THE VULVODYNIA MONOLOGUES:
A LOOK AT AGENDA-SETTING AND THE EFFECTS OF WOMEN'S REPRODUCTIVE HEALTH AMONG AMERICAN WOMEN IN PRINT MEDIA

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by

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ACKNOWLEDGEMENTS

To:

Janet
Hannah
Lacey
Nina
Annika
Linda
Katelyn

and

Every woman who has known this pain,
This is for you.

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ABSTRACT

This study examines the rhetoric of women's reproductive health across *The New York Times*, *The Washington Post*, and the *Los Angeles Times* and attempts to answer the following questions:

> Q1: Do national newspapers write about vulvodynia and other women's reproductive health concerns?
>
> Q2: If they do, what kind of discourse do they create among their audience?
>
> Q3: If they do not, what causes the gap between medical research and media dissemination of information for women?
>
> Q4: How does the media close the gap that may exist?

Using rhetorical criticism with a feminist approach and Glaser and Strauss's constant comparative method, I analyzed online newspaper articles, blog posts, and reader comments in order to identify the way the media writes about women's reproductive health and the public response it receives.

The results of this study show that there are five major areas of discourse on women's reproductive health: medical discourse, economics and politics in conjunction with women's reproductive health, verbiage, choice and empowerment,

and the sharing of personal stories. Each contained a tone of negativity towards the topic, yet there has been an increase in the quantity of discourse since 2008. This study provides a better starting place for further research in women's reproductive health in the media, as there was very minimal scholarship to be found on the topic.

Additionally, this project provides a detailed example of journalism that should be more prevalent when covering complex health topics. Seven women were interviewed and portraits were made in order to personalize their experiences with vulvodynia and women's reproductive health.

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Keywords: vulvodynia, women's reproductive health, print media, rhetorical criticism, portraits, agenda-setting

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1.0 Introduction

When I made the decision to pursue a Master's degree in Photojournalism my friends and family all let out a sigh of, "Finally." Somehow they all knew I belonged in photojournalism long before I did. I've always had a passion for photography, more in the form of art, but nonetheless any chance to make photographs was a welcomed opportunity for me.

I remember in middle school being the one with a simple point and shoot that utilized 110 mm film and being the one "documenting" my friend's daily lives. I was always the one with the camera. Not much has changed. My passion for photography is even stronger than before and my time in the University of Missouri's Journalism school has made my work even better.

The last year I've had the opportunity to improve my portrait work. I found that I enjoy the one on one interaction and the challenge of making a portrait that portrays an individual's unique self. I've been working on family and child photography while finishing the journalism work for this project. Eventually I would like to continue portrait work or go into editorial editing.

The content and concept for this proposed project came from me knowing that I, and plenty of other women, have a story to tell concerning women's reproductive

health concerns. I've always had an interest in the sciences. In fact, I stated my undergraduate work in biology before switching to English. I've always believed that the public needs good communicators for science based topics. Science and health should be easily accessible to anyone and having effective written and visual communication can make a world of difference in the way the public interacts with complex topics.

The way the media views women's health and the very specific issues women suffer from need to be talked about. I'm in a unique position to have women open up to me about our shared condition. I feel I'm the one who is prepared, passionate, and ready to tell this story on behalf of the millions of women in the United States who are not heard.

2.0 Field Notes

The following individual reflections address the following:

1. Atmosphere
2. Their Story in Brief
3. Most Moving Moment
4. Challenges in Photo
5. Challenges in Audio

2.1 Janet, 53 9/20/13

Janet was my first subject and I couldn't have asked for a better one. Janet was 53 and had been experiencing vulvar pain for three years, possibly due to menopause onset. Walking into my first interview and shoot had my nerves all over the place. I had done some test photos the day before of myself so I knew my set up, but I wasn't sure how anything was going to go. Janet welcomed me into her home and I asked if we could do the interview first. I did this to get to know her story and get a feel of her personality. It is essential that I get to know these women and a little of their personality so I can find ways to bring that out in each portrait. Since I'm using the same lighting set up in each shoot, I wanted the audience to really see each woman as an individual.

I was surprised by how easily Janet opened up to me during the interview. Talking about vulvodynia tends to be difficult for most women. I know I even have issues opening up to my doctors sometimes. My first topic I asked Janet to address was a summary of her medical history and experience with vulvodynia. She jumped right in and was pretty detailed. Because she's only had sexual pain for three years and later in life, her story was pretty simple and laid out. However, the most interesting moment for me was when she talked about a late term miscarriage when she was younger. Her passion for wanting to be a mother and the love she gave her adopted daughter after that difficult pregnancy really moved me. She wanted to be a mother again and knew that's what she wanted. She had a biological son prior to adopting her daughter as well. Luckily, vulvodynia never made that dream impossible.

Prior to this project, I have done little audio outside of the required class assignments. Even then I've avoided it pretty effectively. This project is so important to allow the women to tell their story in their own words because so much of it has happened in the past. Janet's apartment was great for doing audio. Her daughter was quiet. The kitchen was great to set up in. However, I did not notice until after the fact that there was a clock in the living room. For some reason I didn't hear the ticking in the headphones until much later in the conversation; after

we had finished recording. I'm not sure how this will affect the final audio until I cut it.

Logistically, Janet had a beautiful little yoga room that I could shoot in. This was my first time setting up my portable studio outside of my own living room. Because of the small size of the room and the white walls, the grey backdrop remained very grey. As it was my first set up, that's what I thought I wanted but later after more shoots and some contemplation that is not the case. Doing this specific set up multiple times really has given me a stronger understanding of how the environment can affect the lighting and final images. She was really patient with me in my posing. Janet had said that she wasn't a fan of having her picture taken, but by the end mentioned that I had put her at ease. I was just happy to have her patience and flexibility with me. As much as vulvodynia is a serious topic, I do not believe that every image has to be serious. These women are all different and unique. Some of them are even very happy and laid-back individuals. I'd rather have their personal individuality come out over the seriousness of the vulvodynia. We are not defined by our condition.

2.2 Hannah, 23 10/27/13

Hannah's pose and self-confidence is how I wished I had handled my condition at her age. To photograph Hannah, my mom and I packed up the car and headed East for a weekend in Hugoton, Kansas. Hugoton is a little town in the middle of nowhere western Kansas that has one bed and breakfast run by the Mayor and a couple run-down motels. The town used to be known for natural gas but now they're building an ethanol plant just outside the town, which is what brought Hannah from New Mexico to Kansas. She started having discomfort around age 15 and was just recently diagnosed with spastic pelvic muscles that cause a lot of pain. She had such a difficult time getting a diagnosis because she's always lived in more rural communities. Even during her undergraduate degree, she talked about the difficulties in trying to get treatment because of the time constraints of being an engineering student and the long drive to knowledgeable doctors. This challenge still continues for her.

I really loved getting to know Hannah. I'd never had the opportunity to talk with anyone my age that had experienced sexual difficulties as such a formative age. Her openness to speak about how her vulvodynia symptoms have affected relationships and her personal growth was really moving. Her candor, rewarding.

She had a wonderfully open and spacious basement apartment. It was really easy to set up the photo equipment and there was even a high basement window that acted as a high soft box/hair light. Because of the open space it was interesting to realize how dark the backdrop would go with the added space to angle the flash further away from the grey. It sounds odd, but I feel like I have more control over the image and light when I have more room to move the setup and myself around. This shoot really clicked and Hannah was really great. She was confident and has a great smile. I couldn't see picking a portrait of Hannah where she isn't smiling, just because it's such as part of her personality.

Her interview was candid, open, and detailed. The space was quiet and there was absolutely no problem getting clean audio from Hannah. She also was very good about keeping thoughts going from a simple question. I joke that it's called rambling, but really it's just effective sharing of lots of information. Some people answer questions in such short sentences and do not like to elaborate. Hannah is not one of those. I really don't think I can say enough good things about Hannah and her positive outlook on life and life with her condition.

2.3 Lacey, 35 11/10/13

Each interview was a unique experience and came with different challenges. The hardest one was with Lacey and driving out to Durango, Colorado, finding a kindred spirit, and not being able to see/talk with her on a regular basis. I met Lacey just prior to my own wedding. I had yet to talk with a woman who had vulvodynia, was young, and was in a committed relationship. Lacey's enthusiasm and need to talk with another couple about their experiences coping with vulvodynia was very apparent upon meeting her.

Something that I still have yet to understand is how men have never heard of vaginal pain. I think that the area of men's experiences with vulvodynia is a greatly underexplored and under-acknowledged range of difficulties. I was very surprised and impressed that Lacey's husband (her "sexy sniper") stayed around to talk with me when I first arrived. I wish I had brought my husband (then fiancé) so the men could chat. Talking with various women who have been in or are in serious relationships makes me think that there is some sort of need for men to get support with how to deal with vulvodynia too.

One of the big issues we talked about during the audio interview was what it is like trying to receive care and afford care for vulvodynia when a woman does not live in a major metropolitan area. Lacey has to drive to Arizona for Botox injections and had to fly to New York for her surgery. The time and cost involved in trying to receive effective treatment is pretty astounding. On top of receiving medical treatment for the pain, Lacey and Travis see a couple's councilor to help with the psychological and relationship difficulties that occur with the condition. Even with everything going on in her life, Lacey had a surprisingly upbeat and positive outlook on treatment. I have the urge to believe this is a mix of her personality, the recentness of her surgery (just after Hurricane Sandy), and the support from her husband. It's interesting how quickly vulvodynia can cause negativity but in Lacey's case, she seems to have found ways to manage and move forward.

On the technical side, I swear I have the worst luck with recording audio in homes with hardwood or tile floors. Is carpet no longer popular? There are a few moments you can definitely hear one of her dog's tap, tap, tapping around the room on the floor before we scooted the pup's cute fuzzy butt out of the room. Overall everything was very quiet, all be it a bit echo inducing. I wish I had a portable sound studio for this project; unfortunately it's just a recorder and me. Lacey was easy to talk to and had some great stories about how she's gone about trying to get treatment.

For the portrait, I was able to set up near their bedroom and use painters tape to hang the backdrop on the wall. Stands are great when there is room but taping up the backdrop to an empty wall really has been the best solution for my portable studio. The space I was given was great for everything. Lacey is the first woman

who I took more than about 20 frames of. She was a challenge for me. My lighting setup is not ideal for individuals with round faces. If the backlight catches the face, it makes the individual's face look rounder than it actually is. Because of the nature of this portrait series I did not want to change the lighting setup so my other option is to really focus on posing to best use the light in the correct areas. I made 75 frames of Lacey and cannot thank her enough for her patience and flexibility with experimenting with poses. The simplest solution in hindsight was just keeping the light off her face and making sure it stayed just a hair light. This kept the light on her face more even and didn't emphasize the round shape in an overly awkward way. My favorite frame with her was one I took standing on a stool. The downward angle worked really nicely. Looking back through the full take, I think I tried to get too complicated in the posing and utilization of her hands. The simplest really worked best and seems most compelling.

2.4 Nina, 56 11/11/13

My time with Nina is very difficult to explain, reflect on, and articulate. Let me start by explaining the situation that surrounds my interview with Nina. I was approached by a woman out of New York who is in the processes of filming a documentary surrounding birth control and the many aspects of vulvodynia. She found me through the National Vulvodynia Association in much the same fashion as I have found many contacts for my project. This documentary is fully funded and was inspired by Rachel's own experiences with vulvodynia. In our communications, I had mentioned my phone discussions with Nina and how I thought she would be a compelling story to add to the documentary as well.

Now the question to answer is why did I decide that Nina was the interview to propose to the documentary team? She called me up one day after the first email I sent out in order to try and recruit individuals. She explained to me that she has had vulvodynia since 1987 (check year) and was diagnosed with breast cancer shortly after her vaginal pain started. She's been through the change and growth in the medical community and has a unique perspective on how truly life-changing vulvodynia is. She survived two types of cancer she wasn't expected to and over 25 years later still has severe vulvodynia. It's dictated her work life, her relationships, her sense of self-worth, and culminated in a real fear that she may never get better.

Nina lives in Denver, making her easily accessible for a film crew and myself. I wish I could just paste the film crew's footage here because of how hard some of this is to explain.

The film crew was three individuals and we all arrived at Nina's townhome together. It was oddly difficult to go about my work with them doing their work. Film needs things to be resaid multiple times and some things done multiple times, such as even saying hello. This is not how I work, even with photo. I was at the whims of the crew to some extent.

Nina and I were able to sit down in the kitchen for the audio interview. My "luck" with hardwood floors continued, and this time I had a cameraman walking around on those floors while I was recording audio. Nina also has a cat with a bit of separation anxiety so there are definitely many meows in the audio. The biggest struggle was balancing my project needs with theirs. I find that having others around can change the dynamic of the interview considering it is such a personal topic; this was not the case with Nina. She was very open and forthcoming with information and her experiences. I'm pretty sure there were several points that Nina's story not only had me tearing up, but the whole crew. After about 20 minutes of audio, I went to get set up in the living room to photograph and we kept talking. Nina kept getting more and more in-depth in her story and by the end she had us all bawling. Rachel (the producer) and myself could heavily empathize with the pain, but some of her medical stories had us floored. She talked about how in the late

1980s she saw a pathologist that left her on the table after a biopsy and the clinic had closed down with her still there. They left her. Nina's story really is about pain and struggle that continues to this day. She is so incredibly strong to have made it through everything that she's been put through. The doctors didn't even think she would be alive today because of her cancer and radiation poisoning. But she is.

Janet, Hannah, and Lacey all approach their pain with much more positivity and determination. But Nina has been truly determined and really let down by doctors along the way. How could you not be angry at the world and the medical community after everything she had experienced? The difficulty I will face with her interview is being able to cut it down to about two minutes. I think this will (unfortunately) be dictated by audio flaws from the camera crew and not by content. But the content is all so good and pertinent that maybe they did me a favor.

I had very little time to work with Nina on the portraits. In fact, she almost didn't want to do them that afternoon because she had been crying. I actually think that her having cried added a real quality to the image. I didn't take many images with her, but I did try something different. I had her get down on the floor and used the stool more like a table than something to sit on. It gave her images something a little different. Most of all, after looking through the images, I love her eyes. They do have a wet quality to them that is beautiful. I really do think her images are my favorite I have done for this series even though I had little time and flexibility to work with her. The shooting schedule was tight for the film crew so we had to leave pretty quickly to go interview my sex therapist. In 48 hours, I interviewed both Lacey and Nina, was interviewed myself, and helped interview my therapist. The amount of decompression I needed after that weekend was astounding. It brought a lot of issues forward for myself and gave me a lot to think about in my own life as well as with this project. Women like Nina who are desperate to see change are a major reason I am doing this. So many women don't talk about their pain or are unable to get help and that is not okay. Women like Nina who have had pain for so long and lost so much are a constant reminder for me to never give up on this project or myself.

2.5 Annika, 22 1/3/14

Annika emailed me and it took several months to be able to meet up with her. She's a Colorado Springs native, but currently lives and works in Boston. We were finally able to meet up just after New Year's. Annika is the youngest individual I've talked with and the only one that has come to my apartment instead of me going to them. In some ways, I think the location does affect the interview. I offer to go to the individuals for the quality of the interview. I have found that women open up more in their own homes, even if it presents me with technical sound and shooting issues. I don't know if it was comfort or the difficultly of the topic, but I found that Annika was the least willing to open up about her very specific experiences with vulvodynia.

She did make some excellent points and talk on topics that are pertinent that no one else had addressed. She spoke a lot about the secretiveness of the pain and the necessity for honesty in all the relationship in one's life.

There is something to be said for being young and having a chronic pain condition that does affect the psychological development of healthy relationships and being young definitely forces a woman to seek answers. In the same respect, finding the time and money to get answers when you're young is its own challenge.

After listening to Annika's interview again, I found her extremely eloquent and well spoken, especially for her age. Her ability to talk on point and articulate many of the difficulties that come with vulvodynia was spot on.

Since she came to my apartment, I was able to turn off the fridge and air conditioning. I controlled the audio situation well. Only problem was my audio recorder has been notorious about holding a charge in the last few months, but being at my apartment I had the charge cord on hand.

The photography was also much easier to control and set up a head of time. I felt comfortable moving much of my furniture out of the way (in our tiny 700 sq. ft. apartment) and just doing what I need to do. I tried a few different approaches to the photographs. Annika has beautiful doe eyes and I really wanted to emphasize them, so I attempted an approach with her head down bringing her eyes up. Totally didn't work. Those particular shots looked a bit creepy. What did work was getting her hands involved in the shots. I wish I had her hands on the side away from the rim light because when her hands are more prominent, they overwhelm her face. However, when they are lower in the shot they aren't super overwhelming, especially when she looks straight into the camera.

Every single shoot I do has helped me push to finish this project for each and every special woman willing to speak with me.

2.6 Linda, 64 2/18/14

Linda is a woman who really surprised me. Several weeks after I sent out my second attempt at recruiting individuals to photograph I received a call from her. As with most individuals she wanted to know what the project entailed and talk with me a little bit. She was very sure about working with me after about 10 minutes of chatting. Chatting was the easy part, the interview on audio was much more difficult.

She lives south of Castle Rock, Colorado, so when I drove into the neighborhood I was surprised to find she had horses and was mobbed by Golden Retrievers on my entry into the house. The reason I mention her home and animals is because they really seem to give her some relief from her pain and a focus in her life. They're her comfort.

I came in and we spent about two hours talking about both our vulvodynia cases and experiences. I tend to forget that I'm there for journalism and not just for a sense of community. But at this point, I keep getting the feeling that maybe all of us women should create some sort of fact based support group. It's just so easy to talk with many of these women and Linda was no exception. I think many of these women feel like they need someone to talk with and relate to as well. I know until I started this that I had never met another woman with vulvodynia and that seems to be a common theme.

After talking, we moved into the kitchen to recap some of what we talked about onto the audio recorder. There are definitely some challenges with the audio. The rooms are all hard floors and the three dogs (plus one cat) didn't necessarily like to stay put. At one point, the cat even sniffed the recorder and I'm pretty sure that is audible on the recording. I actually think it's interesting that you can hear the dogs a bit because they are so important in Linda's life. There is one point where one of the dogs starts drinking water and we both start laughing about it. I'm hoping to find a way to cut the dog sounds into her audio effectively in some way. I almost wish this had been video, but I don't know if Linda would have come across the same way with video. Having the recorder actually on changed the fluidity of her words and I could detect a little reticence. Where she had been very open just speaking with me, I think she was more thoughtful about what was being put on the recorder. (Who wouldn't be, to be fair?) During my Picture Story course with David Rees, I remember a video piece of a woman talking about her natural hair journey while her child was there. She was determined to tell her story even with all the interruptions from her daughter, and that's the exact same feeling I got from Linda, but in this case with her dogs.

Photographing was an interesting challenge. They have a beautiful home with her husband Bob's wildlife photography work on many of the walls. I had a difficult time finding a good place to work. We settled on a space in the hallway, which was a

tight fit. I MADE IT WORK!!!! I think it was about three feet between the banister and the wall to fit everything including me. I considered using my wide-angle lens, but because all the other images are shot with a 50 mm prime I really wanted to remain consistent. I believe I got some nice images that portray Linda's strength and composure that I saw during her interview. For goodness sakes, she's had vulvodynia pain for 24 years at this point. She definitely has a strength about her having that for so long and raising five children. There was more I wish I had done, but I felt like I was starting to impose on dinner time a bit so made sure I had a couple solid images to choose from before leaving. Going back through the images, we did a few with one of her dogs and I wish I didn't struggle so much with my camera's auto focus because I think there were some nice moments there that came out blurry. My set up for the portraits is not meant for fast movement and well, dogs move fast. It was worth trying.

2.7 Katelyn, 28 2/23/14

Katelyn has a crazy story that makes me feel even luckier than most women who deal with vulvodynia. To put this in context, I was lucky that I had my first sexual experiences before I got married because it did allow me to seek help with pain going into my relationship with my husband knowing that vulvodynia is a part of my life and there are ways to cope. Katelyn, for reasons based on her beliefs, waited for marriage for her first sexual experience with her high school sweetheart (later husband).

It was during this time after their marriage that she found out that she had extreme vulvar pain. Not only did she have to find answers and ways to cope, but so did her husband. As little as vulvodynia is talked about in terms of women's health, men know even less. No man in the U.S. ever expects to marry a woman and have sex limited by unexplainable pain. This pain has dictated many of Katelyn's relationships and life decisions over the last six years. It's just now her and her little dog. As of recently (Aug 2014), Katelyn got in touch with me through email and let me know she had opted for a second surgery with my specialist. Unfortunately, I was in the middle of a full-time internship, because I would have done anything to have used that opportunity to further this particular project.

Katelyn is truly just a sweet and caring individual. Probably, why she went into healthcare. Her strength and belief in God made this interview much more interesting. In many respects, religion and women's sexual health do not get talked about hand in hand. Katelyn brings a great perspective of how you can have great faith and still have an emphasis on women having sexual needs. She has seen this condition from a variety of perspectives and gone through a bunch (as many women do) to try and find a solution. As I write this, I hope her most recent surgery was successful to relieve the pain.

For her portrait, I set up in her living room. I chose to have her sit on the ground instead of the stool I typically bring to have us on a comparable level. Yes, I'm very short. I also allowed more light to fall on the grey backdrop. As I've worked on this collection of portraits, I've needed some lighter backdrops to tie into my first few images. Many of the images have gotten very dark and a few sessions were in small light rooms. This was an image to help tie it all together. Another struggle was that Katelyn has a very round face, like Lacey, and the type of chosen lighting is not ideal for rounder face types. I really liked when she was angled to the camera and looking over her shoulder. In many ways this helped to create some nice images.

Katelyn's interview is actually one of the best I did. She was able to open up completely, talk on topic, and not need guidance and encouragement in the questions. Her home was quiet and ideal to talk. There is a point where her dog starts growling at the neighbor dogs but we just stopped, let the pup finish, and then continued. Her willingness to open up was the clincher for this interview. There

was one point in the audio where you can tell she was crying and this isn't the first time for that to happen during an interview but each time it really gets me. I have the urge to just go hug them or comfort them but by doing so it would really hinder the strength of the interview. I'm pretty sure every interview I've done to date, though, has ended in a hug and further email communication.

3.0 Journalism Component

The next time you're at a Starbucks, count the number of women in the room. Right now I am in a store with fourteen other women. That means that at least three, if not four, will have or have had vulvodynia. One in four women in the United States will experience chronic vulvar pain at some point in their lifetime. Of the four women in this Starbucks, two of them will not seek medical help or if they do, will never receive a diagnosis.

I am 27 years old and I have vulvodynia. I've had chronic burning and stinging pain on the region exterior to my vagina, my vulva, since I was 20. I've had three surgeries, tried various topical and systemic treatments, and am now at a point where the specialists can only offer me topical lidocaine to numb the pain I experience.

There was a time just a few months after I started digging into the research for this project that I didn't know if I could finish it. My personal experiences with vulvodynia started overlapping with the research, leaving me feeling rather hopeless with my own condition. The personal connection I have with vulvodynia allows me the understanding and compassion towards others with the condition but it also requires a lot of introspection on my part.

Unlike many women who suffer from vulvodynia, I've never had a problem telling other people in my life about it. In fact I would take every opportunity I could to articulate the facts about it and made it my personal mission shortly after my own diagnosis to inform the world one person at a time. But like most women I still struggled to cope and find physical relief. The words, "I have vulvodynia," began to consume me. I defined myself by this unseen condition, which became emotionally draining. My condition became my personal story to tell. But when 25% of all American women suffer from vulvar pain, don't they have a similar story to tell too? And the stories were similar.

What kept me going through the several years of research were the interviews and time spent with women who share the daily difficulties that present themselves with vulvodynia. At first it was Janet. Her optimism was simply infectious. And Hannah too. Seeing hope from women who had no reason to believe that their pain could ever get better continues to inspire me. What started as a very personal exploration into vulvodynia turned into a need to help these women tell their own stories. Their own personal struggles.

Many of these women have never shared their stories outside their immediate families and for many it was the first time meeting someone who had vulvodynia as well. "No one knows" was an underlying theme in every interview. By doing these portraits and interviews, I'm putting faces to a very under-recognized condition. It's

a start in creating knowledge and empathy for women who hide this condition from the world and have to cope with it every day.

The original plan for this project was to attempt a photo story with a woman just learning of her diagnosis. The goal was to show the full spectrum of how vulvodynia affects a woman's life and the various treatment options available. The more I worked to make contacts, the more I realized that this is a condition that has a long lifespan. Some women I interviewed have had the condition over 20 years. For the scope of this project, I chose instead to do portraits and interviews, allowing these amazing women to tell their story in their own words and still be able to present the type of journalism that can help improve coverage of the topic.

Recruiting project participants was tricky for this topic. Even though many women experience or have experienced vulvodynia as many as half go undiagnosed and even fewer are willing to speak out publicly about a very private condition. The National Vulvodynia Association (NVA) sent out a network email to individuals subscribed to the association in areas I specified. My initial interested area was any location within 8 hours driving from Denver. This call for participants provided few candidates interested in participating so I asked the NVA to send out a second email to individuals in the western United States. The return from the second email provided me with an additional 15 individuals that I was unable to work with due to location and current budget limitations. Eventually I'm hoping I'll get to speak with them.

Location was key for me. I chose to go to each of my subject's homes because it is essential they feel comfortable enough to open up with me during the interview portion. This obviously can produce audio quality and consistency problems, however, it's an excellent exercise in thinking on my feet and making a situation work for a very constrained set-up.

The portraits were designed as a series using a portable studio. I utilized a warm grey, seamless paper backdrop and one handheld strobe with a white reflector. I wanted to create a more dramatic light with the added feel of mystery or protection. I also wanted the beauty and strength of these women to be accentuated. Each image has a very simple post-production process. The images are taken from camera and converted to Lab color mode. I then select the lightness layer for the black and white conversion. Some occasional light dodging was done near the eyes of some of the women.

Even with the completion of this Master's Professional Project, I have every intention of continuing the work on the journalism component of this piece. My intent was always to visually show the ample number of women experiencing vulvodynia and this project has not reached that point. I would also like to further explore video portraits or video based interviews in conjunction with this topic. Additionally, it could be beneficial for publication purposes for me to further express my history concerning vulvodynia in order to personalize the work.

At this point, however, there are several publication outlets for the story these women have to share. Presenting the portrait series with audio to various outlets such as *The New York Times* Lens Blog, *The Washington Post* Insight Blog or health desk, PhotoVoice, *The Riveter* online, and eventually the National Vulvodynia Association's website. Currently, the entirety of the project can be found online at www.carrieannedurkee.com, (eventually www.caarmes.com).

The lighting diagram, recruitment letters, and full transcripts of each interview can be found in the appendix. The full audio, full size image files, contact sheets, and audio clips can be found in the media folder.

Janet Hildebrant, 57
Boulder, Colorado

“Before the surgery, just having it diagnosed was such a load off my mind. The more information I have the better. I can cope with anything. I can't believe how many women suffer with this and it was something that I had never heard of and doctors have never heard of. I find it completely outrageous that it's just buried.”

Hannah Sullivan, 22
Hugoton, Kansas

“As far as talking with doctors about it, that's been a whole different thing because you can say in my case, ‘Hey it itches down there,’ but that is totally vague and unspecific. They have a very difficult time trying to figure out what I'm trying to tell them and I'm finally learning the lingo. The vulva. The outer lips. The inner lips. The vagina and it's all different names for these different parts. So I can say, ‘Hey I have this part of my body that itches and this other part that hurts when I have sex.’ And now I can say that but when I was younger all I could say was, ‘It itches, do something about it please.’ And no one could really take that and run with it the way I needed them to do that.”

Lacey Enderle, 35
Durango, Colorado

“Like, I’m a woman. I'm supposed to be able to enjoy pleasurable sex with my husband and I can't, so it just makes me feel like, so inadequate because it's not like pain in your arm or pain in your neck. It's pain in the most private, feminine part of your body and it just effects, you know, how you think of yourself and that's a real challenge to overcome.”

Nina Marks, 56
Denver, Colorado

“When I ended up with the cancer, when it came back, I at least knew what I was going to die from. At least it had a label. I mean I knew. And that was almost like a relief because I could say to the world, “Well I'm going to die from cancer. You know, and at least like I could have my head held high. With this vulvodynia, I almost felt like it was like AIDS. Because of the way I couldn't talk about. I don't even use the word. I used to say my bottom was burning. Because of the way the doctors had initially treated me so horribly and that no one knew about it.”

Annika Davis, 22
Boston, Massachusetts

“So, I've had vulvodynia as long as I have been sexual active. Since I was 16. But it took me a long time to find out that that's what I had and for a long time, in my past, I sort of thought that pain during sex was just a normal thing that everybody had and that you just sort of had to deal with it, and that that was kind of the reality of intercourse. And I came to realize, obviously, that that's not the case. It doesn't have to be the reality.”

Linda Karcz, 64
Castle Rock, Colorado

“My life has totally changed because I have the IBS with [vulvodynia] and with my gluten and food allergies, all that combined really makes it difficult to travel. I have a hard time sitting if we take any kind of road trip for any more than 15, 20, 30 minutes. I get pain and I love my horses. I like to go riding once in awhile. It makes that very difficult. I can't really do any exercise programs. A lot of times, I have a hard time if we want to go for a walk for any amount of time or a hike. I can't do that. It really limits my activities, totally.”

Katelyn Gunderson, 28
Centennial, Colorado

“And people just don't understand, because even though it is a really common thing no one knows about it and I think there's a lot of women out there that have and don't want to talk about it and I think I've gotten past that. I've been able to tell people at my work. I'm like, I'm not going to hide this anymore. This is who I am. This is a part of me. This is a medical condition and it shouldn't, it shouldn't isolate me more than it has to. But it is. It's a burden.”

4.0 Analysis
The Vulvodynia Monologues:
Women's Reproductive Health in Mainstream Media

4.1 Trade Length Research and Project Application Summation

Introduction.

