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When Maps Ignore the Territory: An Examination of Gendered Language in Cancer Patient Literature

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When Maps Ignore the Territory:
An Examination of Gendered Language in Cancer Patient Literature

by

Joanna Bartell

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Communication
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DEDICATION

Dedicated to Zoey, who has been by my side the whole damn time, patient and loving, with the sweetest smile I ever did see.

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TABLE OF CONTENTS

List of Tables	iv
List of Figures	v
Abstract	vii
Prelude	1
Chapter 1: Introduction	10
Empire of Light	10
Cartography	10
World Maps en Flux	15
The Importance of Maps: Patient Information Literature	26
Chapter 2: Methods	38
Methods	38
The American Cancer Society	38
The Official Sponsor of Birthdays©	38
Patient Detailed Guides of the American Cancer Society	40
Data Sources	42
Method of Analysis	47
Close Reading	47
Frame	49
Form	52
Genre	52
Visible Structure	52
Narrator	52
Metaphor	53
Allusion	54
Diction	54
Time	54
Plot	58
Desire	58
Example of Close Reading	60
Summary and Overview	61
Chapter 3: Analysis	63
It's a Girl!: Analyzing Women's Cancer Patient Detailed Guides	63
Defining the Female Body	63

Vaginal Cancer.....	63
What is vaginal cancer?: The vagina	63
Cervical Cancer.....	65
What is cervical cancer?	65
Endometrial Cancer	69
What is endometrial cancer?.....	69
About the uterus and endometrium.....	69
Ovarian Cancer	73
Remarks	75
Effects on Information and Reinforcement of Definitions	76
Risk Factors	76
Risk Factors and HPV.....	81
HPV and men.....	91
Condoms and HPV	93
Remarks	94
Treatment Side Effects.....	95
Radiation therapy for cervical, vaginal, and endometrial cancer.....	96
Radiation therapy: Vaginal cancer (excerpt 1)	96
Radiation therapy: Endometrial cancer (excerpt 2)	97
Radiation therapy: Cervical cancer (excerpt 3)	98
Discussion of excerpts	98
Surgery for cervical and vaginal cancers: Sexual impact	101
Sexual impact of hysterectomy.....	102
Sexual impact of radical hysterectomy.....	103
Sexual impact of pelvic exenteration.....	103
Vaginal reconstruction	105
Final Remarks	106
 Chapter 4: Analysis.....	 108
It's a Boy! Analyzing Men's Cancer Patient Detailed Guides	108
Defining the Male Body.....	108
Penile Cancer	108
About the Penis: The Male Sexual Organ.....	108
About the Penis: Normally Circumcised	113
Prostate Cancer	113
About the Prostate.....	113
Testicular Cancer	115
What is Testicular Cancer?	115
Risk Factors	118
Risk Factors and HPV.....	121
Can Penile Cancer be Prevented? Definitely, but Probably Not	127
Genital hygiene	128
Avoiding HPV infection	128
Treatment Side Effects.....	132
Penile Cancer Treatment Effects	132
Effects on urination.....	135

Effects on sexuality.....	136
Testicular Cancer Treatment Effects	139
Prostate Cancer Treatment Effects.....	142
Chapter 5: Results and Discussion.....	145
“‘It is a balancing act, and it is a dream”	145
The Guides: Framing, Misinformation, and Implications	146
Read this as this subject, in this way.....	149
Risk factors and prevention	149
Side effects.....	152
The Implications of Gendered Narratives: Misinformation and Outcomes.....	154
Hormones	155
Sexuality	156
Sexuality and women.....	156
Sexuality and men.....	158
Implications for the American Cancer Society.....	161
Cervical.....	162
Penile.....	162
Recommendations for future revisions	163
Recommendation 1: Ovaries, testicles, and the endocrine sys	164
Recommendation 2: Focus on the people, not the penis.....	164
Recommendation 3: Reproduction and cancer risk	165
Limitations and Future Research	165
Conclusions.....	167
References.....	168

