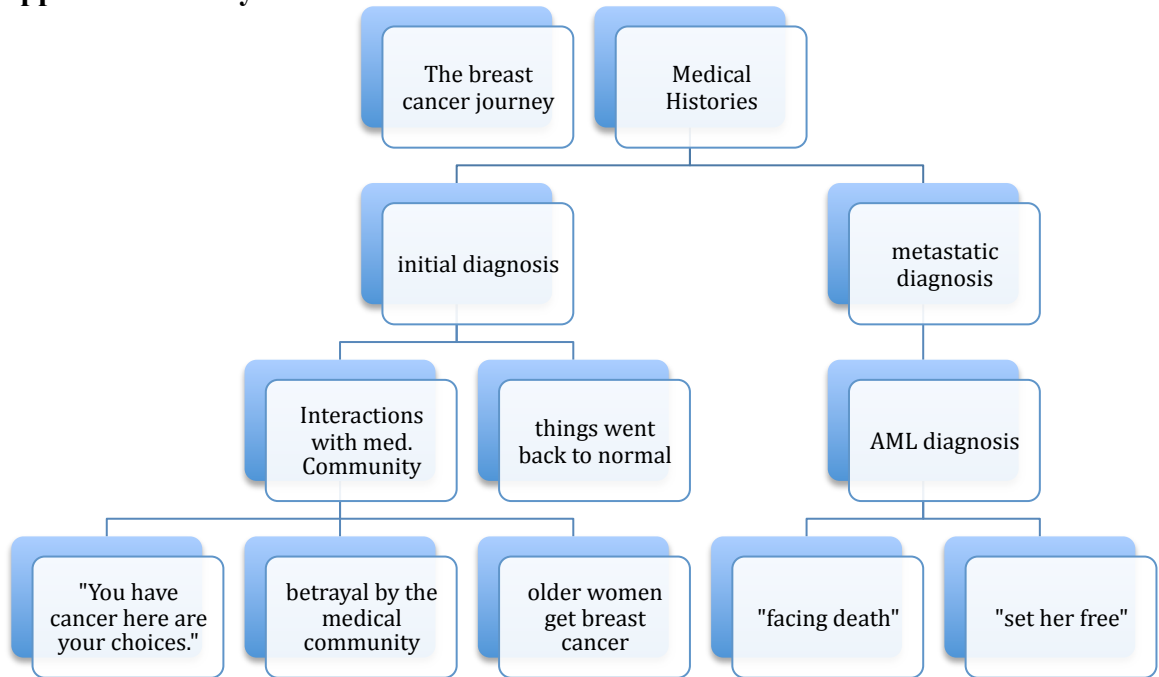
Twin Lakes College	Maria Tearsa Woythaler	Director of the oncology massage program	worldmassage@gmail.com
Palo Alto VA- Palliative Care	V.J.	Professor and Director of the Palliative Care Program	
Metastatic Breast Cancer Support Group	Sam Marye Lewis	Coordinator	(408) 267-4397 1515 Meridian Avenue, #206, San Jose

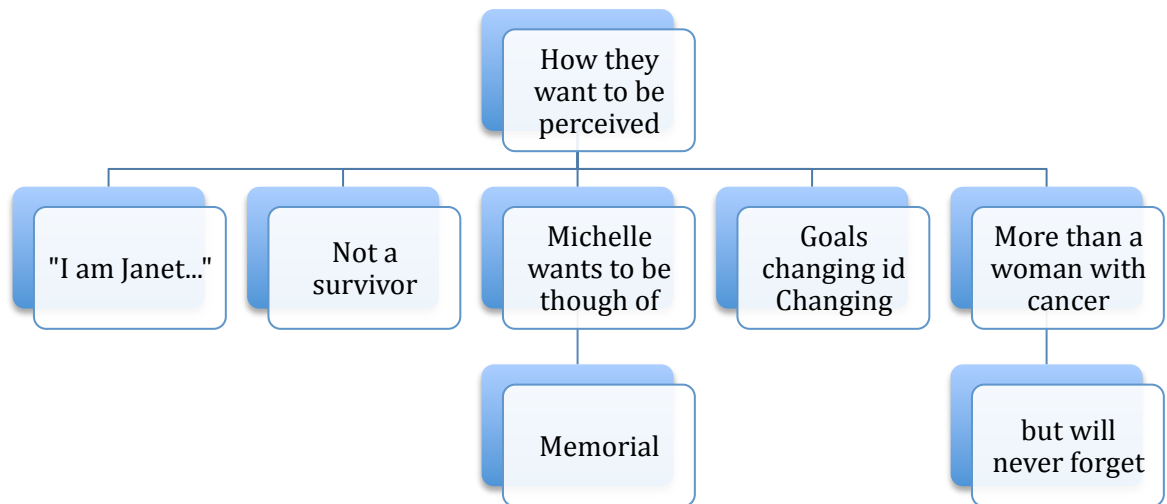
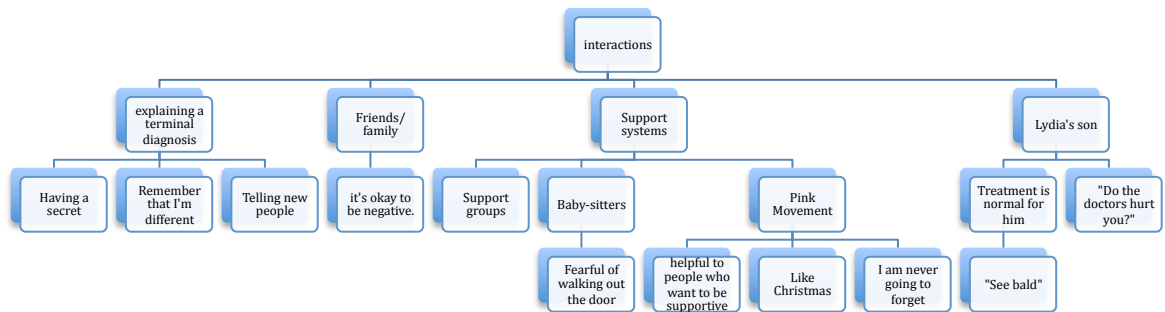
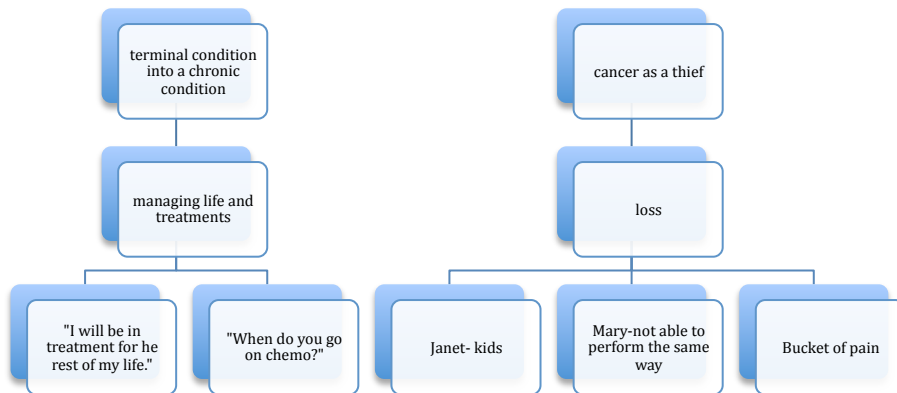
Metastatic Breast Cancer Support Group Community Breast Health Project	Deborah Rosenberg	Coordinator	545 Bryant Street, Palo Alto (650) 342-3749
Oncology Nursing Society- Santa Clara	Ms Sunny Yuan	RN OCN [®] MSN MBA	mysunnymail@gmail.com