In the United States, one in every 12 women will have breast cancer at some point in her life. One in every 10 adults will acquire Type 2 diabetes. One in every six men will have prostate cancer over the course of his life. One in every four women will have vulvodynia (Reed, 2012).

According to a recent research study from the University of Michigan published in February of 2012, "vulvodynia causes substantial pain and suffering for millions of women in the United States, yet the disorder remains under-diagnosed and inadequately treated" (Reed, 2012). What is this condition that haunts millions of women? Vulvodynia is defined as "vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible findings of specific, clinically identifiable, neurologic disorder" by the International Society for the Study of Vulvovaginal Disease (Ponte, 2008). The level of understanding among doctors about vulvodynia is limited and knowledge of the condition among the general public is even less prevalent.

The University of Michigan study examining the prevalence of vulvodynia among American women concluded, "vulvodynia is a common pain syndrome affecting more than 8% of women at any one time and more than one-quarter of women at some point in their life span" (Reed, 2012). This is a drastic increase from what was recognized as average numbers in 2003 where it was estimated that "an incidence of up to 16% of women, suggesting that as many as 14 million women in the United States may [have] experienced vulvodynia" (Ponte, 2008). Chronic vaginal pain is not a new condition limited to the last decade or two. A French gynecologist, named S.J. Pozzi, made the earliest mention of unexplained vulvar pain in medical journals around 1890 before the current working definition of vulvodynia was created in 1987 by E.G. Friedrich (Plante, 2007). The initial observance of vulvodynia-like symptoms occurred almost a full century prior to the standardized scientific definition.

Medical research tends to be years ahead of what information reaches the general population. Vulvodynia is a prime example. Vulvodynia gained ground in medical literature during the late 1980s. Not much was known about the cause of the condition, but it became considered a valid medical condition that was not attributed to a physiological disorder by the 1990s. The first noted article focused on vulvodynia, from the three examined newspapers of *The New York Times*, the *Los Angeles Times*, and *The Washington Post*; was published in *The New York Times* in 1993 by Jane Brody. Then the condition is not touched on again until the same journalist publishes in 2008. That is 15 years of significant medical research

missing in the mass media. The *L.A. Times*, which has never previously published on vulvodynia, published a 12-page spread on women's pelvic pain in March of 2014. So, why has it taken the media so long to catch onto women's reproductive healthcare as a medical versus political topic? Why is there such a prevalent gap between medical research and the media?

McCombs and Shaw first presented agenda setting theory in 1972 in the context of election coverage. However, there is very little work done on agenda setting in women's reproductive health communication. McCombs and Reynolds define agenda setting as, "the news media can set the agenda for public thought and discussion" (Ogata Jones, 2006). Ogata Jones et al continue to explain that health agenda setting can promote change and health literacy among the readership population.

National coverage of a topic drives all forms of agenda-setting content and trickles down to the local level (Young, 2011). If information is not disseminated at the national level, then the likelihood that information is disseminated on a more local level is slim. Whether or not the media covers women's reproductive health dictates public discourse, general awareness, and research funding.

Traditional news and media overwhelmingly focuses on men. White males are the average voices interviewed and their readership is what drives discourse and the agenda setting actions of journalists. Non-traditional media outlets, such as

Facebook, Pintrest, and Twitter, provide unedited voices from users. A research study for the Pew Research Center's Internet & American Life project showed that the majority of users on social media platforms are women. Seventy-one percent of women use social media sites compared to sixty-two percent of men. This suggests that social media has more available feminine discourse than traditional media and therefore may allow for a greater percentage of female voices to be heard over traditional media outlets.

Comment threads, blogs, and social media are all factors in today's information dissemination. These forms of communication allow for two very important factors: 1) content is driven by users and 2) content is typically unedited. These factors potentially lead to the development of a more feminine discourse through interpersonal communication whereas newspapers have been traditionally masculine.

In many ways, any discourse concerning vulvodynia is created mostly through interpersonal communication. First hand experience through the journalism component associated with this research emphasizes that women are more willing to share information face-to-face than by other means. There is an element of shared experience that allowed women to open up and discuss a difficult and often very personal topic to someone who has had similar experiences.

Until I began this project, I had never met another woman with vulvodynia. All seven women I interviewed said the exact same thing. For how prevalent the condition is, there is very minimal interconnectedness and open discussion among affected women. Not only did the disconnect from a community stand out to me, but also the recurring feeling that "no one knows" about this condition. Doctors, husbands, family members, and friends don't know much about the condition even when associated with a woman experiencing pain.

As unique as each woman's individual experiences are, there are many similarities in emotional duress and physical pain when enduring symptoms of vulvodynia, and yet, even doctors struggle with fully understanding the condition. Many of these women wanted to be advocates for themselves and the shared pain but didn't know how. The limited availability of information on vulvodynia and the lack of a community led me to ask why do so few people talk about vulvodynia and women's reproductive health on a national scale? When national newspapers do talk about women's reproductive health, what kind of discourse is created among the audiences? And lastly, how can the discussion of women's reproductive health concerns be improved in traditional media to include voices that are considered more of a minority?

Methods.

The articles selected for this research study were all collected from online during the research process between the months of November 2012 and March of 2013.

Eighteen articles were the final artifact selection from three different newspapers: *The New York Times*, *The Washington Post*, and the *Los Angeles Times*. These three newspapers were chosen due to their liberal leaning history, strong health sections, and national standing. All three newspapers are known for their health desks and have specialized health reporters instead of utilizing work by general news reporters or off the Wires. This does suggest that there would be higher rates of women's reproductive health articles than in regional or local level newspapers. The number of articles was determined through topic saturation. When articles could no longer add new concepts to the discourse, no further articles were added.

All the articles utilized were published between 2008 and early 2013, though others were found on topic prior to this time frame. The most pertinent and timely topics fell in between 2008 to 2012 leading to further discussion as to why that would be. Most articles contained some form of reader feedback such as comment forums or letters to the editor. Comment discourse was selected based on similar themes and discourse as the articles.

The article coding helps create the theory and data for the rhetorical criticism utilizing a feminist critique. How do *The New York Times*, *The Washington Post*, and *L.A. Times* view women's reproductive health and therefore, contribute to the shaping of women's identities?

Codes from the examined articles occur the most often as points of discourse for journalists and their readership. The codes were then grouped into five larger topics of discourse identifying the themes found in the artifacts of inquiry: medical discourse, economics and politics in conjunction with women's reproductive health, verbiage, choice and empowerment, and the sharing of personal stories. Each theme will be further defined and examined later in this research. It is important to note that each discourse theme came as a result of current societal atmosphere and created mostly reactionary discussion. The only theme that creates action and leads to better journalism is the ability to share personal stories.

Findings.

In a time when American politics focus on abortion, trans-vaginal ultrasounds, birth control, and other reproductive rights, women's healthcare is still not considered front page worthy for some of America's top newspapers. The *New York Times* contained twice as many relevant articles on women's reproductive health as *The Washington Post* and *L.A. Times* combined, yet across all three platforms the most pertinent articles fell under editorials or blog postings. For medical discourse, is this the best place for discussion or should women's reproductive health fall under the category of hard news? A summation of findings based on coded themes follows.

Public medical discourse.

Medical discourse attempts to create a factual and informative construction of women's reproductive health based on the majority of situations experienced by women. However, different conditions and situations experienced by the minority, such as vulvodynia at twenty-five percent of the American female population, affect what is the perceived normality for sexuality. This summary will touch on the major points creating the norms of women's sexuality, why they exist, and how they affect the current perceptions of reproductive health.

The commenter *Ana* gets at the heart of the issue when discussing the law suits against the Affordable Care Act's (ACA) requirement to provide birth control:

> "Contraceptives are part of the medical tools necessary to women's health. Like abortion, they are part of the full range of services that must be made available to women in case of a medical emergency, or to manage disease and dysfunction in the reproductive functions unique to a woman's body. Birth control pills are not just for contraception; they are also used to manage peri-menopause, menopause, uterine bleeding, and overall women's health. The morning after pill is an important option for women who may not be ready or able to have a child, for whatever reasons…Women take these issues very seriously, let them decide, not an employer's ideological bent" (Bronner, 2013).

Her overall point is that the general population does not understand women's reproductive health, ways to treat different conditions, or even the possible

conditions that exist. This exemplifies the repeating question of what is normal and how do we come to understand what is normal.

This simple question of "what is normal" becomes a societal construct. "Normal" is not based on the scientific method, but on a human definition. Based on Saussure's work, the perceived meaning of words is a socially agreed upon definition. In the *New York Times* article "When desire fades," a reader under the user name *35iana* makes an important and thoughtful comment: "What IS normal? It seems that normality is defined by what MEN want women to be" (Parker-Pope, 2009). The rhetoric choices by men and women surrounding the topic of women's reproductive health forms, defines, and perpetuates the view women have of themselves and their personal health. When men define the normal for women's reproductive health through laws, verbiage, and culture, men start defining the entire sphere of women's sexual identity. This becomes a cycle in which, if men define women's sexual identity, then women see themselves as the new normal defined by those men.

Economics and politics.

One particular instance exemplifies the type of language and attitudes taken among the generalized political sphere during the 2012 presidential cycle and after. As noted earlier, the amount of discussion and major newspaper coverage of women's reproductive health issues is sparse during non-presidential election years prior to 2013.

Lisa Brown, a Democrat state legislator in Michigan, was banned from speaking on the House floor for using the word "vagina" during a debate on a stringent abortion law proposal (Petri, 2012). She and one other female legislator were banned for a breach in "decorum of the House" and due to the offensive nature of the word. This initial incident was not covered by the *L.A. Times* or the *New York Times* and only in one opinion article in *The Washington Post*.

Both the example with Brown and a similar situation with Sandra Fluke not being allowed to speak before a congressional committee on birth control reminds society that talking about women and sex or sexual health in the same sentence is still a cultural taboo. The notion that women have reproductive needs and need reproductive healthcare, by extension, becomes taboo. This cultural perception that is exacerbated in the political sphere filters over into a more personal feminine identity. By publically denouncing the anatomical term "vagina" not only does the word become taboo, but even privately taboo. It becomes something to be ashamed of. Something that is even difficult to say in a doctor's office or to a close female friend. Female voices are then further silenced not only in the public sphere but also in their personal lives.

Verbiage.

The verbiage utilized to define women and their choices surrounding reproductive health creates a societal structure under which women are viewed. Take the

example of Sandra Fluke where Rush Limbaugh publically called her a "slut" and "prostitute" on his radio program. Both words are chosen in order to indicate promiscuity associated with birth control use. Women's voices are not only being quieted through discouragement of the use of words relating to women's reproductive health like "vagina," but feminine discourse is also being repressed through negative public backlash.

"Maybe it is the stress of combined pressures telling us to be sexy, but not slutty, but smart, but not nerdy, but successful career women, but nurturing wives and mothers, but ambitious, but warm and fuzzy," notes reader *Kelly* (Parker-Pope, 2008). If one comment could sum up the verbiage and the mind-set of what a woman should be in American society this is it. The expectations for a woman to be a set list of traits as defined by society and not any of the believed negative traits. The same goes for the belief of female sexuality. Notice the first descriptors *Kelly* mentioned were women must "be sexy, but not slutty." These words are typically utilized towards women in terms of sexual choices; the construct of what women's sexuality should be among American society.

Personal choice.

The idea that choice and personal liberties are being restricted by political decisions is a sizeable topic among reader response discourse. There are two sides to this argument. One side is the restriction of personal liberties and the second is the degradation of moral beliefs. Reader *LAGirl1* states, "Women all across the political

spectrum have been walking the walk of feminism, which at its core, is about women not being restricted from making decisions that are best for their families, without prejudice from the legal system, the media and the culture" (Traister, 2012). This individual points out the major areas that create discourse for women's reproductive healthcare, including women's autonomy in general, at its center.

The problem with creating laws that follow these ideologies are also twofold. The laws currently being discussed do not take into account medically relevant reasons for abortion or birth control. An example being the right to abort non-viable fetuses. These laws also do not consider the economic stress the restrictions for medical care place on lower and middle class Americans. During a heated commenter discussion on a *New York Times* article over the ACA's allowance of affordable birth control coverage, reader *rik* stated, "Healthcare itself, involves highly personal choices" (Bronner, 2013). This further draws on the idea that each individual, male or female, should be allowed to make a healthcare decision for him or herself based on their own personal needs and experiences.

Shared experience.

Lastly, the most personal discourse created by women's reproductive health articles in the three examined newspapers is story sharing. *crickett44*, a regular commenter on *The Washington Post* stories concerning women's sexual health, points out that "this country has a very childish relationship with sex. We DON'T talk about it, like grown-ups, near enough" (Butler, 2012). The type of discourse that the handful of

women's reproductive health articles create are rife with women sharing their experiences. As much as inter-personal discussion does not seem to be openly prevalent for women's reproductive and sexual health, the newspaper forums provide relatable content allowing many women, and even some men, to open up with their own stories. During this research, it was found that the majority of story sharing occurred on the *New York Times* articles, over *The Washington Post* and *L.A. Times*, and more specifically on the blog articles over the standard newspaper print articles.

Whereas the other code topics are typically part of the lack of women's reproductive health information in the media, sharing stories is the only one that is truly part of improving journalism on women's reproductive health. These stories identified in the comments of various sexual health articles fall into two categories. The stories either commiserate a lack of medical care and choice for women, or they are stories shared with empathy in order to reiterate that no one is alone. Both are a way of coping and creating a shared experience. According to Rodgers, "The Internet is increasingly becoming a medium in which women with breast cancer not only receive information and/or support about illness but also compose and circulate their own stories about breast cancer. Telling stories enables individuals to construct their own identity" (Rodgers, 2005). Each individual's story has merit and adds to the greater discourse on the topic of women's health, bringing more visibility to the topic and creating further connections among individuals. Vulvodynia is an isolating and hidden condition, therefore, the more women who

can share and connect with women in similar distress, the more normalized the condition becomes. This sharing also helps gather medical information and works towards helping medical professionals connect-the-dots for overall treatment.

The sharing of stories depicting lack of care and choice for women concerning their own reproductive health is essential in forcing change and understanding. Where women's reproductive and sexual health concerns are treated as taboo topics, the sharing of personal stories puts a name to the issue. Contributing stories gives many difficult conditions a face. Also, when women share stories of a lack of care or poor care, this helps hold the medical industry accountable and informs other patients to take control of their health.

Steps toward any improvement in the media on women's reproductive health rely on creating a candid and honest conversation on the topic versus relying on scientific press releases. While journalists do use appropriate medical and politically correct terminology when writing about women's reproductive health, the topics are superficial. By creating positive discourse online and among their readership, journalists help to remove shame, stigma, and taboo associated with many of these health topics. Breast cancer not only used to be a death sentence, but it also was not readily talked about in the general public.

Journalists have to humanize these women and put faces to the conditions they write about, not simply rely on press releases for events or procedures, in order to

bring attention to women's reproductive health. As a reader, one may not connect with statistics but will connect with a personal story. Rodgers and Chen found that, "the longer women belonged to the online discussion board and the more they participated, the more their stories reflected positive well-being" among online breast cancer communities (Rodgers, 2005). Long term and more in-depth journalistic projects can help improve visibility, connection, and sympathy as well as public knowledge for topics in women's reproductive health. Taking these approaches to medical journalism can help address the bigger issue noted by commenter *Ross Mitchell*, "More importantly, however, is to address the cultural or habitual inheritance of attitudes and dispositions" (Kristof, 2008). Positive, informative, and humanizing journalism will help change the national attitudes and female identity over time, creating a shift in how Americans see women's reproductive and sexual health.

Conclusion.

Discourse for women's reproductive health in national newspapers is an under-discussed and often under-appreciated topic of importance. Women's reproductive health concerns branch into many areas of life including culture, politics, and economics making the public access to information even more important. In the changing cultural landscape of the United States, having correct, accurate, and personal information available on a variety of women's reproductive health topics is essential. Talking about sex and using the word "vagina" is not as taboo as it was even 10 years ago; however, there is still a lot of room for growth on the topic. This

research looked at the many different ways that women's reproductive health is discussed by journalists at national newspapers and the response they received from the commenting audience in order to better understand the current reception of women's reproductive health in the media.

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4.2 Introduction/Relevance

In the United States, one in every 12 women will have breast cancer at some point in her life. One in every 10 adults will acquire Type 2 diabetes. One in every six men will have prostate cancer over the course of his life. One in every four women will have vulvodynia (Reed, 2012).

Vulvodynia is unexplained external vaginal pain without a known cause and without a consistent treatment. The understanding of vulvodynia is limited even among doctors and public knowledge on the condition is even less prevalent. A qualitative study on gynecologic cancer in the United States found that "most participants had not heard of vaginal, vulvar, or gynecologic cancer. Not only were they unfamiliar with vulvar cancer, but also many reported they were unsure of the anatomical location of the vulva" (Cooper et al, 2011). The lack of knowledge about women's reproductive health and associated conditions can be blamed on many different sources: doctors, interpersonal communication, and especially the mass media.

With politics concerning women's reproductive health more prominent than ever it's important to consider the information and discourse in society surrounding them.

Legislation, including trans-vaginal ultrasounds, parental permission for Sexually Transmitted Infection (STI) testing, and birth control controversy, could lead to further difficulties in women getting necessary healthcare they need. Nicholas

Kristof, writer for *The New York Times*, points out that "few areas have more impact on more people than birth control—and few are more central to efforts to chip away at poverty" (Kristof, 2012). The effects of women's reproductive health are far further reaching than one would expect.

This research article will proceed to explore the coverage and portrayal of women's reproductive health in the United States print media through the use of feminist rhetorical criticism of select newspaper articles and their comment threads.

4.3 Literature Review

What is vulvodynia?: A quick summary.

According to a recent research study from the University of Michigan published in February of 2012, "vulvodynia causes substantial pain and suffering for millions of women in the United States, yet the disorder remains under-diagnosed and inadequately treated" (Reed, 2012). What is this condition that haunts millions of women? Vulvodynia is defined as "vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible findings of specific, clinically identifiable, neurologic disorder" by the International Society for the Study of Vulvovaginal Disease (Ponte, 2008). The National Vulvodynia Association (NVA) divides vulvodynia into two subcategories that are typically recognized: vulvar vestibulitis syndrome, which is localized to the vestibule, and generalized vulvodynia.

The University of Michigan study concluded, "vulvodynia is a common pain syndrome affecting more than 8% of women at any one time and more than one-quarter of women at some point in their life span" (Reed, 2012). This is a drastic increase from what was recognized as average numbers in 2003 where it was estimated that "an incidence of up to 16% of women, suggesting that as many as 14 million women in the United States may [have] experienced vulvodynia" (Ponte, 2008). Chronic vaginal pain is not a new condition limited to the last decade or two. A famous French gynecologist, named S.J. Pozzi, made the earliest mention of unexplained vulvar pain in medical journals around 1890 before the current working definition of vulvodynia was created in 1987 by E.G. Friedrich (Plante, 2007).

Vulvodynia is not only a painful condition but also causes an economic burden, according to several studies done in the last decade. One particular study done by Tulane University states, "The findings of these studies suggest that vulvodynia may pose a significant medical, social, and financial burden to women with vulvodynia, the healthcare system, and the U.S. economy" (Xie, 2012). These issues occur when 60% of women with vulvodynia have to consult "at least three healthcare providers while seeking a diagnosis, 40% of whom remained undiagnosed after three medical consults" (Xie, 2012). Furthermore, Xie notes that, "evidence-based guidelines for the medical management of vulvodynia do not exist" (Xie, 2012). An earlier journal article, written in 1996, on chronic pelvic pain estimated "total annual direct costs (physician costs plus out-of-pocket expenses) to be $2.8 billion" (Mathias et al,

1996). Based on inflation and not including the newest estimates of women suspected of having the condition, this would be equivalent to over $4 billion annually in 2013.

Many of the more recent research papers on vulvodynia support the overall idea that vulvodynia effects many different facets of life and the economy. The University of Michigan's study quantitatively found that the mean duration of the condition for any one woman suffering from vulvodynia is 12.5 years (Reed, 2012). That means that for 12.5 years one individual woman has difficultly receiving a diagnosis and lives in pain.

Several quality of life studies have been done based on vulvodynia. Ponte's study titled "Effects of vulvodynia on quality of life" found that "women with vulvodynia were more likely than others in the sample to report that their vulvar condition often or always makes them feel depressed, angry, or frustrated" and also "that their condition affects how close they can be with those they love, that it makes showing affection difficult, and that it interferes with their sex life" (Ponte, 2008). This is just the beginning of a list of emotional and physical symptoms linked to a condition that very few people know about and even fewer know how to treat. Treatment options, once diagnosed, range from tri-cyclic antidepressants, to creams including lidocaine or gabapentin, to surgery, among other options, depending on the severity and localization of the pain. However, recent studies concerning the use of lidocaine and desipramine as a common treatment for vulvodynia suggest that these treatments

fail to relieve pain more than the placebos administered, leaving many women without treatment options (Foster, 2010).

Agenda-setting theory.

Agenda-setting is a well supported and often utilized communication theory. McCombs and Shaw first presented it in 1972 in the context of election coverage. Many other studies have followed expanding on political content. Some even expand on general news coverage and agenda setting in the media at the local level. However, there is very little work done on agenda setting in women's reproductive health communication. The closest comparison is how people chose to inform and communicate on the topic of breast cancer or other general health topics.

McCombs and Reynolds define agenda setting as, "the news media can set the agenda for public thought and discussion" (Ogata Jones, 2006). Ogata Jones et al continue to explain that health agenda setting can promote change and health literacy among the readership population. In the simplest terms, the media can define what people think about and know about, therefore setting the public's information agenda.

National coverage of a topic drives all forms of agenda-setting content and trickles down to the local level (Young, 2011). If information is not disseminated at the national level, then the likelihood that information is disseminated on a more local level is slim. Looking at agenda setting in national newspapers for women's

reproductive and sexual health shows what level of importance this type of information is given. Whether or not the media covers women's reproductive health dictates public discourse, research funding, and general awareness.

The connection between reporters and their readership is a critical factor in the wide spread effects of media communication and dissemination. Agenda setting allows for an examination of what types of topics gain salience in the media and why it's important in the context of women's health. When looking at the media of women's reproductive health, an individual can see that the dissemination of information gets muddled between reporters and their readership. Audience discourse seems to want more information and journalism on women's reproductive health, however, journalists do not seem to be meeting this need. The effect is the lack of agenda setting and lack of communication that works for the topic.

By looking at national print media and their online responses, I will be able to see one way that women gain information, but as Yang and Stone have discussed, traditional media is not the only way people gain information. Interpersonal communication is important in how information is disseminated. Interpersonal communication includes face-to-face discussion as well as also non-traditional online communication. Comment threads, blogs, and social media all are factors in today's information dissemination. These forms of communication allow for two very important factors: 1) content is driven by the readership and 2) content is

unedited. This potentially leads to having more feminine discourse through interpersonal communication whereas newspapers have been traditionally masculine. "News discourse contributes to the ongoing marginalization of women's participation as citizens. 'If what we see and read and hear are men's voices, men's perspectives, men's news [then] women continue to be framed as passive observers rather than active citizens'" (Ross, 2011). Traditional news and media is focused on men. White males are the average voices interviewed and their readership is what drives discourse and the agenda setting actions of journalists. Non-traditional media outlets, such as Facebook, Pintrest, and Twitter, provide unedited voices from the users. A research study for the Pew Research Center's Internet & American Life project showed that the majority of users on multiple social media platforms are women. Seventy-one percent of women use social media sites compared to sixty-two percent of men. The percentage of Facebook users by gender is very similar to general social media usage: seventy-two percent women and sixty-two percent men (Duggan, 2012). This suggests that social media has more available feminine discourse than traditional media.

The possible importance of this theory in conjunction with mass media agenda setting is in how women connect with one another, and therefore how they share information with additional women. As stated above by Ogata Jones et al, only 20% of typical information dissemination is through interpersonal communication, but because of the nature of the topic, the interpersonal communication is essential to address. In many ways, any discourse of vulvodynia is created mostly through

interpersonal communication. First hand experience through the journalism component associated with this research emphasizes that women are more willing to share information face-to-face over other means. There is an element of shared experience that allowed women to open up and discuss a difficult and often very personal topic to someone who has had very similar experiences.

Medicine and the media.

It's important to consider where the majority of the U.S. adult population acquires their knowledge about health information. A conference paper titled "Newspaper Journalists and Public Health Professionals: Building the Health News Agenda in Community Newspapers" cites that "surveys have shown that print media, including books and newspapers, remain a predominant source of health information" (Young, 2011). The same source "showed that print media are a main source of health information for more than half of adults surveyed" (Young, 2011). The importance of national newspapers for the general dissemination of information has never been doubted and became even more pertinent after the identification of agenda setting in the 1970s. However, the ability to cover health effectively and accurately has been a real challenge in the media.

Health is considered "the eighth most covered news topic nationally" (Young, 2011) but finding staff and sources to continue "good" reporting even on the national level is difficult. The real problem seems to be in how the information is controlled and disseminated. Nelkin argues that scientists "view the press as a conduit or pipeline"

for their scientific research (Nelkin, 1996), whereas the press has always viewed what is published as their own. Researchers "see the media as a means of furthering scientific and medical goals" whether they are financial or simply informational (Nelkin, 1996). What many scientists fail to realize is that what is printed in the mass media is simply a matter of newsworthiness and timeliness. "Sources who can best fulfill their role in the news construction process by providing accurate, timely, and relevant information that meet's a journalists' criteria of newsworthiness are more likely to see their stories in the newspaper" (Young, 2011). Nelkin sums it up pretty completely that "scientists and journalists depend on each other in the communication of science and the shaping of the public meaning of science and medicine" (Nelkin, 1996).

In the Internet based society of the last decade, the way media functions and how the public interacts with that information has changed. More information is accessible at the click of a button and more information is accessible from more sources. The general public is no longer reliant solely on newspapers and similar news outlets for their information consumption. According to a study focused on Internet health seeking, health and medical reasons are the fourth highest reason for women to use the Internet. For women without Internet access, it is predicted that health and medical reasons would be second only to current event access (Bowen, 2003). Bowen states that "the Internet may become a more important channel for the dissemination of specialized and individualized materials, such as health information" (Bowen, 2003). A decade later, this statement rings even more true.

Rodgers and Chen hypothesized that when looking at Internet use for women with breast cancer, the Internet is able to provide positive psychological benefits for these women. They examined an online discussion board and the interactions of the individuals in the online community. "Internet use for breast health issues was associated with greater social support and less loneliness than Internet use for other purposes or non-use" (Rodgers, 2005). This suggests that other topics in women's reproductive health would utilize the Internet in a similar pattern. Perhaps newspaper online commenting for women's reproductive health and topics such as vulvodynia would provide social support and information sharing since health is a commonly accessed topic for online newspaper readership.

One particular form of online use merits study in conjunction with women's reproductive health. Commenting on journalistic works creates a new form of discourse and identity among women's reproductive health information. As of 2011, 92% of the 150 top U.S. newspapers had online commenting forums associated with their journalists' works (Santana, 2011). This practice started around 2007 and "some editors reported being pleased with the comments following news stories, deeming them 'high-level' and on topic" (Santana, 2011). Within just a year's time, the view editors and journalists took of online commenting quickly changed. Comments at many major outlets became "raw, racist, sexist, and revolting" according to what journalists were seeing at *The Washington Post* (Santana, 2011). Does this negative form of discourse carry into women's

reproductive health articles and how does that shape the identity of women's perceptions of themselves in the United States? This will be addressed further in the Findings and Discussion of this research.

Women's health in mass communication.

When it comes to women's health, especially women's reproductive health in the mass media, there is very little information. Few studies have been done considering agenda setting of women's reproductive health and the reason for this seems to be that there is a lack of interest to communicate about women's health whether in mass communication or in interpersonal communication situations. In an article from the *Journal of Applied Communication Research*, authors noted "people 'rely on the mass media for about 80% of their information about news and public affairs, and they rely on interpersonal communication for only about 20%'" (Ogata Jones, 2006). They note this in reference to breast cancer screening information in mass communication. They also note that even though doctors play an important role in passing on health information, most information still comes from the mass media. According to Christin Veasley, former Executive Director of the National Vulvodynia Association, more than fifty percent of women with vulvodynia symptoms will never seek help from a medical professional. The best way for these individuals to access information and receive help is through the mass media and Internet resources.

Two important facts came out of Cooper's study on gynecological cancers: 1) women have a large knowledge gap concerning their own health issues and 2) that information is acquired from many different sources. Participants "frequently mentioned acquiring their information through personal experience, the experiences of others (including celebrities), healthcare providers, advertisements, and news and entertainment media" (Cooper, 2011). These various outlets mentioned for acquiring health information say a lot about where women find their health information and the types of information they receive. If women's reproductive healthcare is mostly lifestyle and entertainment based, then the view the general population receives on the topic is that women's healthcare is "soft" and not a pressing or important issue. However, this may simply be a result of the newspaper industry's belief that women mostly read the "soft" news sections. These sections still have the ability to provide factual and informative medical news without relying solely on the entertainment value of a topic. It is for these reasons that it is essential to look at the role the media plays in disseminating health information to the public and what journalists publish.

Ogata Jones et al discuss the importance of the agenda-setting role of the media in health communication. They suggest that the earliest paper covering the "agenda-setting role of the media regarding health behaviors was conducted by Pierce, Dwyer, Chamberlain, Aldrich, and Shelley" in 1987 (Ogata Jones, 2006). This 1987 paper stated the "'possible importance of an agenda-setting role for the mass media in promoting change.'" There have been many examples of this happening on a

variety of health-related topics like AIDS/HIV reform, tobacco policies, and cancer awareness.