LIST OF TABLES

Table 1:	Sample selection	53
Table 2:	Female associated table of risk factors	77
Table 3:	Male associated table of risk factors.....	119

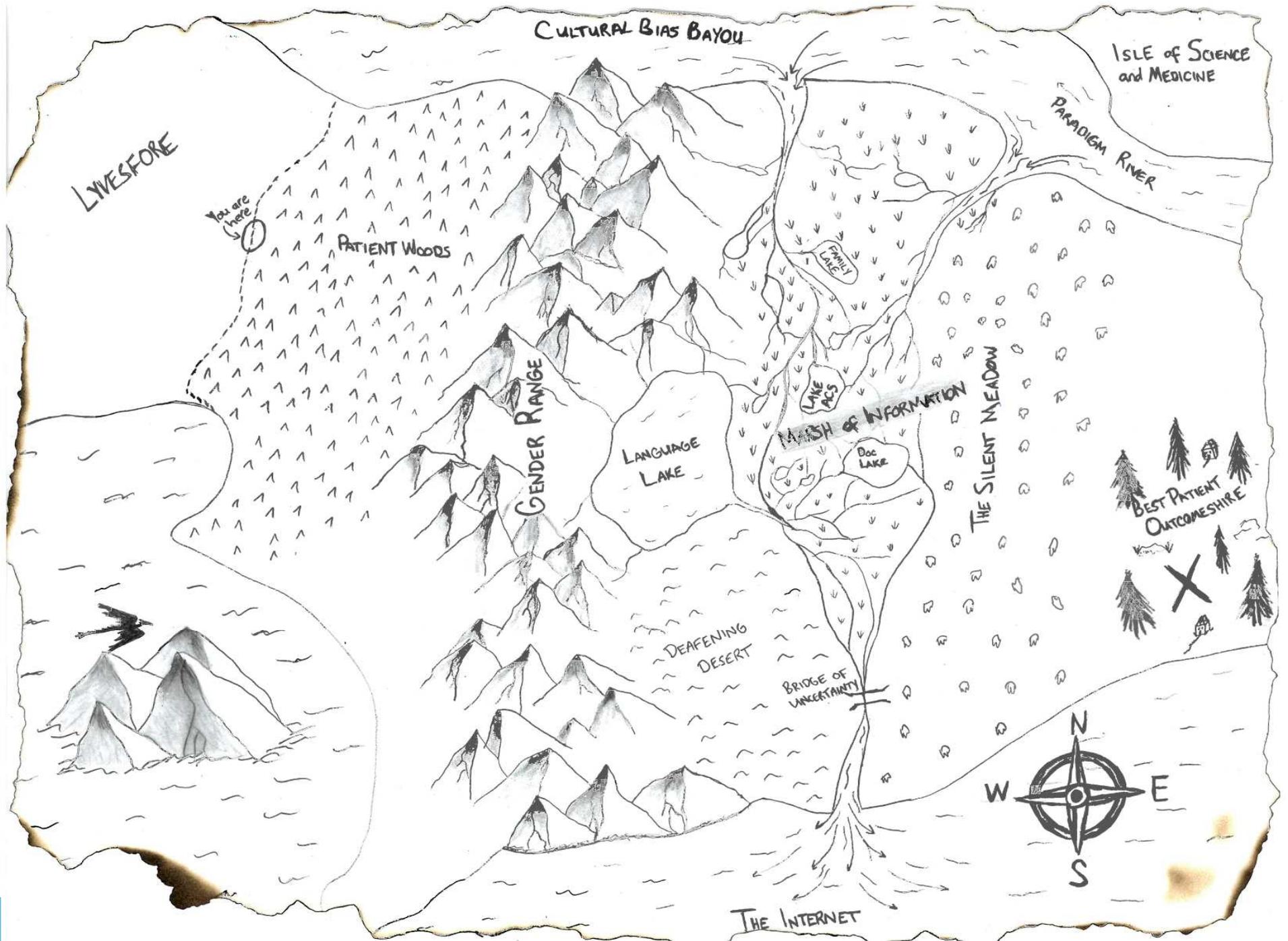
LIST OF FIGURES

Figure 1: Sample page from ACS ovarian cancer guide.....	44
Figure 2: Sample page from ACS ovarian cancer guide.....	45
Figure 3: Analysis exemplar excerpt.....	60
Figure 4: Vaginal cancer definitional section excerpt.....	64
Figure 5: Cervical cancer definitional section excerpt.....	66
Figure 6: Endometrial cancer definitional section excerpt.....	70
Figure 7: Ovarian cancer definitional section excerpt	73
Figure 8: Female associated HPV section excerpt	82
Figure 9: Female associated prevention section excerpt.....	86
Figure 10: Female associated prevention section excerpt HPV and men	91
Figure 11: Female associated prevention section excerpt condoms and HPV	93
Figure 12: Female associated side effects of radiation excerpt.....	97
Figure 13: Female associated long term side effects of radiation excerpt	97
Figure 14: Cervical cancer radiation excerpt	98
Figure 15: Vaginal reconstruction excerpt.....	105
Figure 16: Penile cancer definitional section excerpt	109
Figure 17: Prostate cancer definitional section excerpt	114
Figure 18: Testicular cancer definitional section excerpt	116
Figure 19: Male associated HPV section excerpt.....	122
Figure 20: Male associated prevention section excerpt	129
Figure 21: Penile cancer physical and emotional effects section excerpt.....	133

Figure 22: Testicular cancer possible effects on sexual function and reproduction excerpt.....140
Figure 23: Prostate cancer treatment effects section excerpt142

ABSTRACT

Cancer patients report having a high need for cancer information. Several studies show that the majority of patients surveyed report preferring information from the American Cancer Society (ACS). Ranging up to 129 pages, the ACS' Detailed Guides (DG) are widely distributed throughout the United States, and offer patients an authoritative guide to help patients navigate the difficult terrain of the cancer