People Involved in the Project

Interviewed	Lydia Mackovitch	Participant	lydiamac@ix.netcom.com
Interviewed	Janet Sollod	Participant	jsollod@gmail.com
	Scott Moskalik	Husband	scott@moskalik.com
	Jack Hoeflich	Husband	jackhoeflich@gmail.com
CreaTV			

Appendix D: Story Arc Flow Chart





Appendix D: CreaTV Consent Forms

Talent Release Form

TALENT RELEASE FORM
(Rev. February 22, 2002)

I authorize the undersigned Producer to make use of my appearance on:

PROGRAM TITLE: Beyond Pink
PRODUCER'S NAME: Jessica Donohue
PRODUCER'S PHONE NUMBER: (916) 660-6353
DATE OF TAPING: _____

I understand that I am to receive no compensation for this appearance. The Producer shall have complete ownership of the program. I give the Producer the right to use my name, likeness and biographical material to publicize the program and the services of the Producer.

The Producer may:

1. Photograph me and record my voice and likeness for the purpose of the production mentioned above, whether by film, videotape, magnetic tape, digitally or otherwise;
2. Make copies of the photographs and recordings so made;
3. Use my name and likeness for the purposes of education, promotion or advertising of the sale or trading in the photographs, recordings and any copies so made.

I further understand the master tape remains the property of the Producer and that there will be no restrictions on the number of times that my name and likeness may be used.

Name (please print) _____ Date: _____
Address _____
City _____ State _____ Zip Code _____

Talent Signature (Parent or Guardian if under 18 years of age)

Date: _____

Location Release Form

LOCATION RELEASE

I hereby grant permission to use real property located at:

Address: _____

("the Premises") for the purpose of photographing and recording scenes (interior and exterior) for the use of Producer: _____ ("Producer"). Permission includes but is not limited to the right to bring crew, equipment and property onto the Premises, and the right to remove same from the Premises after completion of work. I agree not to interfere with producer's work on the Premises.

I represent that I own the Premises or otherwise have the authority to enter into this Agreement and grant these rights.

Permission is granted for the following consideration: _____ (payment, acknowledgements, etc.)

The Premises will be used, commencing on or about the following start date: _____ (subject to change in the event of changes in the production schedule or because of weather conditions), and continuing until completion of all scenes and work to be completed on the Premises, currently scheduled to end on date: _____

Producer agrees to restore the Premises to the condition in which they were delivered, reasonable wear and tear expected. Producer agrees to use reasonable care to prevent damage to the Premises. Producer shall not be liable for any indirect, incidental, or consequential damages including, but not limited to, loss of business, loss of use and loss of profits of any party, including myself.

Producer shall own any and all rights to all photographs and recordings made by Producer on or about the Premises, including any photography or recording of any identifying names or signs appearing thereon, and will have the world-wide right to use and license others to use such photographs and recordings in any manner whatsoever, including, but not limited to, the right to exhibit, record, edit and otherwise alter at the sole discretion of the Producer such photographs and recordings or any portion thereof, in any form of media whatsoever, without limitation or restriction.

Agreed to by:

Name _____
Address _____

Producer Jessica Donohue
Address SLSV

Date _____ 8/29/11

Appendix E: Family and Friends Invitation