Ogata Jones et al conclude that "it is important for communication scholars to continue examining the ways in which mass and interpersonal communication may influence health behaviors" (Ogata Jones, 2006). This is especially important for women's reproductive health communication due to the minimal information available through research and the media. Agenda setting is not well understood for women's reproductive health across the United States at this current time. A paper from 1996 by Rogers states that "'preventive health communication faces particular difficulties in bringing about behavior change…[as] many preventive health campaigns must address highly sensitive topics, such as sex, disease, and death, that are difficult to discuss freely'" (Ogata Jones, 2006). The taboo nature of the words "sex" and "vagina" prevent open communication when it comes to reproductive health. This resistance to words and ideas in women's reproductive health must be overcome in the media first for open discussion to occur.

Another study of note concerning women's health communication, is one entitled "Women's Knowledge and Awareness of Gynecologic Cancer: A Multisite Qualitative Study in the United States," notes that in 2007 Congress passed a mandate requiring the increase of "women's knowledge and awareness of gynecologic cancer" (Cooper, 2011). The ramifications of this law have made information and media concerning gynecologic cancer more readily available. Cooper et al utilized focus groups to see

how effective communication has been concerning all forms of gynecologic cancer. Their results include women knowing more about cervical, ovarian, and uterine cancer but "most participants had not heard of vaginal, vulvar, or gynecologic cancer. Not only were they unfamiliar with vulvar cancer, but also many reported they were unsure of the anatomical location of the vulva. A few participants confused the vulva with the clitoris" (Cooper, 2011). This inaccuracy emphasizes that lack of knowledge on women's reproductive anatomy. When women cannot even identify their own anatomy, how are they supposed to advocate for their own health?

4.4 Research Questions

Q1: Do national newspapers write about vulvodynia and other women's reproductive health concerns?

Q2: If they do, what kind of discourse do they create among their audience?

Q3: If they do not, what causes the gap between medical research and media dissemination of information for women?

Q4: How does the media close the gap that may exist?

4.5 Methods

Sample selection criteria.

When approaching the newspaper article research for this paper, it was necessary to define what properties I was looking for in an artifact of inquiry. The articles selected for this study were all collected from online during the research process between the months of November 2012 and March of 2013. Eighteen articles were

the final artifact selection from three different newspapers: *The New York Times*, *The Washington Post*, and *Los Angeles Times*. These three newspapers were chosen due to their liberal leaning history, strong health sections, and national standing. All three newspapers are known for their health desks and have specialized health reporters instead of utilizing work by general news reporters or off the Wires. This does suggest that there would be higher rates of women's reproductive health articles than in regional or local level newspapers. The number of articles was determined through topic saturation. When articles could no longer add new concepts to the discourse no further articles were added.

The selected articles were chosen from an initial group of 46. These 46 articles were selected from hundreds of articles found online utilizing the search terms in the following paragraph. The search process consisted of skimming all three newspapers' databases utilizing the various search terms. Articles were pulled for deeper consideration if they were strongly on topic or pertinent to the discourse as deemed by the researcher. The 46 articles selected by searching and skimming were then read critically for further categorization and appropriateness to the research questions.

An inverted topic approach was created from the research, one in which vulvodynia and sexual pain disorders were the initial focus but is further built on by several levels of motivations and effects in the media as identified in the coding through

women's reproductive health topics. The following table identifies key facts from my research process about the 18 selected newspaper articles.

Newspaper- (# of Artifacts)	# + Category	# + Type of writing	# + Year published	# With Comments
The Washington Post – (6)	Searches 2005-Present			
	• 2 Cultural • 4 Political	• 1 Health/Science • 4 Blog • 1 Opinion/Editorial	• 6-2012	5
Los Angeles Times - (3)	Searches 1985-Present			
	• 1 Cultural • 1 Political • 1 Health	• 1 Blog • 1 Opinion/Editorial • 1 Entertainment	• 3-2012	2
The New York Times – (9)	Searches 1851-Present			
	• 2 Cultural • 2 Political • 5 Health	• 4 Health/Science • 4 Blog • 1 Magazine	• 3-2008 • 2-2009 • 3-2012 • 1-2013	5

According to Sonja K. Foss, in Rhetorical Criticism: Exploration and Practice, appropriate artifacts should intrigue, baffle, or excite the researcher. Searches were done on each newspaper's website utilizing a variety of terms including:

Vulvodynia
Sexual Pain
Birth Control
Vulvar Pain
Vulva
Vagina
Female
Reproductive Health
Women's Health

Female Health
Sexual Pain, Sex Pain
Sex
Sexual Health
Sexual Intercourse, Painful

These terms created a variety of results including topics related to rape, abortion, book and movie reviews, and domestic violence, which were concepts not on par with this line of inquiry. "Grounded theory sees researchers as social beings whose experiences, ideas and assumptions can contribute to their understanding of social processes observed" (Heath, 2004); therefore the elimination of topics was at the researcher's discretion and looked more directly at topics such as birth control, political legislation, cultural perceptions, and specific conditions of women's reproductive health. This led to the three main categories of culture, politics, and health as overarching themes in the media for women's reproductive health. These categories were then further addressed with direct content and codes from the rhetorical criticism.

All the artifacts utilized were published between 2008 and early 2013, though others were found on topic prior to this time frame. The original sample time frame was intended to be 2002 to 2012 in order to look at overall trends and discourse through a decade; however, the most pertinent and timely topics fell in between 2008 to 2012 leading to further discussion as to why that would be. Outliers to this time frame were discarded, as they did not provide additional

information. The outliers only furthered the argument that prior to the present little was published in the mass media on women's reproductive health.

Most articles contained some form of reader feedback such as comment forums or letters to the editor. Comment discourse was selected based on similar themes and discourse as the articles. This will be discussed further in depth under rhetorical criticism. The comments analyzed in this research from the first day of commenting as suggested by the concepts presented in Santana's research on commenting. Santana noted that many comment threads devolved into unsavory political debate no matter the original topic and many journalists as well felt that the longer comment threads continued the more off topic they became (Santana, 2011). This research found this claim to be true and attempted to analyze on topic discourse from initial comments.

Constant comparative method and grounded theory.

After the identification of the research artifacts, this researcher proceeded through several levels of reading and coding of all the articles and comment threads. This process is based on Glaser and Strauss's published work from 1967 utilizing the constant comparative method. The constant comparative method is a form of grounded theory that is broken down into four steps, which guide the researcher (Glaser, 1967):

1) comparing incidents applicable to each category
2) integrating categories and their properties

3) delimiting the theory
4) writing the theory

Glaser and Strauss later took different stands on the coding process for the constant comparative method. Glaser used an initial method of substantive coding which is data dependent. The researcher codes first into many categories and then integrate those categories as the researcher continues addressing more data points. Frameworks and concepts emerge and are then refined to follow a main core idea. Glaser's method has more flow and modifiability and is the method more closely followed for this research. During the analysis of the artifacts, each article and comment thread was read, reread, notated, and then coded. "Since no proof is involved, the constant comparative method in contrast to analytic induction requires only saturation of data—not consideration of all available data" (Glaser, 1967). Once the concepts in the coding started repeating the same main topics, the data was theoretically saturated.

Rhetorical criticism.

The artifact coding helps create the theory and data for the rhetorical criticism utilizing a feminist critique. How do *The New York Times*, *The Washington Post*, and *L.A. Times* view women's reproductive health and therefore, contribute to the shaping of women's identities? "People also learn about the importance of topics in the news based on how the news media emphasize those topics" (McCombs, 2002). By coding the articles and comment threads, a clearer picture of what the media emphasizes as important versus what the public focus on comes into view. The

most pertinent and recurring codes that were identified during the coding process included:

political policy
verbiage
reproduction/reproductive beings
desire
law
hypocrisy
empowerment
battle/fight/war/conflict
economics
choice
sexism/domination/control

These codes were created through a critical reading process. The researcher actively read and noted all articles and comment threads for the 18 selected articles. An example of this process includes the comment threads to a *New York Times* article where the reader *brad* notes, "I imagine that many women who've lost desire feel the same concern and uncertainty. Can they still be loved or will they forever be viewed as damaged goods" (Parker-Pope, 2009). This was a small section of the comment that was highlighted for the verbiage used and a note was made in the margin stating "identity, flux." These notes were made by comparing content and ideas made in the articles and comment threads. They were then integrated into larger topics as suggested by Glaser and Strauss. This integration led to five particular code topics that will then be addressed in the context of the research questions. These codes occur the most often as points of discourse for journalists and their readership. They are medical discourse, economics and politics in conjunction with women's reproductive health, verbiage, choice and empowerment,

and the sharing of personal stories. The discussion section will examine and address how the artifacts interact with the media versus public agenda with women's reproductive health. They will also look at how the rhetorical content frames women's reproductive identity as well as any positives or negatives associated with this framing.

Conflict of interest.

For this research paper, I, Carrie Durkee, must disclose any conflicts of interest. It should be known that I am a woman who is pro-actively involved in bettering women's reproductive health. This has come about because I have personally suffered from vulvodynia since 2008. I've undergone three different surgeries and gone through the docket of doctors to find little relief. Between the cost of medical care and the lack of knowledge, in general, for women's reproductive health, I felt compelled to investigate a facet of this. These conflicts of interest should not be considered hindrances for this research project but assets. As cited in the section on sample criteria selection, I remind the reader that "the constant comparative method is not designed [as methods of quantitative analysis are] to guarantee that two analysts working independently with the same data will achieve the same results; it is designed to allow, with discipline, for some of the vagueness and flexibility that aid the creative generation of theory" (Glaser, 1967).

4.6 Findings and Discussion

4.6.1 Q1: Do national newspapers write about vulvodynia and other women's reproductive health concerns?

Findings.

When looking into how national newspapers portray women's reproductive health, the first question to ask is what topics define women's reproductive health? With the starting point being vulvodynia and women's sexual pain, searches into *The Washington Post, L.A. Times,* and *New York Times* yielded articles of varying nature. Rape, abortion, and domestic violence were "hard" news topics found when searching for women's reproductive health. Even though these topics do touch on women's reproductive health, more relevant topics to this line of inquiry tended to be found in "soft" news areas, such as entertainment and editorials. Health is characterized in all three newspapers as *Lifestyle*, also considered "soft" news. To find topics of relevance, I identified articles that fell into three categories: culture, politics, and health/science. In those categories, few articles exist and even fewer seem to add significant discourse.

Of the three analyzed newspapers, *The New York Times* and *L.A. Times* were the two newspapers that published relevant medical articles based on studies pertinent to women's reproductive health. The *New York Times* contained twice as many relevant articles on women's reproductive health as *The Washington Post* and *L.A. Times* combined, yet across all three platforms the most pertinent articles fell under editorials or blog postings. *The New York Times* even published two articles by the

same writer on vulvodynia and women's high rates of chronic pelvic pain. One article was published in the health section of the paper in 2008, the other published only on the online health blog in 2012.

Women's reproductive health rarely makes front-page news, but it does appear in the three different contexts that were mentioned above: culture, politics, and health/science. Each of these categories for newspaper article presentation provides different informing content, approaches to the presentation in information, and levels of accuracy. They all engage readers in different forms of discourse as discussed later.

Culture is defined in the Oxford English Dictionary as "the arts and other manifestations of human intellectual achievement regarded collectively." Many newspapers cover various cultural events and other manifestations. *The Washington Post* wrote about the effects 50 Shades of Grey is having on women's sexual health. The *L.A. Times* addressed how the word vagina is becoming fashionable and *The New York Times* raised the basic question: are women of the world poorly treated because of sexism or misogyny? All are articles found for this research. These published topics are all cultural approaches to women's reproductive health.

Political agendas act just as strongly on public opinion as traditional news media. The 2012 election cycle brought new awareness to women's reproductive health.

Nothing has been as controversial in decades as the Affordable Care Act (ACA). "A provision requiring the full coverage of contraception remains a matter of fierce controversy. The law says that companies must fully cover all 'contraceptive methods and sterilization procedures' approved by the Food and Drug Administration, including 'morning-after pills' and intrauterine devices whose effects some contend are akin to abortion" (Bronner, 2013). The ability for women to make their own medical choices turned into a conflict between religious freedom and the right to choose. Winning women over through birth control, abortion rights, and non-regulatory action were ways to win votes. While McCombs and Shaw's work specifically pointed out the importance of the media in an agenda-setting function for political purposes, women's reproductive issues just overlap with the political agenda of the present.

The most important aspect of news dissemination for women's reproductive health is in the specific health and science niche. In 2011, print media was cited as the location that over half of American adults receive their information about health (Young, 2011). From 2007 into 2008, "The single disease to get the most attention was cancer, accounting for 10.1% of all health coverage…The number two condition was diabetes/obesity, at 5.2% of coverage, followed by heart disease, at 3.9%, and HIV/AIDS and autism at 2.2% each" (Pew, 2008). In science and health writing for newspapers, there is a trend of having few specialized writers. This makes it difficult for one or two individuals to cover all forms of health effectively and

accurately. It is also common for general news reporters to cover health topics. By having only a few specialists in a field, the diversity of information could be limited.

Discussion.

Eve Ensler, author of The Vagina Monologues, is quoted as saying, "'I used to say 'vagina' was more dangerous than Scud missiles or plutonium. You couldn't put 'vagina' on the front page of a newspaper'" (Keegan, 2012). Her play, which first premiered in New York City in 1996, is still considered groundbreaking. In a time when American politics focus on abortion, trans-vaginal ultrasounds, birth control, and other reproductive rights, women's healthcare is still not considered front page worthy for some of America's top newspapers.

"*The New York Times* frequently plays the role of primary intermedia agenda-setter because an appearance on the front page of the *Times* can legitimize a topic as newsworthy" (McCombs, 2002). The problem being that women's reproductive health rarely makes the cut. With more than 50% of the United States population being female and with "women mak[ing] the primary healthcare decision in two-thirds of American households," it would be logical to assume that women's reproductive health concerns and information would be more legitimized among mainstream media (Kluger, 2010).

Culture is an essential part of what the general population talks about and what shapes what is talked about. Newspapers help create and form culture. The topics

published set the cultural talking agenda and cultural norms. Even as agenda setters, certain topics remain difficult to talk about and difficult to cover on a large public scale. "Preventative health communication faces particular difficulties in bringing about behavior change as many preventive health campaigns must address highly sensitive or taboo topics, such as sex, disease, and death, that are difficult to discuss freely" (Ogata Jones et al, 2006). Through campaigns like breast cancer prevention and shows in the last decade such as Grey's Anatomy, talking about women's health becomes easier for younger generations. Vaginas become more easily talked about and the fear behind the physical anatomy dissipates. Culture helps promote various health topics and view points. But complications in how women's reproductive health is viewed and discussed still arise. "Berman [a clinical professor and OB/GYN], who appeared regularly on 'The Oprah Winfrey Show,' said she pushed Winfrey to start saying 'vagina' in sex and health discussion on her program in 2008. 'I did a mini-intervention with Oprah to get her to stop calling it a 'vajayjay,'' Berman said. 'She saw it as an affectionate term. It still implies to women listening to you that it is something embarrassing to say'" (Keegan, 2012). These view points and perceptions alter what the public comes to find acceptable. The perceptions turn from fear driven and embarrassment into an understanding of technical vocabulary. The public slowly will stop talking about "vajayjays" in whispers and will be able to freely discuss women's reproductive health in an appropriate manor without blushing.

Health is a very diverse field with fewer and fewer reporters each year. Topics that affect women, which should rank as high importance, fall to the wayside. Mothers are considered the head of the household in care of themselves and their children. Therefore topics affecting those groups would logically be considered a high priority by the media. Arguably topics like chicken pox, shingles, PCOS, endometrios, cervical cancer, and postpartum depression should be more prominent in the media than erectile dysfunction, diabetes, and sleeping disorders.

This being said, many individuals commented on specific health articles on *The New York Times* health blog noting their appreciation for the coverage of certain topics. Two different individuals commented on Tara Parker-Pope's article on "When Desire Fades," about low libido and female sexual dysfunction, both with the same main point. Screen name *tuesday* stated, "Thank you for publishing this article. You only see articles about men's sexuality usually" (Parker-Pope, 2009). This individual seems pleased to see any form of information from the *New York Times* on women's libido and specifically points out noticing a discrepancy between men and women's sexual health. Screen name *EAS* stated, "Just another area where women's healthcare falls far, FAR short of men's. Not even female researchers take the female libido seriously" (Parker-Pope, 2009). This comment has a harsher undertone of dissatisfaction with women's health as a whole, not just the print media. It reflects the overall perceptions that women's reproductive and sexual health is secondary. This is unacceptable to many individuals when women

discredit women's reproductive health. What is important to note is that these types of comments are typical for niched women's reproductive health articles.

Jane Brody has been a health columnist for the *New York Times* since 1965 and has a strong background in science. However, she writes on a wide variety of topics. Brody is one of the few national writers who have tackled the topic of vulvodynia and chronic vaginal pain. In two different articles, one published in 2008 and the other in 2012, she addresses the number of women suffering from, and the possible causes for, vulvodynia. Looking at the 2008 article in 2013, several of the facts are now outdated and inaccurate. Brody notes that 1 in 6 women suffer from vulvodynia which was the number considered accurate at the time but now has been revised to 1 in 4 based on current research (Brody, 2008). She also discusses what a specialist has to say about the causes: "Dr. Ledger has found two genetically based predisposing factors. In one, the women produce inadequate amounts of a substance that blocks an inflammatory response. 'They get an inflammatory response to an infection,' Dr. Ledger said, 'but it doesn't go away.' Another genetic aberration results in unstable production of a substance that normally responds to an invasion by yeast or bacteria, placing them at increased risk of chronic infections" (Brody, 2008). None of these claims have been substantiated in recent medical research or prominent medical practitioners in the field and yet they are featured in print media. This case is not a failure of the writer, but one of the medical communities. The interview source Brody utilizes talks in generalities and is exceptionally vague for her 2008 article.

In 2012, Brody tackles the topic of vulvodynia again. In her 2012 article "Persistence is key to treating sexual pain," Brody makes generalized assumptions, which lead to inaccuracies. She leads the article with, "millions of women experience vaginal discomfort, and sometimes crippling pain, for a variety of reasons, most often a loss of estrogen. The resulting vaginal dryness and atrophy can make sexual intercourse, a pelvic exam, urinating, or even sitting, walking or cycling a painful nightmare" (Brody, 2012). Once again, there is no literature to support the statement "most often a loss of estrogen" in the medical docket. The problem with even small inaccuracies in any form of health or science writing is that many individuals with the conditions written about are looking for answers. Inaccurate answers are more discouraging to many than not having information at all. Overall accuracy is strived for in effective journalism, which seeks to avoid misinformation, however with a lack of medical knowledge it is often difficult for journalists to provide such accuracy.

4.6.2 Q2: If they do, what kind of discourse do they create among their audience?

Findings for public medical discourse.

When discussing medical issues it is reasoned that much of the discussion will revolve around strictly medical facts, whether they are in newspaper articles or the comments that follow. Medical discourse is the sharing of information directly

related to medical conditions or general human health. Articles concerning women's reproductive health lead to more questions from readers than the ability to provide answers. One pertinent question that was noted when examining the medical discourse in the comment threads following several articles is: "What is normal?" This question came up most pointedly in the *New York Times* when looking at topics of sexual satisfaction or in most cases dissatisfaction.

Sexual satisfaction and desire is a hot topic found in all three major newspapers examined for this research. Female sexual dysfunction (FSD) is more prominent a topic in the media than issues considered by medical faculty as pertinent concerns, such as endometriosis or vulvodynia. FSD gained prominence and a medical definition around the time Viagra was released to the public in 1998. In a letter to the editor in 2009 concerning an article on sexual dysfunction and desire, Deborah J. Nedelman, Ph.D., noted that, "the most profound insight we gained was how little women know about how other women function sexually. Repeatedly we were asked, 'What is normal?'" (Bergner, 2009). This suggests that interpersonal communication may be less used for women's reproductive health than other topics, such as child rearing or the work place.

Medical discourse attempts to create a factual and informative construction of women's reproductive health based on the majority of situations experienced by women. However, different conditions and situations experienced by the minority, such as vulvodynia at twenty-five percent of the American female population, affect

what is the perceived normality for sexuality. Much of this paper will continue to discuss where the norms for women's sexuality come from, why they exist, and how they affect the current perceptions of reproductive health.

Discussion of public medical discourse.

This simple idea of "what is normal" becomes a societal construct. "Normal" is not based on the scientific method, but on a human definition. Based on Saussure's work, the perceived meaning of words is a socially agreed upon definition. In the *New York Times* article "When desire fades," a reader under the user name *diana* makes an important and thoughtful comment: "What IS normal? It seems that normality is defined by what MEN want women to be" (Parker-Pope, 2009). The rhetoric choices by men and women surrounding the topic of women's reproductive health forms, defines, and perpetuates the view women have on themselves and their personal health. When men define the normal for women's reproductive health through laws, verbiage, and culture; men start defining the entire sphere of women's sexual identity. This becomes a cycle where if men define women's sexual identity then women see themselves as the new defined normal.

Tara Parker-Pope's article titled "When desire fades" gained many similar responses to Bergner's article on normality, but these comments brought about additional concerns to the approach to women's medical treatment. "Maybe a weak sex drive is just normal and natural for some women – not a disease, not something that

needs drugs or therapy," (Parker-Pope, 2009) commented *mari* on Parker-Pope's blog article. There are two important parts to note in *mari's* comment. First, the comment starts with the word maybe. Maybe indicates uncertainty. Uncertainty surrounds the information received by news consumers on women's reproductive health. The media is unable to answer what is normal because the information that is disseminated from the medical community typically fails to answer that question in a fashion accessible to the general populous. Also note the use of the word "weak." The use of the word "weak" in conjunction with a woman's sex drive suggests that there is a lack of something, in this case sexual desire. That leads to the belief that a woman's sex drive is abnormal in comparison to a man's. The norm to strive for becomes measured by a man's standard. The final factor of note in *mari's* comment is the opposition to treating an unspecific condition with drugs or therapy. Drugs and therapy are the options presented to many women suffering from a variety of reproductive conditions, but the solutions presented are not always helpful or in-line with options that are ideal for the patient and yet make large sums of money for major pharmaceuticals.

When readership does discuss women's reproductive health as medical fact, opinion is often included. With the recent addition of the ACA into law, the discussion over birth control has increased during 2013 as laws become enforced in the 2014 year. The *New York Times* heavily covered the ACA and has created adamant opposition among commenters. Generally, the two sides argue that birth control should not be covered by employers who do not agree with it because of the belief that the only

possible use for birth control could be pregnancy prevention. The commenter *Ana* states the contrary argument:

> "Contraceptives are part of the medical tools necessary to women's health. Like abortion, they are part of the full range of services that must be made available to women in case of a medical emergency, or to manage disease and dysfunction in the reproductive functions unique to a woman's body. Birth control pills are not just for contraception; they are also used to manage peri-menopause, menopause, uterine bleeding, and overall women's health. The morning after pill is an important option for women who may not be ready or able to have a child, for whatever reasons…Women take these issues very seriously, let them decide, not an employer's ideological bent" (Bronner, 2013).

This commenter gets at the heart of the issue, that the general population does not understand women's reproductive health, ways to treat different conditions, or even the possible conditions that exist. This circles back to the question of what is normal. Based strictly on numbers contraceptives are normal. Seventeen percent of American women aged 15-44 between the years 2006-2010 were on the pill according to a report by the Center of Disease Control and 62% used some form of contraception (Jones, 2012). *Ana* addresses medical conditions that are not often talked about, as well as the overall concept of women's choice. By providing these medical services, women become more empowered by being allowed to use the tools for their personal reproductive health.

American society was constructed on patriarchal principals that continue to dictate how every approach of women's medical care is viewed. These principles place male needs and voices over that of the female, placing female needs at a lower priority. It is the ingrained and often under-acknowledge sexism created from the historically patriarchal building blocks of American society that were initiated through economic and political power.

Findings for the economics and politics of vaginas.

The right to vote in the U.S. was granted to women by Congress in 1920 after a 90-year period of women and groups campaigning for this right. Today with political parties more divided than ever, the involvement of women in politics and voting for representatives that best address largely female needs heavily effects how women receive reproductive healthcare. Even with the ability to vote, have their voices heard, and be involved in the political process, women's healthcare has taken a contradictory turn for a first world government.

The New York Times heavily covered the outcry against contraception coverage by the ACA. The amount of law suits that corporations submitted to the judicial system in order to not cover birth control was overwhelming and the comments in return were even more so. In an opinion column run by the *L.A. Times* in February of 2012, conservative Charlotte Allen described birth control as a "non-health related goodie" (LeTellier, 2012). In response to many similar descriptions made by

conservatives in the average population, individuals responded back with comments of confusion and opposition. User name *Eric* on the *New York Times* site states, "What I don't understand is why so many women vote against their interest by electing non pro-choice, pro-contraceptive, or pro-sex education representatives" (Bronner, 2013). Based on the user name, one would make the assumption that this commenter is male. He is assuming that the main concern for American women involves reproductive health.

But reproductive health actually ranks as a very low priority for the majority of women. There are several plausible causes for women's reproductive health seeming to take a lower priority across the nation. During the 2012 presidential election cycle with Obama vs. Romney, one might think that the election was solely about women's reproductive healthcare. The number of articles covering various women's health topics in the media spiked dramatically, but not all the media was positive for women's medical care due to the type of legislation being presented in Congress.

There are two paths that legislation takes concerning women's reproductive healthcare. There is positive legislation like what was passed in 1990, helping to inform and provide care to women concerning cervical and breast cancers. This type of legislation helps to provide more information to the general population and create access for women who may not be able to afford screening and treatment. The other type of legislation in current years is restrictive legislation. This type of

legislation includes reducing access to medically relevant abortions, required intrauterine ultrasounds, and restrictions to hormone therapies all of which could possibly make reproductive care less accessible for many women.

There are several different levels of the American government that provide different types of legislation and viewpoints on women's reproductive health from the national government down to city representatives. Two instances exemplify the type of language and attitudes taken among the generalized political sphere during the 2012 presidential cycle and after. As noted earlier, the amount of discussion and major newspaper coverage of women's reproductive health issues is sparse during non-presidential election years prior to 2013.

In February 2012, then Georgetown law student Sandra Fluke stood before House Democratic members in order to give testimony for the positive effects of providing affordable birth control through the ACA at religious based institutions. Rush Limbaugh proceeded to ridicule her on his radio show the same week calling her a "slut" and "prostitute" for arguing that the lack of affordable birth control can economically hurt women who utilize it to treat medical conditions (Sonmez, 2012). Fluke spoke before a congressional committee as part of the American democratic process. Does her informed opinion merit the level of ridicule she received? On top of the ridicule, Fluke had to speak at a second congressional meeting after being denied access to the first. The first meeting's testimony consisted solely of men, mostly clergy, speaking on the various results of birth control. Fluke received

apologies from Obama and Limbaugh saw a loss in the number of sponsors for his radio program. Fluke later commented, '"I'm just happy that what seems to be happening in the process is that America is hearing the voices of women affected by lack of contraception coverage and who will benefit from this policy"' (Sonmez, 2012).

Fluke's story is not unique. Instead, it falls into the norm within the political sphere. Just a few months after Fluke spoke before a congressional committee, Lisa Brown, a Democrat state legislator in Michigan, was banned from speaking on the House floor for using the word "vagina" during a debate on a stringent abortion law proposal (Petri, 2012). She and one other female legislator were banned for a breach in "decorum of the House" and due to the offensive nature of the word. This incident was not covered by the *L.A. Times* or the *New York Times* and only in one opinion article in *The Washington Post*.

Next, consider the burden on the economy and individual families for women's healthcare utilization. According to a study by A.K. Taylor et al. examining "Women's use and expenditures for medical care in the U.S." in the year 2000 "third-party payers accounted for almost 80% of mean health expenses; nearly 22% was paid out of pocket" (Taylor et al., 2006). This indicates that on average private and public insurance does help to divert the cost of medical expenses but for every $100 in medical expenses $20 must come from the woman and potentially her family. Another study looking specifically at the economic burden of vulvodynia in the U.S.

extrapolates that the annual cost per patient with vulvodynia is $17,724.80 (Xie, 2012). If each year 20% of that cost is taken on by the patient as suggested by Taylor et al, that means each vulvodynia patient is paying $3,544.96 out of pocket for treatment. Xie continued to examine the annual national burden of vulvodynia: "Our estimate of annual national burden ranged from $31 billion to $72 billion, based on the range of reported prevalence. This was higher than the estimated burden of endometriosis in 2002 ($22 billion), fibromyalgia ($20 billion) and interstitial cystitis in 2000 ($66 million)" (Xie, 2012). The estimate that Xie makes was based on a prevalence of vulvodynia in 3-7% of the population in the United States. Estimates have now been revised to 8-16% depending on the study sample area, which would substantially increase the economic burden felt by women and their families with this condition.

Based on the numbers, it would seem that women's reproductive health should be a priority for politicians and economists. Most importantly, the women who experience even basic preventative reproductive healthcare should see care and access as a priority. However, polls across America show that this is not the case. "[American women] are concerned about money and jobs. That sentiment echoes the Kaiser poll, which shows 60 percent of registered female voters, regardless of political party or ideology, are most concerned about the economy. Only 2 percent care about women's issues and another 5 percent about abortion" (Parker, 2012). This poll suggests that the link between women's issues and the economy is neither strongly seen nor fully understood by the average American woman.

Discussion for the politics and economics of vaginas.

Strong negative emotions are prominent and expressed concerning the ballot issues of birth control restrictions and required intrauterine ultrasounds in many states. Legislation in the recent political past has had a focus on restricting women's reproductive health rights over creating opportunities to improve health. Through these restrictions, women's reproductive health as a whole seems to become a lesser priority. Disease research and treatment take a backseat and conditions like vulvodynia remain hidden.