journey. This dissertation examines the ACS' cervical, endometrial, ovarian, penile, prostate, testicular, and vaginal cancer guides. Through a rhetorical analysis of the 7 guides, it was shown that the ACS DGs in question foster gendered narratives that strictly limit the type, range, and quality of information offered to cancer patients. These limitations and their resulting exclusions pose serious risks of misinformation and isolation among vulnerable patient populations with high information needs. Three recommendations are offered to help mitigate the issues identified within the ACS DGs, to improve the quality of information offered in the DGs, and to subsequently help improve patient quality of life.



PRELUDE

We sat in the little room chatting idly while we waited. My sister, Carrie, was in a chair in the corner, and I was on the exam table, where the nurse had directed me to sit. We had been waiting for about 15 minutes when the door suddenly swung open, pushing a wall of air into the room. The doctor swept into the room behind his clipboard, the air seemingly pulling them both forward. “This... this isn’t good,” he said to the clipboard. “This is bad. This is cancer.” I peeked around the doctor through the closing door, hoping no one had heard the announcement.

I turned my attention to the doctor, who was speaking partly to me, and partly to the clipboard. From the first time I met the doctor, I was struck and amused by his resemblance to Lewis Black. The doctor generally appeared agitated in the same way that Lewis Black appears agitated when he performs for an audience: his voice was scratchy and uneven, ranging between a low growl and surprisingly high notes; he used his hands and arms to emphasize words or points, and sometimes just because; and he tended to shake or move his head in ways that seemed unrelated to what he said. The combination of his voice variation, often surprising cadence, and disjointed and jerky movements gave the doctor the appearance of being simultaneously agitated, angry, excited, and surprised – much like Lewis Black.