In a *Washington Post* article discussing the focus on women's rights during the 2012 Democratic National Convention (DNC), commenter *cricket44* summarizes the atmosphere of frustration that comes with politics overlapping personal decisions: "For the last decade, at least, more and more legislation has been put forth that takes rights of autonomy away from women and the anti-choice narrative of 'evil, wicked females who have sex' and all the accompanying falsehoods has taken hold" (Hanneberger, 2012). This change in proposed legislation could be detrimental to the medical and political sphere in which women's reproductive healthcare functions, and also the cultural identity it intensifies. The lack of autonomy for women, especially in the healthcare arena, creates a cultural norm that women are lesser and deserve less than men. This may result in changes to sexual identity in other aspects of society.

Both previous examples with Fluke and Brown remind society that talking about women and sex or sexual health in the same sentence is still a cultural taboo. The notion that women have reproductive needs and need reproductive healthcare, by extension, becomes taboo. This cultural perception that is exacerbated in the political sphere filters over into more personal feminine identity. By publically denouncing the anatomical term "vagina" not only does it become publicly taboo, but even privately taboo. It becomes something to be ashamed of. Something that is even difficult to say in a doctor's office or to a close female friend.

So, why are abortion, birth control, and other women's medical issues so strongly politicized? Many of the politics come down to two issues: economics and moral beliefs. Moral beliefs and personal ethics will be covered later when discussing a woman's right to choose. However, the economic effects of women's healthcare have a greater and further reaching impact on U.S. society as a whole than many other core topics.

Across the world it has been shown time and time again that allowing women access to birth control and education are two essential aspects that can drastically reduce poverty and improve a country's economy standing (Kristof, 2012). Nicholas Kristof is a *New York Times* columnist, two-time Pulitzer Prize winning writer, and co-author of several books, including ones specifically on empowering women in poverty around the world. Around the same time Sandra Fluke spoke to Congress,

Kristof took a deeper look at how birth control affects the economics in the U.S. during his twice-weekly column. He points out that, "the cost of birth control is one reason poor women are more than three times as likely to end up pregnant unintentionally as middle-class women" and "that it costs employers at least an extra 15 percent if they don't cover contraception in their health plans" (Kristof, 2012). The ability for birth control, proper family planning, and preventative reproductive healthcare to drastically reduce taxpayer's expenses is immense. Even if someone is a single male, money from taxes goes towards Medicaid, which would pay for the healthcare of unplanned children of low means. Or if you own a business with employees, being able to reduce healthcare costs by fifteen percent is a hefty amount to save simply by allowing birth control coverage.

Another argument proposed by a commenter on Tara Parker-Pope's *New York Times* discussion asking if doctors view all women as "pre-pregnant" points out the economic basis for women receiving different, typically less, medical treatment than men. "Women have always received a lower priority and less consideration than men in drug development and testing – even in the development, testing and administration of protocols for indications specific to women. I feel this is because women have traditionally had less economic power than men, and our medical systems are mostly financially oriented," noted user name *Gene S* (Parker-Pope, 2008). Here, the discussion ventures into providing appropriately equal medical care no matter the individual's sex.

What individuals of both genders need to keep in mind is that preventative care for women, such as easy access to birth control, has a cyclical effect on the economy. Women who cannot afford or do not have easy access to birth control do not stop having sex, they are simply opened up to increasing chances of unplanned pregnancies and higher health costs. This in turn means less money for medical costs. Or even if a woman doesn't have children, the amount of money put into preventative medical care alone is enough to help pay for groceries or pay on student loans.

User name *MaineWomen* made a very pressing point while discussing the war on women, "When you can't pay your mortgage or feed your kids is exactly when you need to be concerned about birth control, the necessary adjunct to sex when having more children is impractical economically" (Parker, 2012). This issue isn't simply for young, single women in college but it touches all ages, even past menopause. Many in the younger generations are struggling to pay back student loans, which just broke $1 trillion dollars owed, and have to go to the older generations for financial support. Women placing reproductive healthcare as a low priority raises the economic impact that these issues have.

Findings for sex crazed slut shaming: The words we pick.

In many ways, the low priority that women's reproductive health receives in the political and economic sphere is due to the cultural view of women's health. This

cultural perception is created through public reaction and word choice all across the country. The media provides a major outlet for public opinion. The verbiage in articles used by both the writers and the individuals quoted help to shape female identity. What words are used in conjunction to women's reproductive health and what kind of reaction do these words create among the general public? What type of tone and mind-set do these words convey?

Looking back at the discussion about Sandra Fluke, it's important to remember that Limbaugh publicly called her a "slut" and "prostitute" on the radio. This particular incident received a decent amount of outrage; however, that is not the norm. The verbiage surrounding women, sex, and sexual health helps create the lens in which women view their own sexual identity. Through the examination of *The Washington Post*, *L.A. Times*, and the *New York Times* articles, certain trends in verbiage stood out in comment reaction over the articles themselves. Due to the nature of the publications and professionalism, all their articles were considered politically correct and only quoted words such as "slut" or "vagina" when quoted by an individual or as medically relevant.

Many articles on women in society come from news writers posing a question in line with the topics discussed in this paper. Kristof posed a discussion on the differences between misogyny and sexism towards women. He was inspired to ask this of his readership due to the 2008 election cycle, he notes. He further goes on to explain what definitions he has seen in the past, why those definitions exist, and why he

thinks they may not be correct based on his observations internationally. Many of his readers try to help better the definitions of sexism and misogyny as they are seen in American society and abroad. Reader *thawley* makes a case for the definitions of each word:

> "Instead it may be prudent to search for similarities in apparent roots of gender bias. This is because not all sexism is misogyny and vice versa. However, misogynistic tendencies probably have a sexist foundation. For instance, if I beat my wife it is both misogynist and sexism. However, if I think that a woman's place is 'barefoot and pregnant' then it is sexism, but not misogyny. In the end it seems that sexism is the cause of misogyny and the act of violence against women is in essence culturally justified sexism" (Kristof, 2008).

The reader's point is that misogyny has its roots in sexism. The initial issues that are present in societies all around the world are that sexism exists because females are given a lesser status than men; therefore females do not receive equivalent rights and treatment as males.

Discussion for sex crazed slut shaming: The words we pick.

Tara Parker-Pope is a *New York Times* columnist writing the "Well" blog on a variety of health topics. Her blog covers everything from obesity, sleep disorders, exercise, and mental health all in the same forum. The idea behind the blog is to have a place where readers can ask questions about health related topics and be able to receive informed answers. On occasion, Parker-Pope will pose opinion questions to readers

and what sparked the question. In 2008, she asked, "Do doctors view women as 'pre-pregnant?'" This topic was sparked by a reader discussion off a report analyzing "women of childbearing age sharing prescription drugs." The readers took the discussion into one of how women are typically viewed as "pre-pregnant" within the health system.

The term "pre-pregnant" is used in many online health outlets indicating a potential to become pregnant. In fact, the comments following Parker-Pope's question had many women sharing stories in where they couldn't get the medical help they required or their medical issues were put secondary because there was a possibility that they could get pregnant. Reader *perra* chimes in with the overall thoughts many women were verbalizing, "Is it any wonder that so many women are 'a little sensitive' about being treated as if being a breeder is our sole function in life?" (Parker-Pope, 2008). This reader utilizes a synonym to "pre-pregnant:" breeder. Both these words create a lesser-than perception for female identity. Breeder is a term typically utilized when describing animals and rarely ever used in the description of men in society. Does this term utilized in reference to women place their reproductive rights on the same level as animals or less? "Pre-pregnant" seems more medically sterile than breeder. However, the term makes the assumption that all women are "pre-pregnant," placing value only on their ability to become pregnant. Does this terminology create a constrictive mind-set in society, placing breeding value on women and reducing their roles to solely that?

The Washington Post spent a lot of their political coverage during the 2012 election cycle on women's issues including the "war on women" and feminism in politics. As previously discussed, women's reproductive health rights are highly polarized in America. Commenter *HarvardProfessor* stated, "Women are equal, but they must follow biological roles, too. Feminists and liberals are trying to destroy the natural order and implement unnatural socialist policies like homosexuality and women rebelling against their husbands and family" in response to an article discussing how recent political campaigns have changed feminist stereotypes (Traister, 2012). This is an extension of the "pre-pregnant" mind-set found within American society. Not everyone agrees with *HarvardProfessor*; however, his expressed beliefs are not uncommon either. This sexist mind-set assumes that it is natural and correct for women to become pregnant, and are therefore always in a state of "pre-pregnancy." It extends the idea that it is natural for women to have families and be defined by them, and that it is therefore unnatural for a woman to see herself or to be seen by others as anything else. Also, the use of the word "rebelling" could suggest that women should be submissive to their husbands and families. It also denotes that women seeking equivalent healthcare are being purposefully disruptive and therefore, a rude inconvenience while reaching for a positive quality of life.

Sexism leads to further perpetuation of an entitlement cycle. Men believe they are entitled to more than women because that is the way they were raised. It becomes truth and is not viewed as being sexist. Take a research study from the University of Tennessee that examined gender stereotypes in healthcare decisions. They found

that women received less aggressive treatment and have a 50% greater chance of dying than men from heart infarctions. Women were "less likely than men to receive life saving interventions such as bypass surgery" for the number one killer of both sexes (Travis, 2012). Sexism has even found a way into the American medical system. When researchers are investigating new medical procedures or pharmaceutical treatments, the grants go to men's issues such as prostate cancer prior to similar women's medical issues, for example breast cancer. These methods have become culturally justified through individual perceptions built up over centuries.

What many women experience in addition to a secondary status, is the feeling of needing to be everything. The discussion of women being viewed as "pre-pregnant" led to many further discussions of women's defined and expected role in society: "Maybe it is the stress of combined pressures telling us to be sexy, but not slutty, but smart, but not nerdy, but successful career women, but nurturing wives and mothers, but ambitious, but warm and fuzzy," notes reader *Kelly* (Parker-Pope, 2008). If one comment could sum up the verbiage and the mind-set of what a woman's identity should be in American society this one is it. The expectations for a woman to be a set list of traits as defined by society and not any of the believed negative traits. The same goes for the belief of female sexuality. Notice the first descriptors *Kelly* mentioned were women must "be sexy, but not slutty." These words are typically utilized towards women in terms of sexual choices. There is not a version of a male slut and the expectation for a man to be "sexy" is not as strong of

a social pressure. Word choices such as these add to the strains on women in American sexual culture. These perceptions filter into the medical industry when women ask what is normal; implying what should be acceptable for women's health and what should be the standard for women's reproductive expectations.

Findings for the right to choose.

Each coded category thus far has held various importance on women's reproductive health for the three newspapers examined, but the most prominent by far is the topics of choice and empowerment for women and their sexual health. Choice and empowerment for women in their healthcare decisions is strongly tied to both the current political atmosphere and to American culture.

As previously mentioned, abortion and women's rights were strongly expressed topic issues during the Obama vs. Romney presidential election cycle. Many readers of political news at the time were able to point out, "The topic isn't abortion. It is choice. It is personal liberty. That is what is at stake here," as stated by reader *drae* (Hanneberger, 2012). This idea that choice and personal liberties are being restricted by political decisions is a sizeable topic among reader response discourse.

Not only does the political sphere create discourse about choice and empowerment, but so does the media and culture. There is a lot of discussion on *The Washington Post* about whether the "War on Women" exists or not. Reader *LAGirl1* states,

"Women all across the political spectrum have been walking the walk of feminism, which at its core, is about women not being restricted from making decisions that are best for their families, without prejudice from the legal system, the media and the culture" (Traister, 2012). This individual points out the major areas that create discourse for women's reproductive healthcare, including women's autonomy in general, at its center.

Discussion for the right to choose.

There are two sides to this argument. One side is the restriction of personal liberties and the second is the degradation of moral beliefs. Take abortion as the example. One side is that women believe they should be allowed to make decisions regarding their health and abortions can be seen as a necessary medical tool. On the other side, some women and other individuals believe that by allowing abortion people are allowing murder of a human life no matter at what stage the abortion takes place. This means that the individuals that believe abortions shouldn't happen are trying to tell others that they aren't allowed the choice; where as those same individuals still have the right to choose not to have an abortion. The problems with creating laws that follow these ideologies are also two fold. The laws currently being discussed do not take into count medically relevant reasons for abortion or birth control such as non-viable fetuses. These laws also do not consider the economic stress the restrictions for medical care place on lower and middle class Americans. During a heated commenter discussion on a *New York Times* article over the ACA's allowance of affordable birth control coverage, reader *rik* stated,

"Healthcare itself, involves highly personal choices" (Bronner, 2013). This further draws on the idea that each individual, male or female, should be allowed to make a healthcare decision for himself or herself based on their personal needs and experiences.

In 2012, the *New York Times* published an article looking at how the book 50 Shades of Grey could be seen as improving women's sexual health. This book has become a cultural phenomenon, deemed "mommy-porn" and is set to release as a movie in February 2015. Opinions over the book and its prevalence have been relatively polarized. Where "'there is good data showing that sexual health and wellness leads to overall health and wellness,' says gynecologist Michael Krychman" (Butler, 2012), many still struggle to understand what is normal and healthy among sexual relationships. The 50 Shades of Grey series has sold over 100 million copies worldwide. This seems contrary when there are many commenters who take a similar stance as *keeladog*: "As a Christian, I have been taught, and know, that sex is wicked. WICKED. My reverend says that those who practice it except for procreation WILL BURN IN HELL. So fie on all ye fornicators!! Fie!!" (Butler, 2012). Where sex is prevalent in American culture, the ability to discuss sex or sexual health publicly is still heavily taboo. The belief that exists in many parts of the United States is contrary to cultural visibility and heavily hinders the ability to move forward with women's reproductive healthcare.

Commenter *jmoooo* argues the opposing side as to why erotica can be beneficial in healthy relationships: "The book empowers relationships because its pure angst free erotica, no one could argue that intimacy in a committed relationship is unhealthy or wrong yet –still, today it clearly is" (Butler, 2012). Much of this belief that women are not sexual individuals harkens back to how word choices, culture, and media have created a set perception of feminine sexual identity in America. This perception limits choices and empowerment as individuals place emphasis on the negativity of sex. In a letter to the editor on an article concerning women's sexual desire, Deborah J. Nedelman, Ph.D., states, "We must recognize that women have little to go on other than popular media's exaggerated view of female sexuality when making that judgment of themselves" (Bergner, 2009). Her point is that to empower women there must be credible and accurate information on female sexuality and health. Poor information leads to difficult decision-making and the results are not always ideal. Helping choices to be made with good information should help to create a cultural atmosphere of empowerment. Outcomes from a variety of good decisions can lead to further positive action.

Findings for #yesallwomen: Shared experience.

Lastly, the most personal discourse created by women's reproductive health articles in the three examined newspapers is story sharing. *crickett44*, a regular commenter on *The Washington Post* stories concerning women's sexual health, points out that "this country has a very childish relationship with sex. We DON'T talk about it, like

grown-ups, near enough" (Butler, 2012). The types of discourse that the handful of women's reproductive health articles create is ripe with women sharing their experiences. As much as inter-personal discussion does not seem to be prevalent for women's reproductive and sexual health, the newspaper forums provide relatable content allowing many women, and even some men, to open up with their own stories. During this research, it was found that the majority of story sharing occurred on the *New York Times* articles, over *The Washington Post* and *L.A. Times*, and more specifically, on the blog articles over the standard newspaper print articles.

Even though forums exist, depending on the condition, for individuals to share stories in a more discrete environment online newspapers allow for a wider audience and many of the headlines bring in a varied population of readers. Sharing stories is different among the identified codes discussed earlier in this research paper. Whereas the other code topics are typically part of the lack of women's reproductive health information in the media, sharing stories is the only one that can be part of the solution. These stories identified in the comments of various sexual health articles fall into two categories. The stories either share a lack of medical care and choice for women or they are shared stories with empathy, shared in order to reiterate that no one is alone. Both are a way of coping and creating a shared experience. "The Internet is increasingly becoming a medium in which women with breast cancer not only receive information and/or support about illness but also compose and circulate their own stories about breast cancer. Telling

stories enables individuals to construct their own identity" (Rodgers, 2005). Each individual's story has merit and adds to the greater discourse on the topic of women's health, bringing more visibility to the topic and creating further connections among individuals.

The more discussion on the topic leads news writers to investigate further and perhaps publish more. A research paper examining reader's comments as a "new opinion pipeline" found that around 25% of reporters added more sources and more facts to their articles because of the addition of online commenting in recent years. However, only a quarter of reporters stated that "reader comments changed their thinking on the newsworthiness of a topics at some level" often or sometimes (Santana, 2011). This leaves 75% of reporters rarely or never utilizing comments and reader feedback to inform their topic choices.

Discussion for #yesallwomen: Shared experience.

Vulvodynia is an isolating and hidden condition, therefore, the more women who can share and connect with women in similar distress the more normalized the condition becomes. This sharing helps gather medical information and works towards helping medical professionals connect the dots for overall treatment. Both the medical industry and the media benefit from story sharing and the normalization of under recognized conditions.

The sharing of stories depicting lack of care and choice for women concerning their own reproductive health is essential in forcing change and understanding. Where women's reproductive and sexual health concerns are treated as taboo topics, the sharing of personal stories puts a name to the issue. It gives many difficult conditions a face. Also, when women share stories of a lack of care or poor care, this helps hold the medical industry accountable and informs other patients to take control of their health. Tara Parker-Pope's blog post on if doctors consider all women "pre-pregnant" really struck a cord with many women. Several shared their experiences when doctors viewed them as eventual mothers over being an individual. One in particular stood out and carried the general feel every story contained. Commenter *Stephanie* shared:

> "I'm a 19 year old with a serious heart condition. After I switched from my pediatric cardiologist to one specializing in adults, I was told that I had to switch heart meds because the one I was taking could be harmful to a fetus. I was the only person in the room who thought it might be more important that my heart keep beating than a hypothetical unplanned pregnancy go perfectly (also, I have a family history of infertility and am on birth control)" (Parker-Pope, 2008).

Many women shared stories where their immediate health came secondary to a non-existent fetus. The ability to receive the best treatment as an individual has become secondary to that of eventual mother. The underlying idea is that there should be a choice in personal healthcare. Doctors are required to perform due diligence in letting a woman know the possible side effects healthcare decisions can

cause for future pregnancies, but shouldn't women still be allowed to place their health first?

Where some stories are meant to inform and make note of a negative situation, some story sharing is simply in an empathetic manner. Many stories on difficult health conditions have the intention of telling others reading the post that they are not alone in their struggles. Whether it is because shared pain isn't as hard to process or as a coping mechanism, several stories focused around providing empathy. From the first article published in any of the observed newspapers on vulvodynia, one woman named *Patsy Martin* wrote a letter to the editor that was later published in print, sharing her pain: "Having suffered from vulvodynia for 11 years, my favorite saying is, 'When Oprah gets it, they'll find a cure.' With articles like Jane Brody's, there may be hope yet. Until now, I have been thankful that it is me suffering from this and not my daughters. But now, I am thankful that you have let others suffering from this know that they are not alone and maybe there is hope for us all" (Brody, 2008). This particular story utilizes positive verbiage such as "cure," "thankful," and "hope." Difficult conditions make it hard to have any of these feelings yet being able to share her own pain story and be thankful for the print article helps provide further encouragement for similar stories. For a condition that affects 1 in 4 women, can you name a single suffering individual? By having women like Patsy share their suffering, she adds her name in association with the condition. A community is created and each story further builds a more accurate identity for a currently faceless condition.

Not only women are affected by sexual health concerns. On a blog post covering women's sexual health and desire, a man shared his feelings about having a condition that causes similar emotional difficulties. Reader *brad* commented, "As someone who has lost none of his desire but most of his ability, I think the question burning in the back mind of anyone whose sexuality has been compromised is, 'am I still lovable?'…I imagine that many women who've lost desire feel the same concern and uncertainty. Can they still be loved or will they forever be viewed as damaged goods?" (Parker-Pope, 2009) This man managed to vocalize what many women who have conditions that compromise their sexual ability feel. His main concern is being able to vocalize the emotional difficulties, no matter the condition, that poor sexual health cause. He also is able to empathize with a woman in similar condition. Most importantly is that he creates sympathy whether you are hurting or completely healthy. The sympathy helps to inform the pain felt by some and allows readers to connect. He creates a shared experience. This shared experience through empathetic stories can help drive news creation on similar topics. It also has the ability to make men's and women's health issues have different but equal concern and care. Where many comment threads went into the political and negative female identity verbiage, comment threads with shared stories make the topics more pertinent to a larger audience.

4.6.3 Q3: If they do not, what causes the gap between medical research and media dissemination of information for women?

Findings.

As this paper has examined, women's reproductive healthcare topics are talked about in the media to some extent. The main topics discussed in the last decade or so take the form of abortion, birth control, and political discourse. These topics do not help to inform women about everyday care and common conditions. Conditions like vulvodynia, endometriosis, post-partum depression, and PCOS are all very common yet sparsely covered. Even issues such as cervical cancer, which has the Breast and Cervical Cancer Mortality Prevention Act of 1990 as law, did little to bring media attention to women's preventative healthcare on the whole. Breast cancer itself has gotten major attention across the nation for other reasons and that will be discussed later.

Medical research tends to be years ahead of what information reaches the general population. Take vulvodynia as a prime example. Vulvodynia gained ground in the medical literature in the late 1980s. Not a lot was known about the cause of the condition, but it was understood as a valid medical condition that was not attributed to a physiological disorder by this time. The first article focused on vulvodynia from the three examined was published in *The New York Times* in 1993 by Jane Brody. Then nothing is touched on again until the same writer publishes in 2008. That is 15 years of significant medical research missing in the mass media. The *L.A. Times*, which has never published on vulvodynia, published a 12-page spread on women's

pelvic pain in March of 2014. So, why has it taken the media so long to catch onto women's reproductive healthcare as a medical versus political topic? Why is there such a prevalent gap between medical research and the media?

Three major reasons seem to exist for the gap between medical research and media dissemination for women's reproductive healthcare. Several of these reasons could be extrapolated to the coverage of a variety of medical topics. These reasons include journalist choice, taboo topics, and issue prominence.

Journalists are considered the gatekeepers in media. They are the agenda setters. Journalists have a choice on how much to listen to readers and on what leads to follow. However, in the health and medical topics there seems to be added tension that effects what topics gain visibility. Nelkin suggests,

> "Both scientists and journalists are committed to communicating truth, and the tensions over science reporting have less to do with accuracy than with style. Media constraints of time, brevity, and simplicity preclude the careful documentation, nuanced positions, and precautionary qualifications that scientists feel are necessary to present their work. … Many accusations of inaccuracy can be traced to reporters' efforts to present complex material in a readable and appealing way" (Nelkin, 1996).

In essence, scientists and medical researchers see the media simply as a way to create enough public information to help with funding.

Press releases are not informative enough for complex medical and health topics, however, "a survey of 468 health and medical reporters and editors found that those from small media organizations, were less likely to specialize in health as a beat and were also less likely to use the expert sources traditionally associated with health reporting, such as government scientist, industry scientists, or healthcare providers. They were also less likely to use government Web sites or scientific journals as resources, but more likely to use news releases" (Young, 2011). Based on this information, there seems to be minimal effort made on the researcher's side to work with the media and the media does not seem to make an effort to look into cutting edge medical work except through press releases.

Another major concern with women's reproductive health being covered in the media is voiced by a commenter *C Reynolds* on the issue of vulvodynia: "Doctors either don't care enough to be proactive or have no idea how to treat it themselves. I've often thought that if men had this problem, there would be a solution by now" (Brody, 2012). If doctors are not looking into the topic and releasing information on a condition the press doesn't have much of a way of covering the health issue. In many cases, researchers and doctors are releasing information that isn't being covered but once again, that is not always the case. For difficult and underfunded medical conditions there is little consistent information, even in the medical community.

Women's reproductive and sexual health faces a major hurdle in receiving media attention. Most articles talking about women's sexual health immediately receive criticism as not being appropriate or pertinent. Women and sex in the same space seem to be considered culturally taboo in mainstream media by some members of the public. As noted under research question two, the verbiage under comment reaction tends towards the negative where sex is "wicked" or women are seen as "sluts" for having sexual desire. Women's health is controversial and even the correct medical term "vagina" doesn't seem to pass the journalist "breakfast test." Even sexual desire articles elicit a variety of responses from the public including this comment by *orchid*, "What a…terrible article. I assume the only reason you published it is that since this is an area where so little research is done and so little is written with any value, you thought this article proposal was new and different?" (Parker-Pope, 2009). Several readers had similar responses and stated that topics like sexual desire should be kept private. Not only do journalists typically not choose to write about women's reproductive health, but it's also a taboo topic that doesn't have a lot of public prominence nor support. However, since around 2008 women's reproductive health and care has been gaining ground.

Reporting on women's reproductive health seems to follow the presidential election cycles. Articles gain publication salience around the time of presidential campaigns especially in 2008 and again in 2012. This would suggest that politics see women's issues as being relevant to female voters. "With America so divided on this issue and most people somewhere in the middle, MSNBC's First Read observed on

Wednesday that 'perhaps the most surprising part of last night was that it had more talk about abortion rights than in any Democratic convention since 1992, the first of many self-described 'Year of the Woman' campaign years" (Henneberger, 2012). It's important to see political parties making an effort to incorporate issues that are perceived as being key topics for half of the American population. Candidates want women to vote and perceive many of their key issues as being loosely related to women's reproductive health. Women's issues have been politically boiled down to abortion and birth control in the current political atmosphere. These are both important issues and medically relevant but as discussed above they are not key issues for women voters, unlike the economy and jobs.

"The new regulation [through the ACA] is meant to remove cost as a barrier to birth control, a longtime goal of advocates for women's rights and experts on women's health" (NYT Staff, 2012). By moving forward with the medical care the ACA provides for women, as well as men, the genders become more equalized and medical choices like birth control become more empowering. The difficulty with politics in women's reproductive healthcare is the conservative restrictions being placed on what should be simple procedures. However, the major reason any discourse is happening in the United States on the topic is because of the political prominence. There is a surge of information and various articles on women's reproductive health starting around 2008 and continuing into the present. 2012 continuing into 2013 contained the most information focusing on the ACA and the access to affordable birth control. Though this is not strictly medical discourse,

many issues such as PCOS and endometriosis were brought up during the discussion as reasons for having easier access to birth control across all social economic classes. Where not a lot of information was seen after the DNC of 1992 on women's health and the topic disappeared from the media, this does not seem to be the case with the 2012 election. Women's issues have maintained a relative amount of strength in the media.

4.6.4 Q4: How does the media close the gap that may exist?

Discussion of application.

The media is a functional tool for information dissemination and newspapers play a major role in providing the public with health information and topics. Journalists do not have to be the ones who close the medical information gap but they are in an ideal position to help improve the current discourse on women's reproductive health. The first step towards any improvement in the media on women's reproductive health is to create a candid and honest conversation on the topic. While journalists do use appropriate medical and politically correct terminology when writing about women's reproductive health, the topics are superficial. Culturally 50 Shades of Grey has impacted the U.S. fairly strongly, yet the discussion the *L.A. Times* asks is if the book improves sexual health. Sexual health can be addressed in a slew of other ways that do not polarize and turn off a large part of the newspaper's audience.

Not only does the quantity of articles need to be increased, but also the quality. Overall, medical articles seem to get relatively good feedback from its readers and should be utilized as an example of what works. Jane Brody published a second article on pelvic pain in 2012 and commenter *Anne Hills* responded:

> "No, this articles does not set women's sexual emancipation back. If every possible cause of vaginal pain was discussed, this would have been a book, not an article. I am very glad to find this piece on the NYT site. And the primary point of it was to counter the 'it's all in your head' or 'there isn't a cure' replies from so many providers. The last things we need is another source that runs on about education failures or psychological causes for sexual problems. Thank you NYT for publishing content and references about what is a large and often dismissed public health issue" (Brody, 2012).

This reader's feelings were pretty well agreed upon across a variety of similar articles and across newspapers.

By creating positive discourse online and among their readership, journalists help to remove shame, stigma, and taboo associated with many of these health topics. Breast cancer not only used to be a death wish, but it also was not readily talked about in the general public. Groups like Susan G. Komen's Race for the Cure have helped to provide information and worked with the media to create a positive identity. In fact, over 40% of their budget each year goes towards public health education.

Journalists have to humanize these women and put faces to the conditions they write about, not simply rely on press releases for events or procedures. Though not a women's reproductive health condition, Post Traumatic Stress Disorder (PTSD) has received its fair share of stigma in the general public and across the media. Craig F. Walker of *The Denver Post* created a photo story following Scott Ostrom in his struggle with PTSD. This photo story went on to win many awards including a Pulitzer Prize. It is an example of a difficult, hidden condition being given a human face. As a reader, one may not connect with statistics but will connect with a personal story. Rodgers and Chen found that, "the longer women belonged to the online discussion board and the more they participated, the more their stories reflected positive well-being" among online breast cancer communities (Rodgers, 2005). Long term and more in-depth projects such as Walker's can help improve visibility, connection, and sympathy as well as public knowledge for topics in women's reproductive health. Taking these approaches to medical journalism can help address the bigger issue noted by commenter *Ross Mitchell*, "More importantly, however, is to address the cultural or habitual inheritance of attitudes and dispositions" (Kristof, 2008). Positive, informative, and humanizing journalism will help change the national attitudes and female identity over time, creating a shift in how Americans see women's reproductive and sexual health.

Maybe the bigger question isn't how are journalists going to close the gap in medical information dissemination for women's reproductive health, but rather, who should? Non-profit organizations have the ability to initiate the conversation on

various topics of interest to the public. Cultivating relationships between medical non-profit organizations and journalists would provide journalists with easy to contact sources for information as well as allow non-profits to have a point of contact in the media. For women's reproductive health, non-profits like Race for the Cure and the National Vulvodynia Association (NVA) are examples of groups that have worked with the media to provide accurate and interesting medical information. The NVA was a major contributor to the 12-page pelvic pain insert with the *L.A. Times* that was mentioned previously. This particular publication was made through the contribution of many different individuals, doctors, non-profits, and medical groups in order to provide vital information that is rarely published by newspapers. The NVA also makes it possible for journalists to get in touch with vulvodynia patients quickly for media requests. This brings back the humanization of a medical story over simply providing statistics. Non-profits are not hindered by HIPAA restrictions the same way doctors are and in the NVA's case many women want the opportunity to tell their stories, they just don't know where.