Thus, as I watched the doctor explain to the clipboard and me that I had cancer – itself an absurd notion – I accidentally smiled. I quickly corrected myself, but it was all too much, and as the doctor tried to explain cancer and surgeries and drugs to me, it became harder and harder to maintain my composure. My face contorted as I tried to wring the smiles out of my mouth and eyes; my shoulders tensed and shook as I tried to stifle myself; and my breathing became choppy

as I attempted to hold in and swallow my laughter. I focused my eyes on the doctor, but my attention was focused entirely inward, and while I could hear that he was speaking, I could not make out what he was saying.

I sat on the edge of my seat, my body tense, fingers wrapped around the edge of the exam table, and lips pressed tightly together. A particularly powerful smile forced the corners of my mouth up as a laugh crept up my throat. The doctor turned his gaze on me and I held my breath and swallowed hard, trying to suffocate the laugh. The doctor paused, his head cocked and eyebrows furrowed ever so slightly. A look of confusion passed over his face as his eyes searched for meaning in my tense body and contorted smile. He looked back at his clipboard and continued speaking, and I forced my mouth down again, knowing I'd been caught.

Finally, the doctor announced that he was going to get some information for me, and he left the room. I held my breath until the door was almost closed, then loosened the constraints of my laughter.

“Don't cry,” Carrie said with great concern in her voice. She had been sitting quietly in the corner as information poured from the doctor into our lives. After the doctor's initial cancer announcement, I hadn't dared to look at her for fear I'd lose it completely and break down into fits of laughter – sisters will do that to you. I also knew that looking at her in such an emotionally charged circumstance might make her sad, and I didn't want to risk making her cry. Or maybe it was me. I can't be sure.

I turned my gaze from the door to Carrie, finally able to look at her without concern for the reputation of my sanity. She appeared worried and confused, ready to jump out of her seat to give me a hug, but not sure if that was appropriate.

“I’m laughing,” I said, smiling. “I knew he was going to say that,” I told her. And I did; I knew as soon as I picked up my cell phone that afternoon and the nurse on the other end asked if I could get to the office by 4:00.

“Damn. What now?”

“I don’t know,” Carrie said softly, genuinely clueless. She looked so uneasy.

“It’s ok,” I assured her, “It’s going to be fine. Don’t worry.”

“I know it’s going to be fine,” she assured me back, “Are you ok?”

I suddenly thought of my brother. Just three weeks before, I had assured him that the biopsy was nothing to worry about. We worked at a family friend’s restaurant; I was a bartender, he was a busser. It was a slow day at work and he was sitting at the bar chatting with me while we waited for customers. Thinking that he knew what was going on, I casually mentioned my upcoming biopsy appointment. He became visibly upset, his over-bright eyes refusing to meet my gaze. I assured him that it was precautionary, that all of the health professionals I had seen felt certain that I did not have breast cancer, and that I just wanted to get it done to be *sure* that everything was ok. “I’m not gonna lie,” he had said to me, his eyes locked on the television over the bar, “I’m trying really hard not to cry right now.”

Sitting there in the exam room, I remembered the sadness in his eyes and the worry on his face. I had lied to him. “Yeah. We need to make sure that Gary is home when we get back,” I said with sudden alarm, feeling panicked. “He should be there.”

“Mom and Dad wanted us to call them as soon as we left,” she reminded me.

“No. We’ll just go home. They’ll be there waiting. We need to make sure Gary is there too; he’ll be leaving for work soon.”

“I’ll try calling him,” she said as she pulled her cell phone out of its clip. He did not answer.

“We should call the restaurant and tell them to send him home when he gets there, we’ll tell them that it’s an emergency and that he needs to go home,” I suggested decisively.

When I called the restaurant the hostess answered and I asked for the only person that I knew I could count on. “Hello?” came Lee’s distinctive voice a minute later.

“Hey Lee, it’s Joey,” I said, suddenly feeling shaky, “I need you to do me a huge favor. It’s a family emergency, but we don’t want Gary to be worried. He needs...” My voice cracked. “We need him to be home—“ My voice cracked again. “Could you...” I sniffed, holding back.

“Joey...? Are you ok?” she asked, confused and concerned.

“Yeah. Could you call Gary and just tell him that it’s not busy and not to worry about coming in until 6:30 or so?” I spit out in a hurried sentence.

“Well, Sam isn’t here, so I don’t know if I should do that,” she replied.

“No, Lee, it’s an emergency. We need him to go h—” I couldn’t finish the word. “Gary needs to come...” My voice cracked again. How could I tell him, my baby brother? “We need him to go hooome,” I drug out the last word in a high-pitched voice. I was losing it. I had just assured him three weeks before that it was going to be fine, that *I* was going to be fine; it was nothing to worry about. I made him believe everything was just fine, and now... now I was going to tear it all down. Now I was going to tell him what was *really* going on, like I had just been playing a sick prank before.

“Joey?” came Lee’s voice again, more concerned than last time.

My voice came out in a strained, high-pitched tone, “He needs to go home now,” I barely managed. I was trying so hard to keep my composure, trying so hard to tell her what I needed her

to do. I was failing. Tears burned my eyes and blurred my vision. I swallowed hard and opened my mouth again to speak, but only a strange whispering sound came out.

“Joey, what’s wrong? What’s the matter?” Lee demanded.

I thrust the phone toward Carrie, whose features I could not make out.

“Lee? Hi, this is Carrie, Gary’s other sister. We just need him to come home but want him to drive carefully, so if you could just come up with some excuse for why he doesn’t need to go to work for a couple of hours that would be really helpful... Ok. Thanks.”

Carrie closed the phone and looked at me. “It’s ok Joey,” she said softly.

“I know... I know,” I said, wiping the runny mucus draining from my nose. “It’s just, I don’t want to tell him. He’s going to be so sad.”

“I know,” she said as her phone began to ring. “It’s Gary,” she announced. My chest tightened as my breath caught in my throat.

“Hey Jr.,” she said into the phone. “Just go home for now, but don’t say anything yet. We’ll be back in a little bit We’re not sure, but we want you to be there when we get home, ok? She’s fine. We’re fine. We just want you to be there too, ok? All right. Love you, bye,” she said and hung up. “He walked into work right after we hung up with Lee and Lee told him that he needed to go home,” Carrie informed me. “When he asked why she told him that we had called. He said that he just turned around and went straight back out the door.” I felt relieved that at least he would have a little bit of time to process the fact that I might have cancer.

The doctor came back and gave me a bunch of little booklets, pamphlets, and sheets of paper about breast cancer, and then gave me a bag to put them all in. At some point it was time to leave, so we did. We floated out of the exam room in a haze of uncertainty to the front desk where we stood for a while, strange smiling at nurses, then through the lobby where all of the old

faces seemed to wonder what we were doing there, then finally out the door and into the familiar embrace of Florida's heat and humidity. On the way to the appointment, Carrie was nervous and antsy and stated several times that she wanted to stop and buy cigarettes – residual urges of a supposedly conquered addiction. As soon as the automatic doors of the office opened into the outside world, we rushed to her Tahoe like anxious teenagers hurrying to a party. We jumped in, giggling like children, and stopped at the first gas station we saw for cigarettes.

We drove down the long, straight country roads with the windows open and the AC blowing full blast while energetic rap and hip hop pumped through the speakers. We laughed and sang along to House of Pain's *Jump Around* while we smoked cigarettes. I called my co-worker Richie to let him know that I had cancer and wouldn't be able to pull a double the following day due to a sudden influx of medical appointments. The smoke burned my throat, providing a comforting contrast to the numbness that was settling over me. My head swam from the lack of oxygen and sudden blast of poisons. "This is pretty dumb, huh?" I laughed, "Hey, I have cancer. Let's go smoke some cigarettes!"