If journalists and non-profits can disseminate information through the media, does it create change for the female cultural identity? What can? The answer seems relatively simple. Social media is a driving force for cultural discourse. The topics that are most discussed are arguably the most popular at the cultural moment. A pertinent example is the hashtag on Twitter #yesallwomen. This hashtag became popular around May 2014 in order for women to share personal stories of sexism and misogyny (Weiss, 2014). The sharing strongly united many women and

brought tough, often taboo, stories to light. *The New Yorker* writer Sasha Weiss notes that, "there is something about the fact that Twitter is primarily designed for speech—for short, strong, declarative utterance—that makes it an especially powerful vehicle for activism, a place of liberation" (Weiss, 2014). Twitter also helps women globally make a statement and be connected through topics like #yesallwomen. Social media carries a viral effect. #yesallwomen went viral and was then discussed in more traditional media and so did the ALS ice bucket challenge in the summer of 2014. How many people knew about ALS prior to the ice bucket challenge? Many participated and donated to the cause over the course of several months without even knowing what ALS was. However, with the challenge going viral across all forms of social media, many people were looking it up and seeing it in the traditional media. It created a stir that created activism and the dissemination of information. According to the ALS Association, over the course of less than 30-days in the summer of 2014, the ice bucket challenge raised over $88.5 million (ALS, 2014). This is an increase from only $2.6 million in the same time frame the previous year. Whether ALS non-profits will be able to continue the social media push or it being a one-time fad, it was still highly effective for disease research and information, much like The Race for the Cure is for breast cancer.

4.7 Conclusion

Discourse for women's reproductive health in national newspapers is an under-discussed and often under-appreciated topic of importance. Women's reproductive

health concerns branch in to many areas of life including culture, politics, and economics making the public access to information even more important. In the changing cultural landscape of the United States, having correct, accurate, and personal information available on a variety of women's reproductive health topics is essential. Talking about sex and using the word "vagina" is not as taboo as it was even 10 years ago; however, there is still a lot of room for growth on the topic. This research looked at the many different ways that women's reproductive health is discussed by journalists at national newspapers and the response they received from the commenting audience in order to better understand the current reception of women's reproductive health in the media.

There are several limitations to this research study that should be noted. The use of only three national newspapers as a sample may provide a sample in which women's reproductive health issues are more prevalent than the average newspaper. Each newspaper selected was chosen for having reasonably substantial health coverage and that may overestimate the amount of health coverage typically seen. There was also no strong base for viewing women's reproductive health through newspapers, which made it difficult to keep a tight focus on issues such as vulvodynia or PCOS. Further research into political views of women's reproductive health and women's reproductive health in social media could be beneficial to the field allowing non-profits and other media outlets a better understanding of how individuals engage on the topic. Also looking at similar discourse through quantitative means could be advantageous. Further research could help in

normalizing the discussion and viability of women's reproductive health across ideal media platforms. It would also allow journalists greater insight in how to address women's needs and move traditional news away from the masculine into a realm where both sexes have equally strong voices.

Women's reproductive health in the media is an evolving discussion that will continue to change over time. Women have the ability to use this to define their own sexual health identity. The change seen over this research's time frame bodes well for even quicker positive change on the topic in the next several years leading up to the next presidential election in 2016 and as the ACA continues to be discussed and reevaluated. Women's reproductive health discourse has made great strides in the media and is going in the right direction. There are still areas that need work as noted but perceptions are changing and will continue to do just that in the coming years.

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Appendix A: Project Proposal

Vulvodynia in United States Society: A Look at Agenda-Setting and the Effects of Vulvodynia Among American Women in Print Media

by Carrie Anne Durkee
December 4, 2012

Chair: Rita Reed and David Rees
With Amanda Hinnant and Jon Stemmle

1.0 Introduction

When I made the decision to pursue a Master's degree in Photojournalism my friends and family all let out a sigh of, "Finally." Somehow they all knew I belonged in photojournalism long before I did. I've always had a passion for photography, more in the form of art, but nonetheless any chance to make photographs was a welcomed opportunity for me. I remember in middle school being the one with a simple point and shoot that utilized 110 mm film and being the one "documenting" my friend's daily lives. I was always the one with the camera. Not much has changed. My passion for photography is even stronger than before and my time in the University of Missouri's Journalism school has made my work even better.

A photographer only ever sees improvement in their work when passion for the craft and subject exist. All my photojournalism classes have brought me to a place where the importance of the subject falls above the rest. I used to think solely about graphical appeal. I used to look simply for the beauty of a subject, which isn't always the truth. The idea of letting your subject speak through your images really resonates with me and letting the subject tell their own story seem essential to me now. The content and concept for this proposed project came from me knowing that I, and plenty of other women have a story to tell concerning women's reproductive health concerns. The way the media views women's health and the very specific issues women suffer from need to be talked about. I feel I'm the one who is prepared, passionate, and ready to tell this story on behalf of the millions of women in the United States who are not heard.

2.0 Literature Review

What is vulvodynia?: A quick summary

According to a recent research study from the University of Michigan published in February of 2012, "vulvodynia causes substantial pain and suffering for millions of women in the United States, yet the disorder remains underdiagnosed and inadequately treated" (Reed, 2012). So what is this conditions that haunts millions of women? Vulvodynia is defined as "vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible findings of specific, clinically identifiable, neurologic disorder" by the International Society for the Study of Vulvovaginal Disease (Ponte, 2008). The National Vulvodynia Association (www.nva.org) divides vulvodynia into two subcategories that are typically recognized: Vulvar Vestibulitis Syndrome, which is more localized to the vestibule, and Generalized Vulvodynia.

The University of Michigan study concluded, "vulvodynia is a common pain syndrome affecting more than 8% of women at any one time and more than one-quarter of women at some point in their life span" (Reed, 2012). This is a drastic

increase from what was recognized as average numbers in 2003 where it was estimated that "an incidence of up to 16% of women, suggesting that as many as 14 million women in the United States may [have] experienced vulvodynia" (Ponte, 2008).

Vulvodynia is not only a pain condition but also a very emotional and economic burden as well according to several studies done in the last decade. One particular study done by Tulane University states, "The findings of these studies suggest that vulvodynia may pose a significant medical, social, and financial burden to women with vulvodynia, the healthcare system, and the US economy" (Xie, 2012). These issues occur when 60% of women have to consult "at least three healthcare providers while seeing a diagnosis, 40% of whom remained undiagnosed after three medical consults" (Xie, 2012). Furthermore, Xie notes that, "evidence-based guidelines for the medical management of vulvodynia do not exist" (Xie, 2012). Many of the newer papers on vulvodynia support the overall idea that vulvodynia affects many different facets of life and the economy. The University of Michigan's study quantitatively found that the mean duration of the condition for any one woman suffering from vulvodynia is 12.5 years (Reed, 2012). That means that for 12.5 years one individual woman has difficultly receiving a diagnosis and lives in pain.

Several quality of life studies have been done based on vulvodynia and the results are pretty astounding. Ponte's study on "Effects of vulvodynia on quality of life" found that "women with vulvodynia were more likely than others in the sample report that their vulvar condition often or always makes them feel depressed, angry, or frustrated" and also "that their condition affects how close they can be with those they love, that it makes showing affection difficult, and that it interferes with their sex life" (Ponte, 2008). This is just the beginning of a list of emotional and physical symptoms linked to a condition that very few people know about and even fewer know how to treat. Treatment options, once diagnosed, range from tri-cyclic antidepressants, to creams including lidocaine or gabapentin, to surgery, among other options, depending on the severity and localization of the pain. However, recent studies concerning the use of lidocaine and desipramine as a common treatment for vulvodynia suggest that these treatments fail to relieve pain more than the placebos administered, leaving many women with out treatment options (Foster, 2010).

Medicine and the Media

It's important to consider where the majority of the US adult population acquires their knowledge about health information. A conference paper titled "Newspaper Journalists and Public Health Professionals: Building the Health News Agenda in Community Newspapers" cites that "surveys have shown that print media, including books and newspapers, remain a predominant source of health information" (Newspaper, 2011). The same source "showed that print media are a main source of

health information for more than half of adults surveyed" (Newspaper, 2011). The importance of national newspapers for the general dissemination of information has never been doubted and became even more pertinent after the identification of agenda-setting in the 1970s. However, the ability to cover health effectively and accurately has been a real challenge in the media.

Health is considered "the eighth most cover news topic nationally" (Newspaper, 2011) but finding staff and sources to continue "good" reporting even on the national level is difficult. The real problem seems to be in how the information is controlled and disseminated. Nelkin argues that scientists "view the press as a conduit or pipeline" for their scientific research (Nelkin, 1996), where as the press has always viewed what is published as their own. Researchers "see the media as a means of furthering scientific and medical goals" whether they are financial or simply informational (Nelkin, 1996). What many scientists fail to realize is that what is printed in the mass media is simply a matter of newsworthiness and timeliness. "Sources who can best fulfill their role in the news construction process by providing accurate, timely, and relevant information that meet's a journalists' criteria of newsworthiness are more likely to see their stories in the newspaper" (Newspaper, 2011). Nelkin sums it up pretty completely that "scientists and journalists depend on each other in the communication of science and the shaping of the public meaning of science and medicine" (Nelkin, 1996).

Women's Health in Mass Communication

When it comes to women's health especially women's reproductive health in the mass media, there is very little information. Few studies have been done considering agenda-setting of women's reproductive health and the reason for this seems to be that there is a lack of will to communication about women's health whether in mass communication or in interpersonal communication situations. In an article from the Journal of Applied Communication Research, authors noted "people 'rely on the mass media for about 80% of their information about news and public affairs, and they rely on interpersonal communication for only about 20%'" (Ogata Jones, 2006). They noted this in reference to breast cancer screening information in mass communication. They also note that even though doctors play an important role in passing on health information, most information still comes from the mass media.

K.O. Jones et al discuss the importance of the agenda-setting role of the media in health communication. They suggest that the earliest paper in regards to the "agenda-setting role of the media regarding health behaviors was conducted by Pierce, Dwyer, Chamberlain, Aldrich, and Shelley" in 1987 (Ogata Jones, 2006). This 1987 paper stated the "'possible importance of an agenda-setting role for the mass media in promoting change.'" There have been many examples of this happening including in AIDS/HIV reform, tobacco policies, and cancer awareness.

K.O. Jones et al conclude that even though there has not been a lot of work with agenda-setting in health communication, that there needs to be more in order to help create more public awareness of various health topics (Ogata Jones, 2006). A paper from 1996 by Rogers states that "'preventive health communication faces particular difficulties in bringing about behavior change…[as] many preventive health campaigns must address highly sensitive topics, such as sex, disease, and death, that are difficult to discuss freely'" (Ogata Jones, 2006). This seems to be a major issue of contention when looking at women's reproductive health, that the words sex and vagina have a taboo nature that must be over come in mass media.

One other study of note in women's health communication is one entitled "Women's Knowledge and Awareness of Gynecologic Cancer: A Multisite Qualitative Study in the United States." Once again this is not a study about sexual pain but does deal with certain areas of women's reproductive health and awareness. The first important fact to note from this paper is that in 2007 Congress passed a mandate requiring the increase of "women's knowledge and awareness of gynecologic cancer" (Cooper, 2011). The ramifications of this law have made information and media concerning gynecologic cancer more readily available. Cooper et al utilized focus groups to see how effective communication has been concerning all forms of gynecologic cancer. Their results include women knowing more about cervical, ovarian, and uterine cancer but "most participants had not heard of vaginal, vulvar, or gynecologic cancer. Not only were they unfamiliar with vulvar cancer, but also many reported they were unsure of the anatomical location of the vulva. A few participants confused the vulva with the clitoris" (Cooper, 2011).

Two important facts came out of this study on gynecological cancers: 1) women have a large knowledge gap concerning their own health issues and 2) that information is acquired from many different sources. Participants "frequently mentioned acquiring their information through personal experience, the experiences of others (including celebrities), healthcare providers, advertisements, and news and entertainment media" (Cooper, 2011). It is for these reasons that it is so essential to look at the role the media plays in disseminating health information to the public and the agenda in which the media chooses to present.

3.0 Professional Skills Component

3.1 Area of Emphasis and Qualifications

My area of study over the last two years at the University of Missouri has focused on Photojournalism and visual storytelling techniques. The specific course sequence has taken me through the process of choosing my subjects to technical lighting, to intensive work on long-term pieces. Along with the photojournalism sequence, the University also prepares me for this professional project through various classes on theory and upper level journalistic thinking.

Two photography classes stand out as improving and preparing me for this cumulative project the most: Advanced Techniques in Photojournalism and Picture Story and the Photographic Essay. These two particular classes strengthen both content and technique in my work. Content is always something I have struggled with in my images and Photo Story forces you to really dig into content while exploring stylistic techniques. Advanced Techniques of Photojournalism is different in the respect that it is more focused on correct lighting technique. Taking the class really improved my work and my understanding of how light works but more than that, being the Teaching Assistant for the class has also enhanced my understanding of the subject matter. I feel more confident utilizing created light sources after teaching the class for one semester than before. Teaching also reminds me that it is necessary to utilize what I teach in order to be a better instructor as well as shooter.

Outside of photography, one class stands out the most in helping me in completing my Master's Degree: Qualitative Research Methods. This class introduced me to research methods most appropriate for photojournalists and to many methods I have never utilized before. Photography is a very subjective way to convey information and needs a research method that can work hand in hand with it. Interviews, rhetorical analysis, and other methods like focus groups allow individuals to tell there own stories and convey information through their own particular point of view. Photojournalism conveys information about an individual or event through a photographer's point of view; so allowing the subject to weigh in is essential when choosing research methods in my field.

One last thing outside of my course work qualifies me to proceed forward with this Professional Master's Project: my personal experience with vulvodynia. As much as course work can prepare me to make photographs and properly research agenda-setting and rhetorical analysis of newspapers, the only thing that can truly prepare me to understand my professional project topic is my personal experiences. I truly believe that my experience with the condition has led me to want and need to spread positive information about vulvodynia. This is not a story that an "outsider" could easily walk into and gain access to personal appointments. This is not a story a man could truly begin to understand in the same way that a woman could. This is a story that needs to be told and who better to do it than someone who has experienced it.

3.2 Detailed Project Description

For the project component, I will complete a photo story with one to three vulvodynia patients focusing on the medical aspect of the issue. Because of the sensitivity of the medical issue one patient with the correct situation as described below should suffice though multiple subjects could add depth that cannot always be fully achieved with one patient. A lot of women have a story to tell and need to be heard, I just have to find the right one who understands that.

The type of patient I would be looking for is one who has been diagnosed with vulvodynia within a recent time frame, within approximately one year of my photo story beginning. This individual could also be a surgical candidate at the University of Colorado Hospital Women's Clinic for visual purposes. I would need one woman over the age of 18 and of any ethnicity allowing me to be welcome in their appointments and home. Vulvodynia is a medical issue and I wish to cover it as such. But vulvodynia also has a strong psychological component, which should be addressed by visual showing everyday life and personal expression.

The types of situations I would shoot include and are not limited to clinic appointments, vulvectomy surgery, life at home, time with significant others, caring for children if any, counseling if any. The idea is to show the medical as well as how this condition takes an emotional toll on the woman. This is about moments that say pain and coping. I also plan to do audio for every subject in order to add history and nuance where images cannot tell the story. Also, it is critical to allow the women to guide and tell their own story.

The process to recruit such an individual I have defined above will involve time from January through May working with Doctor John Slocumb and his staff. Dr. Slocumb is one of the only specialists of the mid-west region that will surgically address vulvodynia. Dr. Slocumb is a board certified OB/GYN, receiving his medical degree from the University of Rochester. He has surpassed retiring age by 10 years and his patients will not let him retire. He has approved the use of letters to his patients through his nurse, Mary Belle, and everything in their power using their personal network to help with this project because he feels that informing the public and creating awareness in the female community is just as important as researching the topic. I will be meeting with them again over winter break in order to clarify any details and present this project proposal to them.

As a backup to utilizing Dr. Slocumb's patients and help with recruiting, the National Vulvodynia Association (www.nva.org) have a strong network of women and forums to recruit from. They have a media contact for interviews that could be helpful in adding to this project. Her name is Christin Veasley and can be reached at 401-398-0830.

A photo story wouldn't be a story without defining what I think it would take to be considered finished and complete. Rita Reed says in class that no matter how long or hard you work on a story, very rarely will it ever feel finished. What I will be looking for in completion of this piece is a clear beginning, middle, and end. I want to see a coherent theme in the piece whether it ends up as an intimate story about a person or the condition. I also want to make sure that the condition vulvodynia is clear in the piece. As much as the individuals are important, the main concern is explaining this medical condition and its ramifications through visual storytelling.

Lastly, if the intimate pieces are not possible I have a backup for the journalistic skills component. My plan for a back up piece would be to go for breadth instead of depth. I would do a large studio portrait series of women who have or have had vulvodyia and include audio interviews about their experiences with diagnosis, treatment, and life in general. This would give more general information about the condition but emphasize that many women have it over the personal repercussions of the condition.

I address my reflexivity and ethical beliefs briefly under the validity section of the methodology a little bit but it needs to be mentioned here as well in terms of the project as a whole and especially in terms of the photo project. Involvement with a topic that is personal in nature always has inherent risks. But I feel they are the same risks that could happen working with any subject. There is always the potential for getting to close to a subject, for empathy getting in the way. Things I consider include, would I be able to photograph a woman crying from an exam. You bet. This single-mindedness comes from a place of wishing that I could have had a reporter or photojournalist work with me and tell my story as I went through two surgeries for vulvodynia.

One of the concerns brought up is the concern of working with my doctor for the subject matter and to gain access to subjects. With HIPAA law it is difficult to gain access to medical issues unless you know the patient closely. Knowing the doctor allows them to give their patients letters of petition from me and the comfort of approval from the medical staff. I think it is also important to remember this isn't investigative journalism but informative storytelling. However, I will speak with the medical staff that I will work with and discuss what they expect and what I expect in order to maintain my journalistic autonomy. This will allow them to understand what I am looking for, what my end goal is, and what I am hoping to achieve from the beginning. I am looking to tell a story in which the women's stories are as essential as the medical aspect. In the same respect, the medical is essential to include and this story cannot be told without it. I will maintain the utmost professionalism in both the medical setting as well as in a personal home setting. I will do so by keeping some distance between my subjects and myself, and trying to adhere to the "fly-on –the-wall" mentality. I believe this is an informative and observational piece that requires trust but not friendship. Distinct separation of the two is essential.

3.3 Work Schedule

The University of Missouri's Journalism program requires all Master's students to spend a minimum of 30 hours a week for 14 weeks on their professional projects, totaling 420 hours in all.

My project will be in process from January 2013 through August of 2013. From January through May, I will spend approximately 20 hours a week on the

Professional Analysis component. I will also use this time to recruit individuals for the Journalistic Skills component during the summer. This schedule will allow me to teach, finish my last class, and complete my research while I have easy and appropriate access to materials in Columbia, Missouri.

I will then move to Denver, Colorado from June to August where I will complete the Professional Skills component of my Master's Project. Over these months I will also spend approximately 20 hours per week shooting and arranging various shooting sessions. My work from January through August will total in approximately 640 hours in total on my project, which more than satisfies the requirements for completion.

3.4 Project Dissemination

The skills component of the professional project skills and the analysis components have two very different publication possibilities. I have a few specific goals for the skills components publication opportunities due to the nature of the advocacy in the work. A strong aspect of this skills component deals with female genitalia. I have challenged myself to be able to have an edit that would be publishable in any newspaper. I could see this piece being run on the New York Times Lens Blog, with the National Vulvodynia Association, 5280. or with The Denver Post. There is a strong local angle to this piece that should be utilized. For example, 5280 does a Top Doctors issue every year and this could be a story that runs in that issue. I would send samples of the piece with a letter of solicitation to the publications.

Or:

For my backup, I would complete a website for all the audio and visual aspects to be combined in one platform. I would like to do this for my main idea as well but I think it would be a sub-set of my portfolio.

3.5 Supervisors

My agreed committee chair is Rita Reed. However, do to unexpected circumstances she will not be approving my proposal but Photojournalism Faculty Chair David Rees will do so. Rita will take charge again starting January 2013 and David will be staying on as a committee member. The other agreed upon member of this committee are professors Amanda Hinnant, from Magazine Journalism and Jon Stemmle, from Strategic and Health Communication. Each professor has various skills to help me complete each piece of this project. Rita's strength is in the professional skills component and will be essential in helping me with the photography. Amanda has strengths in women's health and qualitative analysis while Jon is going to be extremely helpful with the use of agenda-setting research in the health fields.

I will meet with Rita once a month during the spring semester 2013 and communicate through email while in Denver over the summer. I will also meet with Amanda and Jon as needed as well as communicate with them via email for easier questions.

4.0 Professional Analysis Component

4.1 Statement of Topic

For this professional analysis component I will utilize textual and rhetorical analysis to examine the following questions:

> Do national newspapers write about vulvuodynia and other women's reproductive concerns? If they do, what kind of discourse do they create among their audience? And if they do not, what causes the gap between medical research and media dissemination of information for women?

The textual and rhetorical analysis will be paired with an analysis of comment threads on the articles to further look at why the coverage of vulvodynia is the way it is and to help answer the question of what is missing from current coverage.

4.2 Relevance

As seen in the research presented with my professional skills component vulvodynia is a very widespread and important women's reproductive health concern that very few people have heard about. Even the newest statistics out from the University of Michigan indicate that 8.3% of women in Southern Michigan have or have had vulvodynia at some point in their lives (Reed, 2012). This same study also indicates that just over 1% of these women were diagnosed. When these statistics are extrapolated out to the entire United States, the potential numbers suggest that 1 of every 4 women have or have had vulvodynia.

For such a prevalent concern among women's health, very little is know about the condition, access to care, or even the name itself. How is it that vulvodynia isn't a household term? How come many accredited OB/GYNs are unable to diagnosis and treat such a painful condition? Why does the general public not hear about it in the news or read about any new findings in newspapers? Why aren't reporters supporting and advocating for further research when they advocate for breast cancer or diabetes? Only 8.3% of the entire national population has diabetes according to www.diabetes.org and yet it is thought that 12.5% of the same national population suffers from vulvodynia. Everyone knows about diabetes, but who really knows about vulvodynia? I respect that diabetes and breast cancer kill. Diabetes is the 7th leading cause of death in the United States but consider what was discussed in the literature review about quality of life for vulvodynia patients. Vulvodynia

causes physical pain for extended periods of time, high emotional distress, and has a high economic burden due to the costs of medical care.

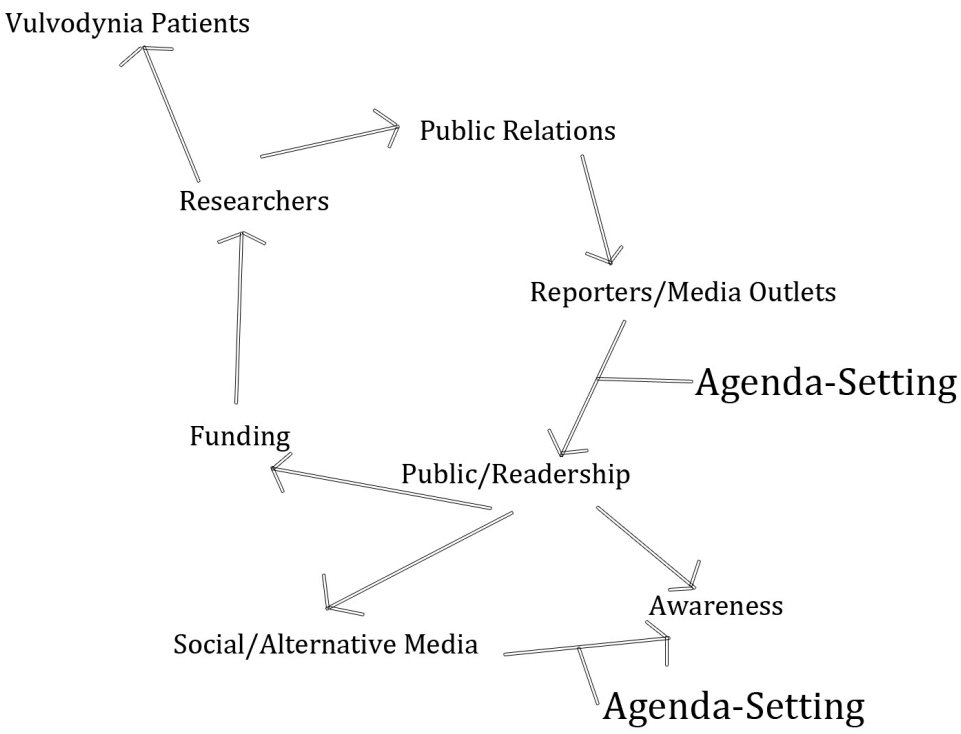
4.3 Theory

Agenda-setting is a supported and heavily utilized communication theory. It was first presented by McCombs and Shaw in 1972 in the context of election coverage. Many other studies have followed expanding on political content. Some even expand on general news coverage and agenda-setting in the media at the local level. However, there is very little work done on agenda-setting in women's reproductive health communication. The closest comparison is how people chose to inform and communicate on the topic of breast cancer.

Agenda-setting is defined by McCombs and Reynolds as, "the news media can set the agenda for public thought and discussion" (Ogata Jones, 2006). K.O. Jones et al continue to explain that health agenda-setting can promote change and health literacy among the readership population. In the simplest terms, the media can define what people think about and know about, therefore setting the public's agenda.

K.O. Jones et al explains that, "people rely on the mass media for about 80% of their information about news and public affairs, and they rely on interpersonal communication for only about 20%" (Ogata Jones, 2006). Mass media can include newspapers, national and local, magazines, and online content. National coverage of a topic drives all forms of agenda-setting content and trickles down to the local level (Newspaper, 2011). If information is not disseminated at the national level then the likelihood that information is disseminated at a more local level is slim. Looking at agenda-setting in national newspapers for women's reproductive and sexual health is suggestive of how information is given importance. Whether or not media covers women's reproductive health dictates public discourse, research funding, and general awareness.

Utilizing agenda-setting in this professional analysis is key in answering my topic questions. Consider the media cycle presented in the figure below:



The connection between reporters and their readership is what I will critically be looking at as an effect of media communication and dissemination. Agenda-setting allows me to examine what types of topics gain salience in the media and why it's important in the context of women's health. The way I keep thinking about it is in the context of the above figure where each component is a barrier to the next and also is representative of the movement of information. When looking at women's reproductive health media, an individual can see that the dissemination of information gets caught between reporters and their readership. The effect is the lack of agenda-setting and lack of communication for the topic.

Communication and dissemination of information happens in two ways, through the media and through interpersonal communication. People talk to each other about various topics with different levels of salience. This theory is called two-step flow. Yang and Stone define two-step flow as one where, "opinion leaders, who are more likely to attend to the media for news and public affairs, will pass this information to the less media reliant through interpersonal communication" (Yang, 2003). This is another form of agenda-setting that is not as pertinent as mass media salience but still has merit and affects how information in women's reproductive health moves through the public.

By looking at national print media I will be able to see one way that women gain information but as Yang and Stone have discuss, traditional media is not the only way in which people gain information. Interpersonal communication is important

in how information is disseminated. Interpersonal communication includes not only face-to-face discussion but also non-traditional online communication. Comment threads, blogs, and social media all are factors in today's form of two-step flow. These forms of communication allow for two very important factors: 1) content is patient driven and 2) content is unedited. This potentially leads to having more feminine discourse through interpersonal communication where as newspapers have been traditionally masculine.

The possible importance of this theory in conjunction with mass media agenda-setting is in how women connect with one another therefore sharing information among women. As stated above by K.O. Jones et al, only 20% of typical information dissemination is through interpersonal communication but because of the nature of the topic, the interpersonal communication is essential to address.

4.4 Methodology

Rhetorical Analysis Utilizing a Feminist Critique

The questions posed in the statement of topic can and should be answered utilizing rhetorical criticism and analysis. The approach I will utilize is a feminist critique of 5-15 articles across three national newspapers paired with a review of current medical research on vulvodynia and vaginal pain. The number will depend on when I reach theoretical saturation and see a replication of themes, which will indicate a correct number of artifacts. Rhetorical criticism is a qualitative method meant to help define and explain reality through analyzing modes, forms, structures, and choices in communication (Foss, 2004).

Sonja Foss defines feminist criticism based on bell hooks' argument that "whether their role be that of discriminator or discriminated against, exploiter or exploited. It is the practice of domination most people are socialized to accept before they even know that other forms of group oppression exist" (Foss, 2004). This further explains that feminism isn't solely about women but any form of defined identity. Utilizing these ideas to look at how print media defines women's reproductive health strongly falls into the category of feminist criticism, especially for an initial study. A feminist critique is a form of deconstructionist theory. This states that any binary such as male/female, up/down, etc is a constructed thought and therefore has constructed meaning (Culler, 1997).

With these theory definitions in mind, I will include 5-15 purposive articles from the New York Times, Washington Post, and LA Times to examine as artifacts. These three newspapers were chosen due to their liberal leaning history, strong health sections, and national standing. Women's reproductive health is not covered in many newspapers to begin with so giving myself the best chance to find good artifacts as defined by Foss is best. I will look for articles that "intrigues, baffles, or

excites" (Foss, 2004) me that addresses women's reproductive health. The following search terms will be used to find viable articles:

Vulvodynia
Sexual Pain
Birth Control
Vulvar Pain
Vulva
Vagina
Reproductive Health
Women's Health
Sexual Pain, Sex Pain
Sexual Health
Sexual Intercourse, Painful
and other related terms

To identify an appropriate artifact for use after utilizing the above list for database searches, I will look for articles that seem to lead opinion and discourse. Specifically I'm looking at how discourse creates an identity for women's reproductive health and what kinds of denotations the language in the articles creates. Does the discourse and language choices used in the articles create a stigma among public knowledge? Or perhaps a more positive message of awareness? Historically, there has been very little coverage and a negative take on women's reproductive health. I will examine what kinds of wording and attitudes are taken in the artifacts in order to gain a better understanding of what types of articles are reaching the general public and the agenda-setting that is taking place. Signifiers that are suggestive of these attitudes could be "war," "unmentionable," "afraid," "It's all in your head," "bias," "punish," "slut," or "promiscuity" in relation to stigma creation and "choices," "equality," "empowered," and "feminist" in relation to more positive messages. I will be examining how these signifiers create signified messages in news print media. I will be basing much of the rhetorical criticism analysis on Saussure's theories of how language and ideas function between each other.

What I will be looking for in artifacts is pretty simple. Foss suggests looking for anything interesting and baffling. To me this suggests articles that are open to talking about women's health in terms of the word vagina. I find it interesting when individuals act on this issue such as Sandra Fluke speaking to Congress about birth control or the several articles out there concerning the "war on women." I will be looking for any article that describes, informs, suggests, or creates dialogue concerning women's reproductive health. I will specifically look at the time period of 2002 to 2012 to match the medical literature. The concept is that if medical literature is being published rapidly during this time frame then the media should follow a similar pattern with a slight delay. I will also be utilizing flexibility in my choices, as they will be made towards the beginning of the research process. Rhetorical analysis is about discovery through research and discourse. Only by

analyzing the articles will I know what I am looking for in ways of attitudes towards women's reproductive health and how it is portrayed in national newspapers.

Non-Traditional Media: Comment Threads

The feminist rhetorical criticism of newspaper articles will be paired with a similar analysis of comment threads from the same articles. Similar search terms and analysis terms will be utilized as well. Because of the sheer number of comments and articles I will be utilizing 1-3 comment threads depending on when I reach theoretical saturation.

These three articles are possibilities for both the newspaper criticism but also for their comment threads:

Persistence is key to treating sexual pain from the New York Times
'Vagina,' once unmentionable, has become a fashionable term from the LA Times
How the 'war on women' quashed feminist stereotypes from the Washington Post

The comment threads range from around 40 comments to over a thousand per article. I will choose only a set or two from each in order to maintain an appropriate scope. What I will look for will be very similar to above and I will use the same signifiers to identify stigmas as well as positive messages. In addition to that I will be looking for individuals telling their own stories of sexual pain or addressing words like vagina. I should be able to tell if the use of online allows for greater discourse over outlets like newspapers or if they lead to further suspicions or inaccuracies.

Validity

This particular research study lends itself to certain levels of validity simply because of its design. Utilizing two types methods shows triangulation through comparative rhetorical analysis of newspaper articles and non-traditional media comment threads. The data also should be able to acquire a certain level of saturation and accuracy due to the limitations in the topic with a moderate artifact scope.

In the rhetorical analysis, low-inference descriptors will lead to a high level of interpretation and accuracy. Direct quotation and exact wording is essential when trying to maintain factual data while removing personal feelings.

Lastly, reflexivity is an essential aspect of any study with personal emotional involvement. Disclosing my personal history is essential to maintain clarity separate from the data collected from my research. It may also be pertinent for me to journal during my time around subjects in order to keep my feelings in check and yet be aware of them during my work.

4.5 Publication Possibilities

The final paper from this independent professional analysis could ideally be published in the Journal and Mass Communication Quarterly, the Journal of Mass Communication and Society, Feminist Media Studies, the Journal of Health Communication, and Health Communication by following the various application processes.

Or:

This paper can also be composed as an editorial piece meant for the newspapers that I will be writing about. I think it would be important to present findings in a way that can be published in the New York Times, Washington Post, and LA Times so that the discourse of women's reproductive health can be furthered in a positive way.

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Appendix B: Recruitment Letter/Emails

To: Fellow Vulvodynia Patients
From: Carrie Anne Durkee, Photojournalist
Date: Fall, 2013
Subject: Advocacy through a Graduate Photojournalism Professional Project

My name is Carrie Durkee and I'm a graduate student at the University of Missouri-Columbia in Photojournalism. In 2009, I was diagnosed with vulvodynia. I had been having symptoms for over a year with no diagnosis. Now, four years later I have had my third surgery with Doctor John Slocumb, to remove further inflammation, at the University of Colorado Hospital.

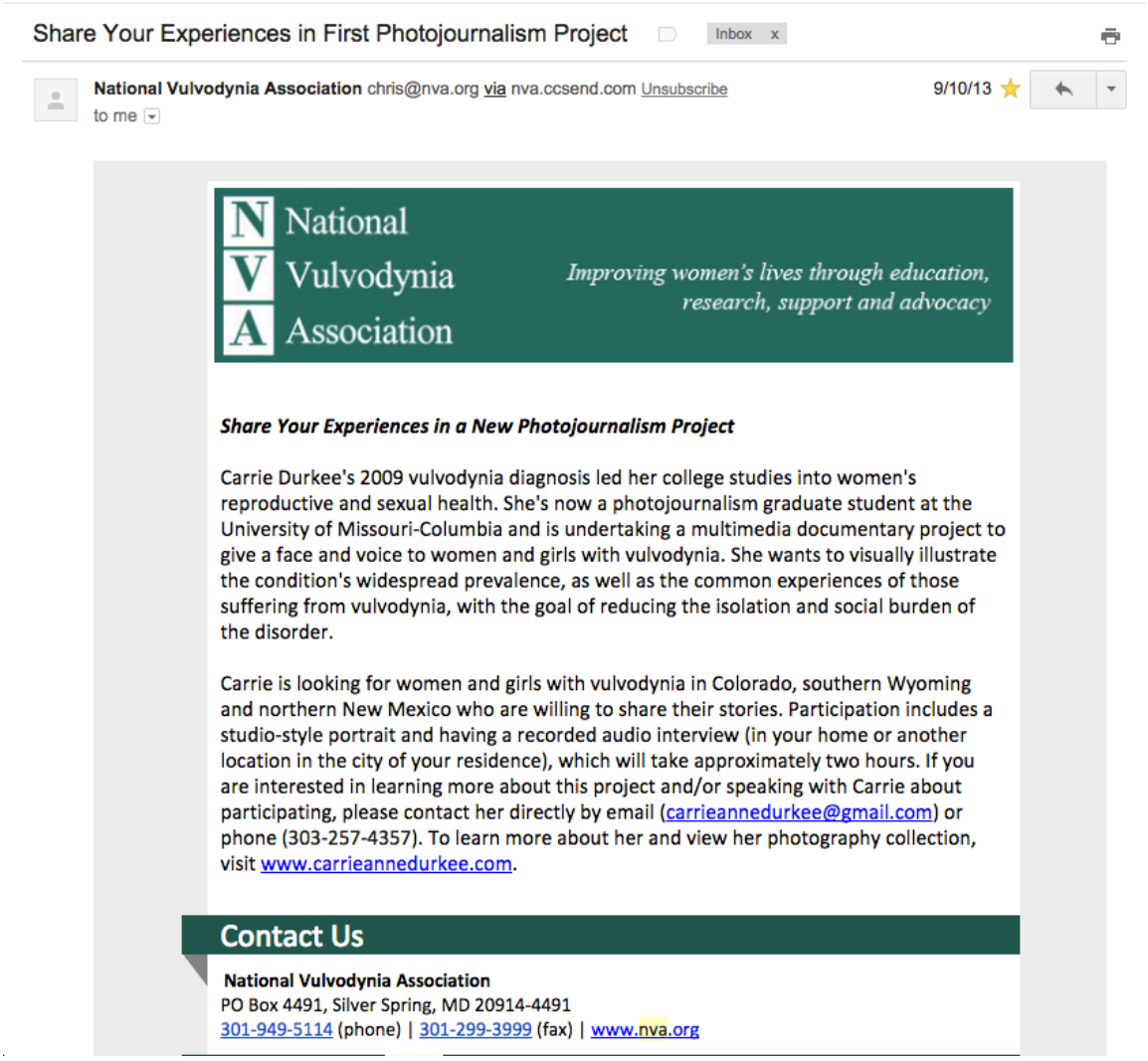
Along the way I've struggled with explaining vulvodynia to family and friends. I've tried to find informative resources in order to learn more and not feel so alone with the pain. The problem is there are very few resources available to individuals. Women's health is not a widely informed topic in the mass media and more information must become available on a wider spectrum of outlets.

To change that, I am exploring women's reproductive health and sexual pain in the newspaper media as well as undertaking a multimedia documentary project that specifically gives voice to those individuals experiencing vulvodynia to complete my degree. This is where I need your help!

I am currently searching for vulvodynia patients who might be willing to talk with me about the possibility of telling their story. I will ask those agreeing to participate to sit for a studio portrait and allow me to record an audio interview of their individual struggle with vulvodynia. This process will take about two hours of their time.

My goal is to help show the commonalities between vulvodynia patients and visually illustrate that 1 in 4 women have the condition at some point in their lives. Each of us have a unique story to tell and it is time to be heard. I appreciate your time in reading this letter and hope there is the possibility of us working together soon.

Please contact me at carrieannedurkee@gmail.com or 303-257-4357



Share Your Experiences in First Photojournalism Project Inbox x

National Vulvodynia Association chris@nva.org via nva.ccsend.com Unsubscribe 9/10/13

to me

National Vulvodynia Association

Improving women's lives through education, research, support and advocacy

Share Your Experiences in a New Photojournalism Project

Carrie Durkee's 2009 vulvodynia diagnosis led her college studies into women's reproductive and sexual health. She's now a photojournalism graduate student at the University of Missouri-Columbia and is undertaking a multimedia documentary project to give a face and voice to women and girls with vulvodynia. She wants to visually illustrate the condition's widespread prevalence, as well as the common experiences of those suffering from vulvodynia, with the goal of reducing the isolation and social burden of the disorder.

Carrie is looking for women and girls with vulvodynia in Colorado, southern Wyoming and northern New Mexico who are willing to share their stories. Participation includes a studio-style portrait and having a recorded audio interview (in your home or another location in the city of your residence), which will take approximately two hours. If you are interested in learning more about this project and/or speaking with Carrie about participating, please contact her directly by email (carrieannedurkee@gmail.com) or phone (303-257-4357). To learn more about her and view her photography collection, visit www.carrieannedurkee.com.

Contact Us

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Appendix C: Interview Questions

1) Tell me about your history with vulvodynia. What have you tried? How does it feel? When was it the worst? How do you help yourself cope on a day-to-day basis? Have you ever had a time without pain?
2) Quality of life?
3) What other symptoms do you experience? Common comorbidities?
4) How does vulvodynia affect relationships in your life? This includes family, friends, and significant others.
5) Most difficult things to do? Most satisfying things in your life? What helps you the most?
6) What advice would you give to other women dealing with vulvodynia?

Appendix D: Transcriptions of Vulvodynia Interviews

Janet Hildebrant, 57 of Boulder, Colorado
Date: 9/21/13
14.13 Minutes

57.1 *If you could just start out saying your full name on here and age and then just give me a little bit about you in general. Like what do you do?*

I've had several parts of my career so I always have to think "okay". So, okay. I'm Janet Hildebrant and I'm 57 years old. I've had quite a varied life.

My first passion was dance. I was a dancer for about 20 years and then while I was doing that I started a personal chef service. Which I did for 18 years and I also started a family during that time, helped my husband through a doctoral program, also did bookkeeping for small businesses, then went back to school to become a high school English teacher. Hated it. Went back to private business and about 5 years ago I started working for the state because I wanted some good benefits and I was a single mom.

And so, I'm still working for the state right now. I work at University of Colorado-Boulder in the sponsored projects accounting department.

2.22.2 *You've been diagnosed with vulvodynia. Tell me about your history there.*

Okay.

Yeah, I never had any pain at all for, you know, the 35, how ever many years I was sexually active until menopause and I guess it was about 3 years ago I started getting pain during intercourse. And I thought, "Oh well it's because I don't have as much lubrication. Menopause is really a drag that way." There's like, it's a drop-off in natural lubrication and so, I tried everything and it just wasn't working and it was getting worse and finally got to where I couldn't even have intercourse at all, so I went to a OBGYN, a woman, and she did the q-tip test and identified that it was my skene's glands which are on either side of the opening of the urethra and then she said well this is where your pain is but I don't know anything about the skene's glad nobody really knows anything about it and I don't even know what to tell you and I don't even know who you should see next. Maybe a urologist.

I just don't know I mean it was completely, ugg, unhelpful so I went to a urologist next and he was pretty rough, um, that was not pleasant. He tried to do a scope up the urethra, um, and it was so painful he couldn't do it. So then (*deep breathe*) another doctor suggested, to me to tell him maybe he should try it by putting me under in case there was, and I forget what it's called now, in case there was this thing up the urethra where there turns into a little pocket of something. Anyway, he

did that. He put me under. He found nothing. Although he tried to tell me it wasn't my skene's glands and he didn't know what it was and so he referred me to a pelvic pain person and I have to admit my, I had this fear that I was going to go and this woman was going to say, "Oh you just need to relax and you know it's all in your head" cause I mean as I said I'm 57 and when I was a teenager and had terrible menstrual cramps that was still the days where they just said, "Oh you're just imagining your cramps" or whatever.

The attitude was terrible so I had quite a bit of fear about that but she was wonderful. I saw Dr. Toya Ellis in Denver through Kaiser and she's just this incredible, incredible woman. She knew exactly what it was. She's seen a lot of it. She told me the different options we had. She did mention surgery but she felt like we needed to look at the other things first. We tried the different topical creams. She also put me on...the medication, I can't think of it right now. It's one of those old fashioned anti-depressants that they discovered doesn't really work for depression but it works for nerve pain and she talked about how I have extra nerves, or whatever. I hated it. It was horrible. (*laughs*) I couldn't stand it. I had such dry mouth I could hardly talk. It was just wacko.

So, I went back to her about 5 weeks later and said I can't do this. And she talked about some of the other things, some of the other procedures I could try. There was something about giving myself a shot everyday for 3 months. And then she said she had done surgery on this particular thing. I think she had done 11 of them. Specifically scooping out the skene's glands. So, I went for that and I had that in February of 2013.

It was, it was pretty successful not completely. One side healed beautifully and the other side didn't quite. One of my, one of the stitches, I guess there were only 3 stitches. But one somehow came out and it's still somewhat painful but I am able to have sex without pain in one position. Which is great because we had just avoided it for so long.

And that's basically my story. Of course another, well either a complicating factor or maybe on the good side, at my age I don't have a lot of sex drive and so sex is not that big of a deal to me at this point in my life. And my husband is great about it and he, to some extent, is the same way. We both have a lot of other issues with our bodies and stuff. But yeah, so.

7.58.8 *Have you found that anything has helped you along the way to cope with having pain or especially being in a relationship? Different ways that you deal with it or make a positive impact on your life?*

8.20 Yeah, one thing that I should say, I'm lucky that mine is mostly. It's called provoked which means it doesn't hurt all the time. However, I can't wear things like blue jeans. I don't know if I ever will again, which, is okay with me. For me, the best

thing is distraction. I sit all day in front of a computer, which is why I can't wear tight, tight clothes but keeping busy is just so important to me.

I've also had a chronic back problem for years and years. And exercise and distraction and doing things and being busy has always been just the best way for anything that comes up in life that's difficult or painful. I mean it definitely, when I first. Before the surgery. I think we went almost two years without being able to have sex at all and it was really hard for me to face the possibility that maybe I would never be able to make love again. It was pretty devastating to think that and think, "Oh my god, what's this going to do to my marriage?" And I have to say it must be so, so difficult to be young and to have it. I mean, if I had had this when I was in my 20s I would have just, I don't even, it would have been horrible.

My husband is just so, so supportive and understanding. I would even go through times where I'd be, I don't know. Maybe, ya know, am I imagining? And he'd be like, "NO, you are not imagining this. There's something wrong and we have to figure out what's wrong and we are going to figure out." He was really, really positive and so supportive. And that too, I think, would be more difficult to find with a younger man who's got, ya know, the normal young man sex drive. Where twice a day is about what makes them happy. But, so did I answer the question?

10.34 *What do find most difficult to do on a daily basis and you said finding distractions really helped you...*

Yeah, well you know. I'm not in that much pain anymore. I guess there are times everyday where I notice it but it's just so much better and just knowing that knowledge. Well, knowledge was the other thing that helped me a lot.

Before the surgery, just having it diagnosed was such a load off my mind. The more information I have the better I can cope with anything. I can't believe how many women suffer with this and it was something that I had never heard of and doctors have never heard of. I find it completely outrageous that it's just buried. It's somewhat typical, I think, of the role of women in our culture. If men had this it would be on all the billboards.

I forget what the question is. Something about daily.

12.02 *Still really pertinent and reminds me of my nurse who's always going on about how if men had this.*

Oh, I know. It's unbelievable.

12.17 *I guess my last question would be do you have any advice for other women or any advice that you foresee that's helped you along the ways. Something you'd like to say to women dealing with this in general.*

I would just say that, you know, be kind to yourself and don't ever doubt that it's real. Do not think it's something that is like this psycho-sematic thing and yes, maybe stress. And I've noticed that stress makes pain worse, but that's true in all body pain.

It doesn't mean you're crazy. It doesn't mean any of that stuff and people who say, "Oh, if you have a positive attitude it's going to heal...that's bullshit. I mean it's not bullshit, but it might help the healing. But it's not all in your head and surround yourself with people who really believe you and understand what a huge impact it has on your life and that you need support. You need a supportive partner. That's so, so important. (*Pause*)

13.41 *Ambient noise*

Annika Davis, 22 from Boston, MA
Date: 1/3/14
21.05.5 Minutes

4.4 *If you could tell me your name and your age and we'll dive in.*

I'm Annika Davis. I'm 22.

26.4 *What we're obviously here to talk about today is having vulvodynia and if you could tell me your history with it? What have you tried? What's worked? What hasn't? Just your general medical history on that and we'll go from there.*

48.1 Okay. So, I've had vulvodynia as long as I have been sexually active. Since I was 16. But, it took me a long time to find out that that's what I had and for a long time, in my past, I sort of thought that pain during sex was just a normal thing that everybody had and that you just sort of had to deal with it and that that was kind of the reality of intercourse. And I came to realize, obviously, that that's not the case. It doesn't have to be the reality.

So after finding that out, I would say when I was probably about 20, I knew that I had something wrong and my pain, umm, comes just from touch. So, if during intercourse or gyno examinations, I get a lot of pain. But luckily I'm not someone who gets it just randomly during the day. I know that is a blessing because a lot of people do. So, when I was about 20 I started bringing it up with different gynecologists and nobody, I was tested for a lot of different things. Different yeast infections, STDs, genital herpes I was tested for about three times and no one, I was testing negative for everything and no one knew why I was having so much pain during intercourse.

And eventually someone referred me to a doctor in Denver who specializes in pelvic pain and that's when I sort of started to figure out what I had and I was diagnosed with vulvodynia. And I started trying different treatments but it was a long and very confusing road to get to that point.

3.29 *Could you describe how it does feel, what the pain feels like and maybe ways you cope with having this?*

So, I have, it's sort of a two part thing, I have sort of external pain at the vulva from touch and then that pain causes a deeper muscular tightening which can lead to just me tightening up a ton. And part of why some doctors thought I had genital herpes was because the tightening would lead to some, like, just cutting and tearing during intercourse which to them looked like herpes but it wasn't.

I've tried a lot of things to deal with it. And definitely in terms of the muscular tightening, that I have found is most helped by me just being in a calm and

comfortable place. Whether it's during sex or during an examination. If I'm, yeah, if I'm comfortable that can go away a lot.

But in terms of the vulvar, just more burning pain, that is something that I've had a lot of trouble solving and I have had some luck with using lidocaine, topical lidocaine. And certainly before an examination I can have a doctor help me use that and it makes things go a lot smoother. But it's hard with intercourse when you're in the mood, like let's get this going, wait a minute I need to get a q-tip and some lidocaine (*laughs*). And that sort of can bring things to a little bit of a screeching halt. So, I've had some luck with that but not a ton of luck.

6.09 *Out of curiosity what doctor did you see in Denver?*

His name is escaping me right now but he's at the university hospital?

UCH? Dr. Slocumb or Dr. Mosher?

Dr. Mosher. Yeah.

That's actually who I would recommend. I see Dr. Slocumb. I've seen Dr. Mosher too.

Yeah, Dr. Mosher was great and it's been hard since I've been living in Boston for a while now and I haven't been seeing anyone.

What do you do in Boston?

I work in an animation studio. I've sort of been, just not, I haven't been having any treatment really. So, that's been kind of hard and I did email Dr. Mosher recently and he sent me to the NVA registry list. So, there is a physical therapist, there are a couple of physical therapists and potentially one doctor in Boston but it's hard, like, when life gets so busy and seeing a doctor gets put on the back burner and then, you know things, treatment, my treatment has taken a little break. So, that's been hard and I need to get back into it. But, certainly finding Dr. Mosher when I did was a, just really, really great thing.

8.05 *Can you talk about how it makes you feel? This is obviously something that people don't see. This isn't obviously, like I got in an accident and had to have my leg amputated or I have the flu and you can tell. So, in that respect how does this make you feel personally as a woman, as something that people don't necessarily know about?*

8.33 I think it's, I mean, it's obviously really hard. It's really hard to live with this very secret and very private pain that even when you do tell someone about it they say "what" I've never heard of that. I didn't even know that was possible. And there's just so little public education about it that it's, it makes it very difficult to

explain and since it's such a private thing it can be very scary to explain it to someone.

And I think a lot of the problem with keeping pelvic pain sort of out of the public eye is that people do come to believe that it doesn't exist and that it's not possible. And that obviously a woman should feel only pleasure during intercourse and that is not the case. And so it's hard meeting new sexual partners who don't even know how to deal with something like that and having to explain it and it makes it, you know. It's hard because it's such a quiet and not talked about thing.

I have dealt with having guilt about having to sort of tell my new boyfriend, you know, "Well I have this thing. So, there're going to be some issues and it is hard." It's not like something that is easy to explain to strangers or acquaintances. It's something that you just sort of have to live with quietly and maybe the people closest to you will know and your doctor will know but it isn't something like a more visible illness that people can see and sort of help you through.

11.16 *Can you talk about how it has affected relationships in your life including significant others, parents, family, friends? Have you been able to talk to parents or friends about this?*

I have. I get better, certainly as time goes on with being able to tell friends and partners about it. My mom has been really supportive since the beginning and she's always been very open with me about body stuff and sex and so having her and having that kind of relationship with her has certainly been really helpful. But until, I mean it's hard when you're a teenager and talking about pelvic pain is really hard with your friends, even with people that you're dating.

I guess I came to learn. I spent a lot of time just not talking about it and thinking maybe I can just ignore it and pretend to be normal because I'm, you know, young. But growing up a little bit has taught me that I don't' want people in my life who I don't feel like I can be honest about that with. So, that's been a really good lesson in terms of friends and significant others. And that if I find someone who I would like to date, who I know that I can be completely honest then that's a good sign.

Me talking about James

13.43 So many men, I feel like, somehow think that they're entitled to having sex just a lot and somehow that attitude makes it really hard when you're a person who can't have sex that often. And when there is a big possibility you might try and it's not going to work out.

As much as that is really sad, that's a really sad reality; it is in a way kind of a nice test whether or not a guy's actually decent. That's like a tiny hidden benefit (*laughs*)

14.41 *Dr. Slocumb and his nurse practitioner Marybelle are always saying, "You know, you gotta bring whoever you're dating here. If you bring him we'll evaluate him." I think they've said they've only been wrong twice when they approve.*

14.59 *Can you talk about how it affects your quality of life? Are there things you find that it affects more than others? Anything that might surprise you that it affected you in a certain way?*

I think that since my vulvodynia is really only affected by physical contact I don't have a lot of day-to-day problems. I know that a lot of people can't even have an office job because they can't sit in a chair all day and they get really bad pain. Luckily, I don't have to deal with that. But everything that is touch related, if I'm going to see a new gyno I have to explain this is a more painful process for me then it is for most people. And then obviously finding new sexual partners, we talked about all that, but other than that I think I've been very lucky that it hasn't affected more of my day-to-day life.

16.27 *Mine is exactly the same way. I totally understand. It's vulvar vestibulitus, provoked.*

16.43 *How do you, are there ever times when you just feel really down about it or it surprises you that it makes you feel not normal, any of those kind of moments? How do you cope with it or help yourself?*

I definitely have moments when it makes me feel pretty down. My whole experience with sex since I first lost my virginity has been riddled with a lot of ups and downs. So, I'm in a place now where I would like it to be more stable. So, it's hard for me when I'm with someone. I dated my last boyfriend for quite awhile and lived with him and it's hard those nights where, you know, I would really like to have good and comfortable sex with this person that I love and that I'm very close with and I just can't and it hurts and I feel like I'm personally disappointed. And I have a lot of trouble getting away from the fact that I'm disappointing him and it just makes me very sad, so I've definitely had those times.

And I think it helps just to choose the right partner and have someone who can say, you know, "It's okay. I'm not disappointed and we'll try again another time and I'm here for you." And being able to choose people that I know will say those things has been the biggest help. But there, I know that there will always be times when I get sad and frustrated.

19.04 *This is your opportunity to say what ever you want to other women dealing with the same issue. So, what advise would you give to women with vulvodynia?*

I guess my biggest piece of advice would just be to be honest with yourself and with the people around you. Which I've learned from experience and I spent a lot of time

not being honest with myself and not being honest with the people in my life and that made it a lot worse.

And when you're not being honest with yourself it can be hard to go see a doctor because you don't want to admit that you have to deal with this thing. But seeing a doctor and telling your family and friends and significant others is so important. Not just for yourself but also for letting people know this is a thing and I guess that's my other piece of advice is just participating in projects like this. Doing projects like this, sort of spreading the word and letting people in the world know that a lot of women deal with this and that it shouldn't have to be a secret private, shameful thing.

So, yeah I think I would say just honesty and openness are very important. And choosing people to become close to who will make you feel better and not worse about it.

Hannah Sullivan, 22 of Hugoton, Kansas
Date: 10/27/13
22.29.0 Minutes

15.8 *So, Hannah, how old are you?*

I'm 22.

Just graduated and I am the youngest person by far employed at this new plant. So, it's kind of fun to be a girl and the youngest person. It's kind of weird.

1.42.4 *Tell me about your experiences with your pelvic pain. You went and saw a specialist, so tell me about that experience.*

Okay, so the story behind me is when I was about 15 or 16 I started experiencing itching. That was the only way I could describe the symptoms to any doctor. It itches down there. You know, it itches in my pubic region.

First went to a health clinic and they did some tests. Oh, maybe it's a yeast infection type, type idea. All right, so cool I have a yeast infection. I'll take the little pill and you know see if it works in two days and all that jazz. So, that didn't really help and the symptoms I have are not anything that I can't live with. It's just there. So, riding a bike or wearing tight pants is just uncomfortable.

From there, a couple years passed. I finally ended up going to a gynecologist who was well recommended and of course, she did all the normal tests. The pap smears, and even took a sample of my skin's tissues wondering if I had a fungal infection on the outside of my skin. And so, you know, that came back with maybe you do have a fungal infection because we all have yeasts and things living on our skin. That's just how it is. So, I took some more medication. Took a months worth of anti-fungals systematic and that always scares the heck out of me. I grew up on a farm. I like to eat good food. I like to take my pro-biotics and just taking all of that medicine is not something I enjoy doing to my body.

So, that didn't help and you know, at the doctor one time she did say, "Oh we could send you over to a physical therapist for pelvic floor rehabilitation." And at that time I had become sexually active and that's when I kind of found out that sex was not comfortable. So, that was her push to say, "Oh well, you could fix maybe this problem with going to a physical therapist," and that was all she said about it. And so I thought I don't need a physical therapist. I'm 19. I'm in great health. I like to run. I like to jump. Why would I need a physical therapist?

So, that lead nowhere, right and that's the thing I probably should have followed up on. My experiences with doctors, the gynecologists have always been kind of not engaged enough for me. They're going to do the normal checks and the normal

things and maybe they don't ask quite the right questions and then it just leads to a dead end.

So, finally I started reading up online. I looked into candida. The systematic fungal infections. I did, I must have dieted for six months. Taking out the sugar, the wheat, the yeast, the everything. I'm skinny as it is and that makes me even more skinny. And that didn't really help.

The next step was I finally found the NVA and started saying, "Hey, you know these are very like my symptoms." Pain with sex. Some sort of irritation down there. I just need to follow up on this.

So, living in Hugoton it is very difficult to find a specialist doctor. So, I've been sending emails to Michelle at the NVA. Can you send me the spreadsheet of the doctors in Colorado, or Texas or Kansas? So, I finally got an appointment with a doctor in Denver. And he was like the dream doctor.

You go in. He's soft spoken. He asks all the right questions. He nods like he understands that you have these symptoms and they're not just dumb. They're not just dumb symptoms. They're not just in your head. They're symptoms that are actually legitimate symptoms.

That was just a month ago and it turns out I have spastic pelvic floor muscles. He wasn't quite so sure about the itching which has always been the thing that has always confused everyone. Why do you itch? You don't have a vaginal infection of some sort. So, I saw him. He recommended that I see a physical therapist for pelvic floor rehabilitation. So, I will be driving to Amarillo in December to go to that because it's, just have to find a doctor within five hours of driving to see.