Carrie smiled, "Well, we see how well *not* smoking has worked out for you."

The closer we got to home, the more anxious I became until finally the butterflies in my stomach were completely out of control, threatening to fly out through my throat and block my airway until I suffocated. I kept thinking about holding my brother when he was a baby, feeding him, helping him learn to sit, translating for him when my sister and I were the only people that could understand what he said, teaching him math and English, defending him when bigger kids picked on him, cheering him at his various sporting events, and singing with him on Jupiter beach the day before I left for England – a song I made up on the spot when I became overwhelmingly sad that I was not going to see him for many months. We were celebrating his

18th birthday in four days, and now I was going to drop him. Throw him on the ground. Just like that.

We parked, took deep breaths, then bounded up the stairs of the stilt house we grew up in. Dad rushed me at the entrance, flinging the screen door open and eagerly asking me how it went. I carefully drew out a response as I maneuvered my way into the foyer so I could tell all three of them at the same time. “We-ell,” I said as I slid by Dad, positioning myself at the base of their triangular formation, “I have cancer,” I announced cheerfully, the words coming out almost accidentally, without consideration of how I said it or if anyone was standing near any objects they might fall and impale themselves on as the words tumbled forcefully out of my mouth and went slamming into them. I laughed, “That sounds weird, doesn’t it?”

Dad took the news the way he usually takes bad news; obviously upset but ready to do something about it. He started pacing a bit, not certain of what that “something” was. Mom buckled at the knees and grabbed on to a nearby chair for support: she obviously needed comforting.

Gary said nothing. He just sat where he had been sitting when we made our entrance, staring blankly at the floor. I tried to hug him, but he had drawn into himself and only responded mechanically. He wouldn’t even look at me. I stood staring at him, trying to figure out how to fix it. I wanted to tell him that it was going to be fine, that everything was going to be alright and that he didn’t have to worry about anything, but that was a lie.

“At least it’s not AIDS!” I said, laughing. But his tiny, forced smile withered as soon as it appeared, and he just continued staring at the floor. I had crushed him. I was crushed.

“I’m sorry,” I whispered, jaw clenched, throat tight – I could barely breathe

“I’m sorry.”

Later that night, I sat down on the couch with the booklets, pamphlets, and papers the doctor had given me. I began reading each little piece of information, trying to learn more about my disease. My mom walked into the room and paused in the doorway.

“Hey baby,” she said, a weak smile on her face.

“Hey,” I responded, smiling.

Her eyes were closed and she was shaking her head. “It should be me,” she said sorrowfully. “This should be happening to *me*,” she repeated as she leaned against the doorframe, her head pressed against her forearm, “not *you*.”

“Statistically speaking, you’re right,” I retorted. “My chances of developing breast cancer are very slim.”

“I’m so sorry,” she said into the doorframe.

“At least it’s not AIDS,” I said, trying the joke again.

“Oh, Joey!” she scolded, frustration in her voice.

“Look, Mom,” I started, “Yes, statistically speaking, you’re more likely to get cancer. But you didn’t get cancer. I did. And now we have to deal with that.”

She looked at me, smiling. “Here you are, just diagnosed with cancer, and *you’re* comforting *me*. How backwards is that?”

“It’s not,” I stated simply. “Your kid has cancer. Of course you’re upset.”

“How’d I get so lucky?” she asked, walking toward the couch. “What are you doing?”

“Tryin’ to figure out what I’m up against,” I said, holding up some of the literature.

For the next couple hours, we sat together on the couch thumbing through the booklets and leaflets, reading up on the disease, learning about my upcoming scans, and discussing some

of the procedures, options, and potential side effects. We read through the “Risk Factors” section, crossing off most of the potential risk factor categories as we laughed about how unlikely I was to develop breast cancer. We talked about breast surgeries, staging, and hair loss. We threw out possibilities and came up with plans. We talked about coping and taking things one day at a time.