I've played with some medical dilators. I'm trying to work on that. But it's very hard to try and help yourself when you don't know how. So, I'm hoping the physical therapist will. I've got a two hour session with her, so hopefully she will give me some tips to do the right stretching and help myself heal. Because I think it's going to just be that. I can't go driving three hours every week one way to see a doctor. It's just going to be me trying to figure it out for myself. And I'm willing to do that. I'm willing to put in the time because I want to be normal, I guess, and have nice physical sexual relationships with people and not be, you know, yeah...It's a very opened ended unfinished sentence.

7.56.7 *What doctor did you see in Denver?*

He's with the Pelvic Solutions Center. His name is Dr. Lukban. And there are two doctors there. Supposedly both are very good.

Chatting about docs, UCH etc.

Urogynecologist
Accreditation for pelvic floor work in the last year. First time offered for specialty.

Slowly becoming well known that these things occur but really we need to spread the word because all of the doctors I've seen, they never would have imagined (9.22.1) something like pelvic floor disorders.

More chatting about my research.

10.25 *You mentioned that your pain started at 16 and how's that affected, I mean these are very formative years. Mine started at 20 and I'm 25 almost 26. So, it's very formative years and how has that affected your sense of self, how you feel about things, how you have relationships?*

10.59 That's a very good question. My first boyfriend was a lot older than me and I don't know how my parents let me even date this guy. Now he's 5 years older than me and I was 16, 17 years old. But Ben was just a sweet heart. There's no other word for him.

I've been so lucky with the guys in my life. Because, you know, I never had sex with Ben probably because I was young. But my next boyfriend, Alex, he was my first. He was always (*sigh*) so understanding about things. And actually sex was not that bad for me. So, if I practiced enough it was alright and that was helpful. We were very frustrated that I could never have pleasure when he had pleasure because it's just not there for me yet. I didn't know at the time whether or not that was just me not knowing my body well enough to get there or if it was part of the itching problem.

That's, it's kind of how those relationships went. But, I was just always so lucky to have the guys that I did who would understand.

As far as sense of self, I'm very lucky in my physical stature. I am skinny and I match all of the modern day stereotypes for pretty woman so that has never really been a problem but I could imagine not being myself and feeling very uncomfortable with who I was.

12.57 *You mentioned the wanting the normal, what is normal?*

What is normal? Yes. Women are supposed to orgasm at some point during sex, right? That's supposed to happen I assume, otherwise why would we have sex? So that never happening was very frustrating and why, why couldn't I have that?

I'm hoping I can get myself to the point where sex is very comfortable and normal and I can have a normal physical sexual relationship with someone.

13.44 *Have you ever been able to talk about this with any friends or family or do you feel like it is something that you can't talk about with others normally?*

My mom and my sister, I have a younger sister, they've always been so open. So, my mom gave the sex talk when we were 12 or whatever and from then on she was there to say, "Hannah, we'll go to the doctor because you have these symptoms." She also had a friend who had very similar symptoms to mine so I talked to Burt a couple times and Birdy was, she had the candida symptoms. She was the one who got me on the diet idea because why not, you know? You have these itching symptoms and so do I so we'll try the diet.

As far as with guys, yeah it's always been kind of awkward the first couple times to talk about it at all. But like I said before I have been very lucky with the guys in my life. And even recently I've talked with my grandmother about it and she's been so sweet. She finds this newspaper article and sends it to me like, hey, maybe you have this. And I'm like thanks grandma but not really. So, yes, I've been very lucky with that.

As far as talking with doctors about it, that's been a whole different thing because you can say in my case, hey it itches down there but that is totally vague and unspecific. They have a very difficult time trying to figure out what I'm trying to tell them and I'm finally learning the lingo. The vulva. The outer lips. The inner lips. The vagina and it's all different names for these different parts. So, I can say hey I have this part of my body that itches and this other part that hurts when I have sex. And now I can say that, but when I was younger all I could say was it itches, do something about it please. And no one could really take that and run with it the way I needed them to do that.

16.06.9 *Are there things in your life that help you cope with kind of the different feelings and the having to go to the doctors and the symptoms? Are there things that work for you, whether it's medically or emotionally, things like that?*

Yeah, so going to the doctor. That has always been something I don't want to do. Maybe it was because of how I grew up. If we got sick as kids we just stayed home and got better on our own. It wasn't like alright you're going to take the pills and the shots or the whatever to feel better. You let your body do the work.

Going to the doctor is just that. It's going to the doctor and you've got to set out some time for it and say alright I'm going to the doctor. In the past 5 or 6 years that I've had this I've really not been to that many doctors. It's when I can fit a doctor in. Which is probably not the best way to go about but going through college, I didn't have a car the nearest gynecologist was an hour away so it meant borrowing someone's car. It meant going to the doctor. Making the appointment. Taking out time from school and that's just not something I had as an engineering student was time to go to the doctor, so I did make a couple trips and it went no where.

Now that I'm here I don't know. I'm in the middle of nowhere, so going to the doctor is harder.

But what makes me feel better? I think that's more the main question. I always feel comfortable after a nice hot shower. Birde gave me the idea of mixing a little bit of tea tree oil with aloe vera jelly so just a drop of tea tree and a squirt of aloe vera. You mix that up and it's this kind of cooling effect. So you put that on and that feels good going to bed.

Emotionally, you know, it doesn't other that the physical and the sexual relationships that I've had. (*sigh*) Those were such nice relationships that I didn't have a problem and I do get down every now and then when it's when it's the next step of researching. When the doctor has said take these pills for 30 days and I take them and nothing happens. That's like, alright, it didn't work again so now where do I go and the internet has been really helpful with that but the internet can be so misleading because you put in your symptoms and you come up with all these ideas and you never know. Some of them are bogus and some of them are just like, "Why should I have that condition? I shouldn't have that condition."

So yes, I feel down after something doesn't work but you carry on and I'm rambling I think. (*Laughs*)

19.28.6 *I guess my last questions is there any advice for other women out there who maybe experiencing something similar? Any kind of words of wisdom you might have for others?*

I think that the biggest words are just be patient because with how quiet we are about these kind of things as women you really need to be proactive in trying to find a solution. But you also need to be patient when the solution doesn't arrive after one doctor's visit because otherwise you'll just get down in the dumps and you won't keep looking. You'll say, "Alright, I have this problem and no one knows what it is so I'm just going to have to live with it for the rest of my life and that's not how it should be."

We all should be able to find the solution to that problem though. Otherwise, yeah, use the Internet and try to find out what you have because sometimes the doctors, they think they know and maybe they do and maybe they don't. And that was something that as you grow up you look up to your parents, they know everything, you look up to these professionals. They know everything and now, becoming a professional in the work force, you don't know everything and interacting with these doctors you really have to understand when they say "I don't know what it is" because they don't and it's nice when you find that doctor who's going to go the extra stretch to help you out a little bit.

I just called a physical therapist in Garden City, which is an hour away, and he said I know a little bit about pelvic floor but not very much so let me call my friend in St. Louis and she knows more and she can point you in the right direction. And he gave me his personal cell phone number so I could call him and it was just like, wow thanks. That's great. So, there are the ones that go the extra mile and there are the ones that do their job when you're at the clinic and that's it.

22.07 *Ambient Noise*

Lacey Enderle, 35 of Durango, CO
Date: 11/10/13
21.22 Minutes

4.7 *If you want to start out saying your name and age just so I have a reference.*

My name is Lacey Enderle. I'm 35 years old.

22.2 *What we're talking about, tell me about just generally what you do, when you first started noticing symptoms, your history with vulvodynia, those various things. Give me a brief overview.*

Well, let's see, it started when I was 19 (*pause*). It was pretty sudden. It was pretty much an overnight thing where I just started feeling just constant burning, stinging, pain. Went to the doctor and she did cultures and tests and said everything was normal, everything was fine. She didn't know what was wrong with me. And so I tried to self-medicate a lot. Just over the counter creams, just trying to take care of the pain and nothing really helped. It would come and go.

I'm 35 years old right now. So it wasn't as bad as it is now, or as it was a year or two ago, but when I was 19 it would just kind of come and go. It eventually just relaxed and it would come back and as the years went by I would notice each year it would get more and more painful. More and more intense. It would last longer. It wouldn't have periods of remission.

And so I didn't have health insurance all those years. I didn't really have health insurance until I was 28 and that's when I really began to see the doctors. Really dug in like I need to figure this out and I probably saw 7 or 8 doctors total. And none of them knew what was wrong with me. They would just diagnosis me with just inflammation. Really couldn't prescribe anything or help me out so I just kind of dealt with it all those years.

I didn't have a lot of sex throughout this whole time. I just avoided men because I knew that sex hurt, so that's definitely back to my sex life since I was 19.

So, I was 28. I got health insurance, started seeing doctors, and then it wasn't until I met my husband about 4 years ago and we got married and I realized, "Okay I can't even have a normal sex life with my husband." Like I really need to get serious about this and really search until I find a doctor that can diagnosis me. I found, I went to about 2 doctors that really couldn't help me out, and then I found one in New Mexico, in Farmington. And she said, "Okay, I'm not sure what's wrong with you, but I'm going to figure it out."

She was the first doctor after all these years that just didn't look at me like I was crazy, acknowledged that she understood something was wrong with me, and she

actually wrote a book, she wrote a book about vulvodynia. And she diagnosed me with vestibulodynia. She was amazing. She was the first doctor to put a name to it. She said, "I'm going to do whatever I can to help you." And she did. She prescribed creams, she helped me do lidocaine/gabapentin cream to help with the pain. She prescribed estrogen cream. They actually have a pelvic floor therapist in their office who does the interstim machine, biofeedback. So we did that and that helped a lot. So, that helped me understand that a lot of it was muscular related as well.

Kind of through meeting her, going through that process, she helped me as much as she could but she really encouraged me and gave me that boost of hope that I really needed at that point in time to search for a specialist in it. And that's what led me to New York to Dr. Harris who specializes in vulvodynia and through meeting with her, she's the one that performed the vestibulectomy which made me 80% better. I also found a specialist in Phoenix, AZ who does Botox treatments every 3 months and that makes me about 95% better.

I went from 19 years old getting worse every year, to excruciating pain, to finally getting health insurance, finding the right doctors, and now I'm pretty pain free. It's really amazing now that I think about it. (*Laughs*)

5.18 *One of my questions is what kind of limitations did the pain cause you? Obviously you mentioned wanting to foster and all that stuff and realizing you needed to take care of this before you could put your attentions on that. How did that affect your daily life?*

It affected my daily life (*sigh*) before my surgery, before my treatment I mean everything was affected. I mean sitting down, on a pain scale of 1 to 10, just sitting down was a 10. Any kind of contact, anything that touched me. Clothing, anything just felt like razor blades were cutting me. Walking was painful. It was hard to get through a day's work because I would put a smiling face on.

The pain alone was so physically and mentally exhausting that I was just exhausted and depressed. But it was just like a fight to get through everyday and I had to put a lot of things on hold.

Like at one point in time I really wanted to go to physical therapy assistant school and I had finished all of my classes to get into the program and I realized there's no way I can sit through a six hour day of classes in this pain. And so, it's just really inhibited and stunted a lot of my goals.

I've always wanted to be a foster mom. I've thought about that since I was a teenager and I knew that there's no way I could do it, there's no way I could run around and take care of a kid in this pain. All I can do is lay in bed and just suffer. And so yeah, it definitely was very inhibiting in every aspect of my life until I got better and now that I'm better. I'm not in pain as bad at all. I have the energy back.

I have the psychological health back where I'm happy and I look forward to my days and I can function now and I can function. If it wasn't for this surgery, this Botox, I would still be struggling. I wouldn't be able to pursue my goals of being a foster mom.

7.43.9 *Off of that, I was curious, because this is something I haven't gotten to talk a lot about with other women either, kind of dating and getting married with the chronic pain. How did that go?*

Through my 20s… (*dog sounds*)

8.47 So dating and life, oh man it definitely affected my dating life. Of course because I got it very young, I was a very strong Christian, so I was never very active sexually as a teenager but especially when I turned 19 and the pain kicked in (*puppy whining and put outside*)

9.23 A lot of it was my religious background. I was trying to remain abstinent anyways but when I would get a boyfriend and try to have sex it just hurt. And so pretty much all trough my 20s I just kept to myself.

I didn't have any real serious boyfriends. I just avoided having a strong sexual relationship with anybody because I knew that, I knew something was wrong but I didn't know what was wrong. And that's just kind of how I lived my life.

I just kind of survived. And then when I met my husband and we got married and obviously became sexually active that's when I really hit reality that this pain is not just going to go away over night. It's not just going to go away by itself and that it is affecting my new marriage because, to be frank, he felt like a razor blade going in. And so luckily he was very supportive, very understanding, and really has been by my side through this whole process of finding out what is wrong with me and getting to a place where pain-free sex is possible.

11.09.02 *How's that also effected, you mentioned new marriage and being married 3.5 almost 4 years now, kind of the stressors, the difficulties? How it makes you feel, perceptions of how it makes him feel?*

It's been a challenge. Cause we've basically dealt with this from day one of getting together. Cause my pain has been there. It's been a challenge. When we first got together I think I was still living in a denial state because I had seen so many doctors and they told me there was nothing wrong with me. I was just kind of like accepting the pain and just thinking okay sex is just supposed to hurt.

And then it wasn't until I was with him and finally expressed to him how bad sex hurts that really, like I said, brought it to reality that something's wrong. I need to get this taken care of. I need to search to find a doctor who can help me and

although it's been nice, we've really grown closer as a married couple through these challenges. There has still been a roller coaster of emotions including guilt, shame, anger, confusion. You know it's been very difficult to deal with this emotionally because I think the biggest thing that I think effects women is that it makes you feel less than a women. It makes you feel inadequate. And I think that's still the hardest part for me to cope with is the feelings of inadequacy.

And my husband has actually helped me with that. He's helped me see that even though I have vulvodynia and I've dealt with these pain issues and I can't, you know I have to be careful with sex, he's really helped boost my confidence that I'm still adequate. And that's been the biggest part.

It's also been a burden, you know, financially. That can be difficult to deal with. We've had to prioritize our money based around my medical issues, based around the vulvodynia, based around going to the doctor. Vulvodynia is just kind of dictated a lot of things and infiltrated every part of our marriage, but like I say we've actually grown closer and stronger because of it.

13.55.2 *I totally can understand that.*

That inadequate feeling is the worst.

Yeah, not feeling normal as far as, I always tell James I just want to feel normal. But he's like it's there and you have to deal with it.

Like I'm a woman I'm supposed to be able to enjoy pleasurable sex with my husband and I can't so it just makes me feel like (*sigh*) so inadequate because it's not like pain in your arm or pain in your neck it's pain in the most private feminine part of your body and it just affects, you know, how you think of yourself and that's a real challenge to overcome

14.47.0 *Were you ever able to talk to your parents, your mother, you mentioned your sister came out with you to NY, friends about this condition?*

Yeah, my sisters, I have 4 sisters, and through the years I've told them I've got pain. It hurts. I've been able to definitely share with them even though I didn't know what to call it or what to say it was, but yeah, my mom and my sisters have known all these years that I've got pain. Something's wrong. I was definitely able to talk with them at least.

With friends, I didn't really talk with friends because you know that point in time I didn't know what was wrong with me and I felt shame and I felt abnormal, so I was too afraid to tell people that I wasn't really close to or didn't really trust.

15.52.1 *Did you grow up here in Durango?*

I grew up in San Antonio, TX. I was born and raised there. I moved here in 2006 to get away from the heat. It's terribly hot in Texas, so I moved here in 2006 and that's when I got into the medical field, got health insurance, and that's kind of what started this whole years of figuring out what's wrong with me. And then obviously being in Durango it's a little harder to find doctors. *(me in here)*

16.38.8 *Things that have helped you try and keep hope and things that have been positive and satisfying during the years of difficulty? Were there any particular activities, things, experiences that really helped you cope?*

I'm a pretty stubborn person. I think that that has been a big part in getting through this. I think I was just meant to be born a very stubborn person because if I wasn't I think I would have given up a long time ago.

I've never been suicidal, although I can see how some women could be brought to that point. It's a very excruciating, chronic pain to deal with every day and sometimes you just wonder if life is even worth living because you can barely function. I definitely can see how some women might feel suicidal; I always was just stubborn and was like you know what I can get through anything, I'm going to get through this.

As far as real true coping skills, I just keep busy. Even though I was in pain I just kept busy. Cause there was a long phase where I think I was in denial. Doctors were telling me nothing was wrong with me so I had to believe nothing was wrong with me. And it's just this weird psychological trick I had to play on myself. I kept busy. I worked full time. I had friends. I had a lot of fun. And in the back of my mind I was just suppressing this pain, just ignoring it. Pretending it wasn't there. I don't know if that was a good coping skill but it was a survival coping skill.

And then once I got a diagnosis and I was able to face and really understand and realize what's wrong with me and not live in denial then it was just hanging onto any thread of hope that I could find. Whether it was a book. Whether it was a cream I might be able to try. Whether it was a new doctor I could go see. In all my research any, any thread of hope I could hang onto for possible relief and this pain I just held on to it. Then I just became very fierce in search for a doctor or surgery or whatever would help me. Even when I felt hopeless I just hung in there and told myself it's just got to get better. Just hang in there.

19.33.6 *Off of that, my last question that I like to ask is do you have any advise for other women who are searching for answers and are trying to deal with the pain and don't know what's going on?*

Just like I go back to the word hope, you know hope is a very, very powerful thing. It really is and in the moments where you just feel like there is no hope you just got to

keep searching, keep going to different doctors, keep reading books. Keep reaching out. You just got to keep reaching out because you may not find a 100% pain relief but it's possible to find enough pain relief that you're not in excruciating pain every day. Like for me after my surgery. I'm 80% better and that's good. I can deal with that. You just to hang in there. There's hope. You've got to keep searching. You will find relief. You just can't give up. Just don't ever give up.

20.54.2 *Ambient Noise*

Katelyn Gunderson, 28 of Centennial, CO
Date: 2/23/14
28.03 Minutes

42.0 *Just for starters if you could say your name and age so I have that on the recording.*

I'm Katelyn Gunderson and I'm 28 years old.

58.4 *If you could sum up your history with vulvodynia, your medical history a little bit for me. And some general stuff about how that has affected your life.*

It started when I was 16. I had my first pap smear because I was on birth control and the doctor wanted to get a baseline before and it was extremely painful. I ended up crying and I didn't know why or what had happened or anything. I also have PCOS, which is why I was on the birth control. I waited until I got married at the age of 22 to have sex and from the first time it was extremely painful. Muscles were just so tight I could barely even have it at all. From there I saw a gynecologist who told me, "Oh just keep trying," and I said okay.

So I kept trying and I did research and found information about vaginismis. So I got the vaginismis kit and the book and I did the dilators pretty much every day for a year. All the exercises that go with it and the pain decreased a little but it was still there. So I went to a fertility doctor for my PCOS and she diagnosed me with vulvar vestibulitus and she gave me lidocaine to try. She said try this and see if it helps. It just burns and then completely numbs you pretty much, so it's like a big band aid that does nothing.

Then I went to another gynecologist who put me on amitriptyline. I was on it for about three-four months. I got up to 125 mg, which is a pretty high dosage for that. Did nothing for my pain. She wanted me to try physical therapy. I was leery of it. I didn't think it was going to work. So, I found a natural-path. She's an OBGyn/NP slash natural-path so she was able to prescribe me hormones and stuff. So I tried estrogen from months. I got off birth control. I tried progesterone, which actually makes it worse. Lets see and then I went to another gynecologist, she gave me topical gabapentin. She gave me topical steroids. Both steroids are extremely painful. It just irritates the tissue more than anything. The gabapentin did absolutely nothing for me. Then I went to a different gynecologist. He told me to try the low-oxalate diet and I said no. I don't believe it has anything to do with it but thanks. And I said, “Well, what about my hormones?” And he said, “You're too young for hormones, you don't need any hormones.” I’m like well I'm on birth control and I have PCOS, so I do need hormones.

I'm trying to think what else I've tried. I did go to a physical therapist a couple times and I kind of thought it was a joke. She said that she would barely put pressure and

it's not supposed to hurt that much because it can't get better if it hurts that much. So I would say, “That hurts,” and she would say, “I'm barely pressing.” So I'm like okay, I can do this at home for free (*laughs*).

Then I found Dr. Joseph Brooks in Phoenix. He did a phone consult with me. He told me to get off birth control. Try estrogen. So, I did that for about 8 months again and I'm like it still hurts. Well, you need a biopsy to rule out autoimmune disease, so I got a biopsy from another gynecologist. Came back fine, it just said it was thin and irritated pretty much, which is what's to be expected.

So years went by, more treatments, nothing. I finally had the courage to go get the surgery last June (of 2013) and he did a partial vestibulectomy and about a couple months later I was still having pain and it was burning and he was concerned because it was burning so much and I was using estrogen, which should be helping. So I had to go back down and see him and he did a yeast culture and it was a bad yeast infection after the surgery, which happens just because of surgery and bacteria and moisture. It's common after surgeries. So, he put me on boric acid suppositories. I've been doing that every since September. I did get a yeast culture in, a couple months ago, it came back negative.

But I still have pain so I continue to use the boric acid and he wants me to use a topical estrogen with testosterone. So I've been using that along with the boric acid. My pain is getting better. But it is possible, he said, that I may have to go have additional surgery to maybe remove more tissue. He does not use the vaginal advancement technique and I wish he would have because that's where most of the pain is, is at the 6 o clock, the bottom position. The rest of it is better so it's possible he didn't remove enough nerves. I may have to go back and see him and get more surgery but he's a wonderful doctor. He was voted the most compassionate doctor in Arizona in 2008. He was absolutely wonderful. I was terrified to get the surgery even though I was willing to do anything to get better. I was terrified. Because I don't like hospitals, I don't like needles and blood, and all that stuff even though I work at a doctors office.

But I did it and I'm glad I did it. Through having this, I mean technically I’ve had it probably my whole life. I was probably born with it. The congenital neuro-proliferative vesitubulodynia but it is a snowball. It causes muscle spasms, pelvic floor dysfunction, yeast infections, painful urination. I cannot take any type of birth control. I can't take any type of progesterone because progesterone thins the tissue of the vestibule and causes more pain so my surgeon told me if I got back on the pill I’d have a 60% chance of my pain coming back which is extremely difficult for me having PCOS. I can't regulate my hormones without it. So, that has been a huge struggle.

I was married for almost 5 years. It was (*pause*) a challenge and it's been the hardest I’ve had to deal with my whole life. Just not being able to talk to other

people about it ,like you had said the social burden and isolation that it causes. And people just don't understand because even though it is a really common thing no one knows about it and I think there's a lot of women out there that have and don't want to talk about it and I think I've gotten past that. I've been able to tell people at my work. I'm like I'm not going to hide this any more. This is who I am. This is a part of me. This is a medical condition and it shouldn't, it shouldn't isolate me more than it has to. But it is, it's a burden.

It's suffering that you have to go through by yourself unless, I mean, unless you have a great husband. My husband ended up cheating on me and we got a divorce. So that was probably the hardest thing, being with someone. Giving yourself to someone even though it hurt. Even though it killed me every time (*crying*) and then to have him do that to me.

Um sorry (*sniffle*) um God has helped me through everything and (*sniffle*) he wouldn't give me this if he didn't think I could handle it so I know that I can handle it and that in all honestly it's helped me to understand other people's pain and be more compassionate to other people especially working in the medical field. I hate to see other people in pain because I know. I know what it's like. And right now I'm starting to date again and it's extremely difficult because guys want to talk about sex and guys want to have sex and I don't know when to say to them, "Hey, I can't really have it," and I never know what they're going to react and what they're going to say because it's nothing new to me. It's just who I am. It's a part of me and I've accepted that but it's really hard in the dating world to say, hey, I can't do certain things that I know you want to do.

So, I'm still learning what to do with that. I don't know when to tell people if I'm dating them but luckily I have my parents, went with me to Phoenix. Supported me the whole way through with my divorce and the surgery, which was amazing because you need support.

12.35.2 I think I've seen 10 doctors. I've tried every treatment there is except for the injections. Like the nerve blocks because I think it's temporary and they don't necessarily work. So, it's just right now I'm at the point where I'm trying to just continue to heal from my surgery, get the tissue completely healed if possible, and not have to go get more surgery. And I'm trying to motivate myself to the dilators and work on my muscles but I'm sick of it quite honestly. I don't want to, I don't have motivation to it. I'm like I've done this, I don't want to keep doing it. So, that's where I'm at right now.

13.33.6 *Wow, I actually have a ton of names I'm going to have to give you because what you described actually could be very surgical again and Dr. Mosher or Dr. Slocumb could definitely help you out. And I was glad to hear that they recommended the testosterone cream as well (blah blah sister).*

14.18.4 Yeah, I mean the reproductive endocrinologists I've seen, they ask you do you want to be pregnant or not. That's pretty much all they ask you. You're either on birth control or you're on fertility drugs and I'm like well I can't take birth control, so I mean, there's other options and I'm taking other medications...

(me talking about Heather and Kate)

15.23.5 That's another thing no one knows anything about (*dog growl, talking to puppy*)

15.54.3 So yeah, I mean with having vulvodynia and having PCOS I kind of, I always wanted to be a mom. I always wanted to have kids. And I kind of let go of that. And had to just say it's possible I won't have kids and (*puppy*) and that's okay. I've accepted that and if I want to have kids I can adopt and at least it's a guarantee that you get a child. I really don't want to have to go through fertility treatments and all that because it's not a guarantee. And it's still just as expensive. After my divorce though, I don't know if I really want kids. I can't imagine having kids and having to see my ex-husband on a daily or weekly basis so that's, it terrifies me to have kids after my divorce but I have my dog and she's my baby.

16.53.5 *I understand my puppy's my baby. My friend in Italy who just got diagnosised with PCOS so desperately wants a kid but she doesn't want to go through fertility treatments because it wreaks havoc on your body so they're going through the adoption process. Which hey, you know it's one way to do it*

17.10.3 There're millions of children who don't have a mom and dad so why not?

17.15.5 *What part of the medical industry do you work in?*

17.18.8 I work with a family practice doctor's office. I work up front so a little bit of everything. We see everything. We see infants all the way up to if you're 100 years old. From being sick to physicals to everything. Lot of sick people but you kind of just get used to it. Especially during flu season.

(me yammering about various health issues)

18.15.5 We had a patient that came in and she had strep on her vulva.

(more yammering)

18.42.3 *You hit a lot of the things I typically ask. I would like you to talk about maybe some support you've found in your life. You said your parents, you've been able to talk with them and they came with you down to Phoenix. How its affected maybe friendships, relationships, family and in positive ways, how you've been able to get help?*

I did see a counselor, um, just to deal with the anxiety of it and she helped somewhat but then I ended up going through my divorce at the same time so the focus kind of changed. But yes, my parents have always been there for me. Everyone in my family knows about my condition. My eldest brother in Texas texted me the morning of my surgery, "Good luck, I hope it goes well," and my other brother's very supportive. I think a lot of people just don't know what to do. They don't know what to say. It's almost like cancer, like, I'm sorry that sucks. I can't help you with anything. But I write. I write poetry. I write in my journal. And that's probably my biggest outlet for just getting it out.

I could talk to my ex-husband about it but he wasn't emotionally available enough to give me back what I needed. So it was, it was just me a lot of the times. I would say in all honesty the most support I got was from God. It's just encouragement knowing that he's there and he's going to help me and he's going to get me through it.

I struggle with a lot of things, with depression, with anxiety, with social anxiety, and now with chronic low-back pain. Just daily activities, just sitting can hurt. I'm not really too sensitive with clothing as some women are. I can't ride bikes though unless I want to be sore for a week. I think the biggest support is just and honestly is just from God and knowing that he gave me this for a reason. I don't know why but he did and I am the type of person that if something happens to me I want to know everything about it and so I've done so much research on it and every time I go to a doctor's appointment and meet a new doctor I feel like I know more than they do about it because you have to.

You have to be your own advocate unfortunately, especially with this condition because no one knows about it. There're doctors who don't know about it and OBGyns that don't know about it which just astonishes me. Because it's always existed but you know, until 1985 it wasn't an official diagnosis, which is funny because that's when I was born. But I think just personally, for me, writing and just being encouraged by God and my family, just know that they're there for me no matter what and I've met friends. I have friends that are actually patients at my work and they have neuropathy and they know. I have a patient and friend and she has neuropathy in her clitoris and a lot of others in her body and that just started us talking and she's in her late 50s now, but I've learned to just be more open about it and tell people. I don't want to be scared to tell people any more. I want people to know and I don't want the social stigma to be with it anymore. Especially just knowing how isolating it is for you and so, I actually recently went on a date with a guy and (*laughs*) the date did progress and um, I mean it didn't hurt as bad but it still hurt and it's hard to, I think that's the hardest part is to stay focused and say I'm not going to get disappointed.

I'm not going to do that. I'm going to say, "Okay, it didn't hurt as bad so that's a good thing." Like baby steps but I've left doctors offices crying, I've left doctors offices with suicidal thoughts because it's just hopeless. I mean there's no true cure for vulvodynia. And like you said there's 100 different things that can cause it and you don't have just one of them you know. It may have started with my nerves but then it goes to your muscles and then it goes to your brain and then it goes to, and I think with sexuality too it's so difficult because it affects you emotionally, physically, spiritually, sexually, and when you add in the factor of pain it just creates so much more havoc. Sex is just difficult and it shouldn't be that way. And it's not portrayed that way in society but it's a reality.

24.47.7 *The one last thing I would like to ask you is what advice would you give to other women? It's your opportunity to say you know here's what I've learned. Here's the one thing I've really learned and you should stick to, what would that be?*

I would say first do your research and know exactly what you're talking about before you go see a doctor. And do your research on the doctor too. And if you can do a phone consult with them to get a brief idea if they know what they're talking about or not because it's a waste of time if you go to a doctor's office and they really don't know about it and they claim they do.

I would say find a doctor who is, has an aggressive approach, who's not willing to just slap on a band aid and say here numb yourself or here try a pill. I want someone, you need to find someone, that knows what they're doing, who knows what they're talking about but you have to know to. You have to be your own advocate. Especially with this condition and I think to utilize the NVA as well as finding other people if you can.

There is so much stuff online about suffering with vulvodynia; there are books about it. I think that's probably the best thing to do. In all honesty I've talked with a couple women on the phone who have it but I've never talked in person who has it so just finding someone. I think can be helpful in so many ways to be like, you know, exactly what I'm going through and you can relate to everything I'm saying and I won't feel like this weird person that's just going through this horrible disease and just yeah, you have to know what you're talking about when you go to a doctor and you have to know what you want as the next step in treatment and fight for it. No matter what.

And if that doctor is not willing to work with you and try certain things with you it's not worth it. Find someone else. If they tell you to change your underwear to cotton and they tell you to change your diet to low-oxalate, you're wasting your time and your money and I think that's the best thing to do but it's hard because it costs money. Everything costs money and my insurance didn't want to pay for it [my surgery] at first because they said it was cosmetic. Even with the diagnosis of vulvodynia so I think that's really frustrating especially because I work in the

medical community. This is pain. This is nerve pain. It should be covered. But yeah, just to do your research.

Awesome.

No Ambient.

Nina Marks, 56 of Denver, Colorado
Date: 11/11/13
33.19 Minutes
Film Crew on Site

03.3 *If you could just start by saying your name, your age. Just for my reference.*

My name is Nina Marks and I am 56.

Is 56 new or?

I've been 56 since May, so I'm getting halfway to the, you know, 57 point.

(chatting)

39.9 *The biggest thing we're going to talk about today is your medical history with vulvodynia, what you've tried, what absolutely didn't work, how it affects your daily life, and how long your experience with this has been and I'll let you kind of take it from there.*

Okay, when I was in college, that was a long time ago, about 1979. I was diving off a board, a diving board. I was at CU in Boulder with my boyfriend then and I hit the water. I wasn't diving, I jumped and I hit the water between my legs and I actually felt like a knife went through, like my skin had completely ripped. That wasn't vulvodynia then but it was a sign of what was, I guess, to come. So, I ended up calling my mom saying I think something is wrong with me and I came down here [Denver] to have an appointment with an OBG and we did some skin grafting. We took some of the really fine, thin skin out and he took some of the skin from my vagina and pulled it down and stitched it all up and it was great. And I was so happy and everything was great.

And then we fast forward to 1984. I was married and in 198(*pause*)6, I had breast cancer. So um, they said I was going to be okay. I had a mastectomy, a modified radical. Wasn't allowed to have any children, so we adopted our son. So I wasn't really having any sex at that time to tell you the truth (*cat in background I'm pretty sure*). So, I didn't know. It had nothing to do with having sex. So after my son was about, oh I'd say he was about 2 or 1, I was teaching in my 2nd grade classroom and I felt this amazing burning going on in my vulva and of course, my first thought was, "Crap, I have some kind of infection." How I would get something like that I have no idea, but I have something going on so I made an appointment to see the current OBG guy and you know he put me on all this cream, all that cream, all this anti-whatever and this went on for months and months and months.

And I finally brought my husband in at the time to meet, to talk with this doctor because I felt he wasn't hearing me because he started yelling at me and so I needed

to have some support. It was a 6:30 meeting in the evening and basically this doctor wouldn't even look at me in the eye. And he looked straight at my husband and said, "I think your wife has mental illness. I don't see anything down there. I don't know what it is. I think she's making it up. In fact she's pry frigid and you should get her a psychiatrist."

So I left there pretty, pretty upset because this whole time I'm burning and there is nothing, nothing that's worked. He sends me to, I can send her to...because my ex-husband asks, "Well, where do we go from here?" Well, you can go to [the] CU medical center and infectious disease of all things so that doctor was even… Well anyway he did a biopsy.

And he, I'm in the stirrups and I'm in the stirrups and I'm in the stirrups and nobody comes in to say get dressed, do this, do this, do that. So I get dressed and I open the door and the whole clinic has closed. I mean the lights are off. No one is there. Doctors are gone. The front desk, everybody's gone. I've been sitting there for 45 minutes waiting and waiting for somebody to come in and nobody comes in. At this point I'm feeling suicidal. I get dressed. I'm bleeding. I don't know what to do.

I leave 9th, you know CU [University of Colorado] was on 9th Avenue. It's snowing, it's winter, right before Christmas and I don't want to go home. I've lost a lot of weight trying to deal with this thing. I'm not sure if I want to go home or not and I do end up calling my physiologist at the time because I was ready for a bus to come and run me over because I felt like I was being treated like nothing.

So, he made sure that I talked with him awhile. I had a cell phone. I went to see him and he goes are you able to drive? I am able to drive. So I go home. At this point my husband is sick of this, to be honest. He doesn't have any, he wasn't, it was just really hard for him to hear it. And I am screaming to myself in the shower because the chronic burning, burning, burning, and the stick and the needle-like pain and I can't wear anything. I can't wear underwear. I can't wear pants. I can't do anything and I'm trying to work also. I'm trying to teach. So I'm teaching in my skirts with no underwear on and trying to get through the day. I'm not on any painkillers, so the stress is just building, building. So the two weeks go by and I finally get to call that clinic and have another appointment. And I told him he just left me in those stirrups. And of course he is yelling back at me that he did not. We're having a war of words. I'm there by myself and of course it's his word against mine. And he says well you have HPV [Human Papillomavirus]. Which was in the end, that's not what it was. And he just said I didn't ask you to come here, you came here. And I knew I wasn't going to win with this guy either. But the yelling and the, it was pretty frightening. You know, because I'm trying to get help for myself and because these doctors could not help me.

In a way, I thought they were God and they didn't refer me to anybody. It was pretty awful. So my dad and I decided we were going to go to the Mayo Clinic and we call,

get an appointment. And we fly out there and you know, I'm in agony and so we finally meet this old guy. I don't know. I can't remember it was so long ago and he says, well, I do believe he used the word vulvodynia or something like that and he said we could put acid here and here and burn these areas out. That's also the doctor here in town at CU medical center. He prescribed for me a cream called 5FU. It's a chemo that causes blistering. So I used that and I was blistering down there and it was horrible. So we came back. We flew back and said we're going to put acid on here and burn, we're just going to burn the whole thing.

So my physiologist found a gynecologist/oncologist and he hadn't, never had a patient like me before. I had been on every cream known to man kind. Every pill. A lot of Dilantin. Those anti-seizure drugs. And nortriptyline at high dosages. Gabapentin. All of those drugs just made me so out of it. In my head. I always said it's affecting my brain but not my pain. That was all I could say. And I was teaching. This was years of stuff and I finally broke out in hives from all of it. Just the stress of it all. This OBGyn decides we're going to just use a laser and we're going to take it all the way from my clitoris, all the way to my rear-end, my anus and we're going to just get rid of that skin.

So, we go into surgery and you know how you blow up when you burn and your skin just swells out and I go home with burn cream. No painkillers. And I'm told to go to the bathroom and to go to the bathroom in lukewarm water in a tub and it just burns. And now I have a third degree burn down there and you know, I was like on my hands and crawling back and forth and using the burn cream to separate the skin so it wouldn't adhere.

During that time I heard a wheeze in my lung and I'm limping and I went back to him and said I have a wheeze up here. So long story short, we found out that the cancer had spread. So I just had this vulva surgery and now I have cancer in both lungs and in my bones. Now I'm thinking oh my God, now I'm dying, you know, now not only have I been fighting all this. Now I'm dead. So I had a complete mental melt down from all of this cobash on me and I really didn't know what to do first. How to fight that. Fight this fight that so it was a difficult, very difficult when I talk to being seen by an oncologist I told him about the surgery I just had. I was carrying around a donut so I could sit. And he goes well we're not doing anything right now. You got to heal. Wow I really don't know anything about that. So we had a plan just to be on tomoxetin but that had nothing to do with this part. Ultimately, I did go through an autologous bone marrow transplant.

11.14.9 It came out from Duke. Was brand new and I was the 4th patient and I thought that if all that chemo is supposed to kill every cell in my body maybe it will kill whatever's wrong down there. And believe it or not I actually had hope that if I survived that maybe it would cure that part. But it did not. I did survive that bone marrow transplant.

I'm 23 years away from that but the burning problem, boy, it came, you know. It's still there and it's here today. It goes into somewhat of a remission I call it. It kind of pulls back so that burning is not so intense and then it comes back pretty intense with that heat intensity, sometimes a cold burn. Sometimes a non-burn. But I've never been able to wear jeans with a seam. What I'm wearing today. I took a pair of jeans and we cut out the crotch and we put in like you would tights. That kind of a crotch, which I just figured that out a couple years ago after all those years of wearing dresses to work. Just helps. And I've seen, one...many, many doctors and my last visit with this problem was with Kaiser and we tried some shots of Novocain, um not Novocain. I think it was, I'm not sure. Some kind of shots to numb it for a while, but that failed also.

Probably lidocaine.

12.56 Yeah lidocaine. That didn't last very long. So, I have an appointment coming up. It's just, I'm going to see what else we can do. I don't want surgery there because I've had two surgeries down there already and I'm pretty fragile. The skin is fragile. Plus I went through early on-set menopause with the bone marrow which fried my ovaries and really threw me into menopause (*cat*) not really sure what we're looking at.

I know there's a surgery to remove some glands but that's not fool proof. And what happens if that, you know, I'm not sure about that yet. It has really, it is really made a mess of my life. Between the cancer and all this happening so young and having this. It's like I start my life and have to retreat. Start and retreat. It's like I can't just go forward and because I never know when this is going to flare up.

14.04.3 *Off of that you mentioned like always feeling like you're starting your life over at different points, something that I'm kind of curious about. Is there anything that's ever helped you distract yourself, helped you work through just the daily frustrations of being in pain? Having to deal with cancer? All these very frustrating issues, are there things that have brought you joy? Helped you get through it? Cope?*

I think my job did that. I always went back to teaching. No matter how many times I had to take a medical leave. Even our principal once questioned why I was coming back and I said it's because it's what I do and when I was working with those kids even though I was in agony I had to be "on" for them. I think that helps. It's a very big; your work is your distraction. When you're, and then I would come home and I do take Ativan for the anxiety that all this produced and I do take Celexa and I've been on all these different anti-depressant pills because of all this, because of the cancer because of this and I…

I was never depressed really a day in my life before all this started (*Crying*). I was a really happy kid, so I'd have to say I don't understand why we can't figure this out. There are so many women who suffer from this and I know it's frustrating for the

doctors. I'm going to say this, I believe so that if we had penal cancer at the rate of breast cancer or penal cancer at the rate of vulvodynia we'd have a cure by now. I just think it's a very, it's a women's issue. It's not really overt. It's not like you can see something. It's in the nerve endings. I always think it's like shingles in a sense that we have so, it's been a long, long, long time for people to be educated about it. And so that's like the first thing but they still don't know what to do about it. That's where my frustration comes in because I don't want to live the rest of my life, I've lived a quarter of my life with this, more than a quarter of my life with this. I would really love to just I would love to just be able to wear pants, ride a bike and even have sex. That would be nice. But I don't know if that's going to happen.

16.51.6 *I just remember us talking on the phone about what you said about if men had this we'd have a solution for this and it just always reminds me of the nurse I work with who works with Dr. Slocumb right now, Marybelle, and she says the exact same thing and I know I agree with you on that one. It's a big difference in just everything I've looked at so far with all my research even, the way women's health is perceived is very different in a lot of respects. Um, something I'm kind of curious about and if you're okay with talking about it is just how it has affected your relationships in a couple ways. You mentioned you've been married before, so maybe a little about that and also are there people you've been able to go to, to talk to before? Have you ever found any support groups that help? Has your mom, you mentioned, has she been accessible to talk to about this kind of stuff? Are there those people in your life that help support and don't understand? So maybe you could talk a little on that.*

In my marriage, this is, I'm just going to say this. When I got married my husband right away told me he had no libido so we didn't have sex from the very beginning. So this problem happened, including the breast thing. It had nothing to do with sex at that point. It was just ground in further because I was ready to say, I thought man I've to get out of this relationship because if that's what this is going to be and then of course I end up with a mastectomy and then I end up with this and then I end up with late stage breast cancer, so that was a tough marriage because he had no empathy.

His thing was I'm cold, callous, insensitive, take a pill and just why don't you read a good book. No don't read a self-help book. So that was, I didn't have a lot of support there. My dad was a great support to me through everything. He's the one who took me to the Mayo Clinic. We also went to Africa together.

Right after, a year and a half after my bone marrow transplant they told me the cancer was back in my lungs and you know, that was like unbelievable. So this trip to Africa came along and I thought we're going. There, on that safari, I kind of came to terms with myself, not just the vulvodynia, because it was the cancer that was back and I thought, "Geez." My son was maybe 4, 5 and I thought this is (*crying*) what it did is it helped me see the life cycle and helped me see the Maasai and how they deal with life and death. So I thought, "Well, when I die I'm going to be here."

Just let me out of a plane and I will be eaten. I will be reused. I will be I know that sounds really gruesome but when I was there, that's what they do with their people. the Maasai just take their people out and the animals take them. They don't bury them because they're a nomadic people and I thought, wow that's just part of, I mean I can, I don't flesh on myself at least I felt I would be buried that was a huge issue of nightmares. Or burned...uggg...because of what we've gone through so I thought, "Wow I'd just be meat for some buzzards," or whatever and it gave me a little bit of peace but I came back and they did another scan and I was still, the cancer they thought they saw wasn't there.

So we kept scanning every three months to see what was going on and no one really knows what happened there. Some say I had a miracle happen. I kept saying, "Did you have the right scans?" You know, were they someone else's scans. We just don't know. But my dad always had some humor even in the worst scenario. Somehow he was able to find humor in things that, and I could laugh about things that were not funny but I laughed anyway and I think that was great.

And my mom I could just yeah. She knows. My brother and sister ran as fast as they could, as far away as they could because they didn't want to deal with it. And no there hasn't been any support groups because, well nobody heard of it. And with the HIPAA laws you can't get, like I asked certain doctors could I get the number of one of your patients and he goes well you can get NVA, National Vulvodynia Association's site and that's just not what I wanted to do. So, it's harder to find that root support group. Just to remind you that mine was back in the 80s when we didn't have the NVA at that time. It was very, and when it started it was a very new grassroots program of a couple women and a couple doctors. So, it has become larger and bigger but I don't know what else there is to do besides this next surgery. That's all I know that's left.

22.41.3 *Well it's interesting that you mention that particular surgery because that's the surgery that I started with. And actually that's the same surgery that Janet went through as well, one of the other women I've spoken with and for me it, I was 100% pain free for 1.5 years before it came back in the places that hadn't been operated on. It was a conservative partial vulvectomy with the removal of the Barthos glands and yeah, the places that have been operated on are still great, it's the places that haven't that keeps moving about. And I know you also mentioned the shingles stuff, and Rachel will be able to elaborate a little more on, hers was hormonal. I've seen all sorts of different potential causes and it just feels like vulvodynia is an umbrella term.*

It is. For a painful vulva. That's all it is.

For potentially lots of different causes.

I've even been on that diet for high calcium.

The low-oxalate.

Yeah, terrible.

I already have dietary restrictions because I'm allergic to dairy and I'm like no, no we're not cutting things that make me happy out.

I tried that and I was so constipated (*laughs*) but that didn't do anything. We've tried different combination of creams and really for me it's been a total failure. Everything has been a total failure, which is kind of sad, but I just pray that it's going to go back to that remission state where I can stop burning so bad. But when I get these outbreaks or whatever, there's nothing I can do really about it. Ice, I ice and I try to just hang out. I feel my life is on the couch or my life is up on my bed. Which is, I want to be home. I don't want to be out and about.

24.48.9 *This is going to be kind of an odd question, and this is just something I'm curious about, because you dealt with cancer at the same time. Having those go hand in hand. And I read a study that talked about quality of life for vulvodynia patients compared to cancer patients, since you've had both I'm curious about your perspective on which you felt had more of an impact on your life at various times and the difficulties, are they similar difficulties are they very different?*

When I ended up with the cancer, when it came back. I at least knew what I was going to die from. At least it had a label. I mean I knew. And that was almost like a relief because I could say to the world well I'm going to die from cancer. You know, and at least like I could have my head held high. With this vulvodynia I almost felt like it was like AIDS. Because of the way I couldn't talk about. I don't even use the word. I used to say my bottom was burning. Because of the way the doctors had initially treated me so horribly and that no one knew about it.

So it made me feel like some freak person during that time like some non-symbiotic being was invading my body and wreaking havoc with my feminine body parts. Because I was trying to explain it for myself I was trying to comprehend it. It was really hard to. Because I was dealing with this simultaneously and how do you do that you know? You're just in the dregs of society and you're just down there. I remember going to a quality life retreat when the cancer came back and I was so shaky and they asked, the questions w[ere] what's your name and how are you going to fight? And I said I don't know if I want, if I have the ability, if I want to live or die. Because I hadn't decided how I was going to fight because I had been fighting for so long.

I remember going home and saying I don't know if I'm going to fight (*tears*). I don't know if I have it in me and then I looked at my son and I said well, because he's adopted. I said, "Well, I guess I'm going to have to fight for you because I don't want another woman raising you since your birth mother gave you to me. I'm going to

have to be there for ya." So I did wait, the bone marrow transplant didn't come to Denver for a good 9-10 months. I was just doing radiation to my bones and did some holistic stuff out in California.

Even all that didn't do anything with the vulva. I've seen here in town that promise that you know they'll put you on these machines that will change your molecular structure with vibrations and all that. They can fix you and all that. I've done some really funky stuff. Acupuncture, you name it. It's all weird. I've even had goat's urine injected in my butt to see, just all this stuff and I believed in all of it. I thought if I can just believe it, if I believe it it's going to happen. Unfortunately for me, it did not change that part of my anatomy so here I am.

28.38.5 *How old is your son and what's his name?*

His name is Evan and he's 26 now so he's out on his own finally. He's got a girlfriend and he's living with her and life is good. And I was able to raise him and so you know you have to have a purpose and he was my purpose and I did retire because I broke a vertebra just leaning over a table at school and I was in horrible pain because of osteoporosis because of everything and I thought well you know it's 30 years and I wasn't as passionate and now I'm ready to march on and say lets get on Doctor Oz and see what he can do for us. Or lets get on Dr. Phil and see what he can do for us because these guys are powerful and we've tried on our own but it's time to you know pull out the big guns and get help. We need help. We deserve a good life. We've suffered enough.

29.49.7 *(Crew talking)*

31.13.3 Because I think if we have something, if we have a video of all of us or if we come in force, if we come together on his show or somehow make this a big deal we'll get on there and maybe we'll get something out of this but we have to do it and keep pushing it. That's the thing. We're not going to let them say no.

31.39.4 *I only have one more question for this particular recording. My question is what advice would you give other women? Other women? Other family members? People who are like what is this vulvodynia? What is this and what are we going to do about it?*

Well today I think there's more hope, certainly than there was when I started out. I think doctors have more information. They're not going to treat you, hopefully, the way I was treated by yelling at you and I think we have to keep constantly informing our doctors. We are advocates for ourselves. We can't let them have the key. We have to keep advocating for ourselves. It's real and (*sigh*) I'm glad that we have that NVA site.

I'd like to, I'd like to bring more of us together in person and start kind of pounding on some big doors because too many people still hide in the closet. It's very hard for people to talk about. And you know, it's easy to commit suicide over something like this. People use to do that for breast cancer back in the day when that was not, it was such a horrible thing that they would do that. And I almost did and but I didn't so I really think. It can't stop here. The word has got to, we've got to shout. We do. From the top of our lungs. That's my advice. Keep Shouting.

No Ambient

Linda Karcz, 64 of Castle Rock, CO
Date: 2/18/14
14.41 Minutes
3 dogs and 1 cat in the background

02.3 *It's recording and if, like I said, I just have some general questions. A lot of it we've already talked about. And if you could just say your name and your age.*

Linda Karcz and I'm 64.

How do you spell your last name?

K-A-R-C-Z

32.6 *I know we talked about it a little bit already, a little bit of your history? When your vulvodynia started? Explain what it felt like and the things you've tried. Things that may have given you relief? Things that you hated? Kind of that medical history.*

Okay, um, started when I was a kid. I had itching. After my first pregnancy I had a problem with wearing jeans and tight pants, something with a seam. And then when I was 40, I had a really bad flare up and it got worse, a lot worse after that. With, as far as medications, I started out with amitriptyline and some amitriptyline suppositories. And after that didn't do well found Nel Gerig, a urologist, and Dawn Sandalcidi, a physical therapist, in Denver and I'm on gabapentin and a flexeril suppository. Lidocaine did not work.

1.53.4 *Could you tell me a little bit about when (laughs) when you first started realizing you were having difficulties, you said around 40 (Yes), what that was like for you?*

Well, I always had a little bit here and there but at 40 is when it really flared up. It was intolerable and I was in Wisconsin at that time and was referred to somebody in Milwaukee. A pain specialist in Milwaukee. Then sent me to a physical therapist there (*dogs moving*). It, my, it lasted for years before I got any kind of real relief.

2.48.2 *Had you had all 5 of your children by that point?*

Yes I had my last one, I had at 35 so....

And they were all vaginal deliveries, no interventions, no pain medications.

And the largest was 10 pounds and posterior.

3.29.1 *Something I'm interested in, talk about your limitations, how the vulvodynia limits your life, the quality of life with that.*

My life has totally changed because I have the IBS with it and with my gluten and food allergies all that combined really makes it difficult to travel. I have a hard time sitting if we take any kind of road trip for any more than 15, 20, 30 minutes. I get pain and (*she's going to drink your water->cat on counter*) and it makes…I love my horses. I like to go riding once in awhile. It makes that very difficult. I can't really do any exercise programs. A lot of times, I have a hard time if we want to go for a walk for any amount of time or a hike. I can't do that. (*Puppy feet tap tapping the floor*) It really limits my activities, totally.

4.52.3 *You've mentioned that you have 5 grandchildren now, I believe. (Yes) Is most of your family nearby?*

Yeah most of them are nearby or they will be nearby soon.

Recently you mentioned you went to visit your daughter. Maybe tell me a little about being in the car...

Well, I flew there so that's not too bad but even just lifting my grandchildren for any amount of time will give me a flare up. Any kind of lifting will give me a flare up.

Sit, Sit.

(talking to pups)

5.43.7 *So, keeping up with the family seems difficult.*

Yes it is.

5.52.8 *You mentioned your IB,S could you talk about your restrictions with that, and how you were telling me earlier how you feel they kind of go hand in hand and how one will set off the other?*

Yeah, if I have, um, with my IBS. It just to be constipation/diarrhea and now it's more diarrhea which causes problems because it upsets the nerves in that area and colonoscopies are horrible (*laughs*). The prep for it puts me in pain for a really long time. But the IBS, when I have a flare with the IBS I know that soon after I will get a flare up with the vulvodynia also.

6.50.1 *Any other chronic pain issues?*

I get migraines that are hereditary since I've gone through menopause they're not as bad. I would be able to tell when I was going to have my period. I would get a migraine within an hour and so before I get my periods so, I knew when I was going

to get it. So yeah, and that was difficult and I had a lot of pain with my periods too and when I was ovulating.

7.31.6 *Off of that, one of the other things I like to ask is how it affected the relationships in your life whether it be, were you ever able to talk to your mother about, you know, I'm having this discomfort when you were a kid to siblings to your husband or you've mentioned you've been able to talk with your kids a little bit. How has the vulvodynia affected relationships in your life and how is it communicating to others about having vulvodynia? (Dogs in background again drinking water, comment on that)*

8.39.3 All my kids pretty much know about it and when my mother was alive, she and I had problems when I was younger and I was able to talk to her about it and she would suggest things like acupressure and acupuncture. Different herbs and things like that, that I'll try and she just felt really bad that I had it and you know was helpless really to do anything about it. And I can tell like my aunt who I'm very close to now and talk to her about it. If I'm really not feeling good, really bad then I can let my kids know (*dogs, laughing*). So, I can communicate somewhat but not a real lot with my kids about it.

You have 2 daughters and 3 sons?

Yes

9.1.9 *You mentioned earlier that you had some concern about it possibly being genetic and hoping, I'm guessing you might have some granddaughters, they never kind of have it. I know there have been times where I wouldn't wish this on my worst enemy. Have you ever been able to talk with your daughters more specifically about checking in with them?*

Yeah I do. I let them know probably what causes my discomfort and kind of what to watch for and I monitor them and just to see if there are any red flags going up. And they know I'm going to physical therapy for it and specialist so they're aware of what's going on.

10.48.1 *How about with your husband? How is that to, when you first started having pain and being able to talk with him about it?*

I just let him know I had a lot of pain that's all. (*fridge*) There wasn't too much more I could say about it. This was miserable and just couldn't wait to go to bed at night and forget about it and I tried to conceal the pain as much as I could because, you know, you don't like to let anyone know how much pain you're really feeling. You're being a big wimp about it. So…

11.31.3 *Do you think it affects him pretty strongly too since it affects you so much?*

I think he's been understanding about it. I don't think he understands the full impact that it has on my life at all.

11.53.1 *On the flip side of things, what are things that you do that, maybe you're having a bad day and you try things that you can find satisfy or kind of help yourself to get through it. Whether they're activities or things you're able to tell yourself to help you?*

Sometimes I'll try and go and just relax if I can. Lay down and relax if I'm really feeling bad just to get some relief from pain. Or I'll go and brush my horses. Um, I guess, you know I don't really have time to think about it a lot. So, I just try and do the best I can.

12.51.5 *My last question, this is one of my favorites. This is your opportunity to give advice to others in any way shape or form so if you were able to talk to other women who might be just finding out they're having problems or who have had problems for 20 years what would you say to them?*

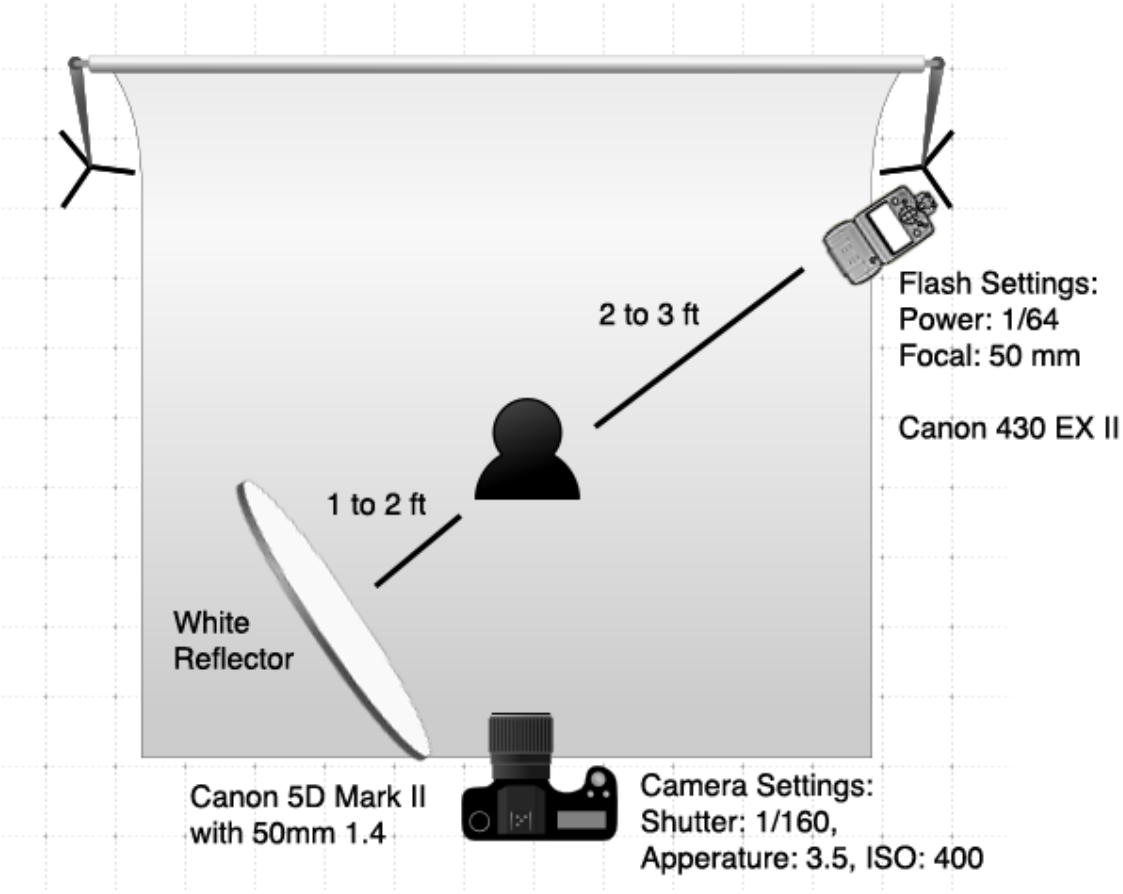
Well, this is kind of interesting because when I was younger and when I was having children and I was a group leader, it was a leader for nursing mothers, and I found that talking to other women about these, about breastfeeding helped and I think that talking to other people about it. Seeing what's worked for them. One thing I do not feel is helpful is reading a lot about other people's problems all the time and the pain they're going through. But talking to other people and seeing what's helped them and knowing you're not the only one going through this and having a support system is really good.

14.01.6 *Is there anything you think I might have missed?*

Not really. I think, I think with what I've found is most helpful for me was finding a physical therapist that could help me, that I could go to. If I do have a flare up, to be able to get in to and having a physician that understands what's going rather than chasing from one person to another and nobody knows what to tell you and it's very frustrating.

No ambient.

Appendix E: Lighting Diagram



Appendix F: Media Folder Contents

Audio Clips
Contact Sheets
Full Audio Interviews
Full Resolution Images