By the end of the evening, we felt confident, armed with information and prepared to move forward. The next morning, we were ready for whatever came next.

CHAPTER 1: INTRODUCTION

The Empire of Light

“If the dream is a translation of waking life, waking life is also a translation of the dream.”

René Magritte

“One describes a tale best by telling the tale. You see? The way one describes a story, to oneself or the world, is by telling the story. It is a balancing act and it is a dream. The more accurate the map, the more it resembles the territory. The most accurate map possible would be the territory, and thus would be perfectly accurate and perfectly useless. The tale is the map that is the territory.”

Neil Gaiman

Cartography

It is rumored that one day, in the middle of a lecture, Alfred Korzybski, Polish-American scholar and founder of the field of general semantics, exclaimed that he needed to eat something. He pulled a package of biscuits out of his briefcase. The package was wrapped in white paper so that the original design of the packaging was not visible, and as he finished his first biscuit, he held the package out to students sitting in the front row. Several of the students happily indulged, and Korzybski commented to the students, “They’re quite nice biscuits, aren’t they?” as he took a second. The students agreed. Korzybski removed the white paper, revealing a dog’s head and the words “Dog Cookies” on the original packaging. Upon discovery of this new information, the students became disgusted, and two of them ran out of the classroom to vomit. Korzybski announced to the remaining students, “You see, I have just demonstrated that people don't just eat food, but also words, and that the taste of the former is often outdone by the taste of the latter.”

I like that story – it makes me smile, and it justifies my preoccupation with making food look as beautiful as I want it to be delicious. But food itself is not exactly the point. The point is that, on a broad level, words accomplish tasks. By denying his students access to the original “map,” so to speak – that of the packaging – Korzybski’s students transferred the role of “map” to Korzybski himself, who projected the reality of “quite nice biscuits.” As such, the students believed they were in “quite nice biscuit” territory, and enjoyed their treats while they were there. Once Korzybski revealed the original map, however, the students found themselves in an alternate version of reality, and quickly developed drastically different perceptions of their surroundings, interaction with Korzybski, and sensory experiences. In this way, Korzybski demonstrated his famous dictum, “the map is not the territory,” and that words both represent our realities and serve to construct them.

There is another story I like to tell myself. It’s about me, and it goes something like this: For as long as I can remember, my questions, comments, concerns, and observations have prompted social others – strangers and less-strangers alike – to remark that I am “overly-analytical.” At some point, I stopped verbalizing my questions and thoughts as much, tired of accusations I did not understand; but I didn’t stop *thinking* those things. When I was 17, I went on a study abroad trip to Belgium and the Netherlands, where I fell in love with the paintings of Belgian surrealist artist René Magritte. I especially loved his series “L’empire des lumières” (The Empire of Light), which depicted contradictory night-/daytime images such as dark streets lit by lamplight under a bright, blue daytime sky. Soon after, as an undergraduate, I became enamored of law and political theory, and I used Jacques Derrida, Thomas Kuhn, John R. Searle, and Georg W.F. Hegel to discuss the evolution of constitutional law in my undergraduate thesis. A few years after that, I began graduate school. The first graduate class I took was called “Social

Constructions of Reality,” and the following semester, in a theories and histories course, I learned that Magritte is often invoked in discussions of symbols, representation, language, perception, and reality. In that same course, I learned about performance theory, and my world, it seemed, suddenly had context. My M.A. thesis focused on social constructions and performances of identity, and my doctoral dissertation sprouted from some of the ideas cultivated there. In this world, I was never in danger being accused of over-analyticalness; I was only prompted to construct more extensive lines of inquiry, to examine more thoroughly, and to observe more thoughtfully. In this world, I was at home.

“Of course I ended up here,” I tell myself now, as I write.

Of course.

It’s a nice little story, a story that forms a nice little map that shows how I got to this point in my life. But this story leaves a lot of information out; not due to an intent to deceive, or because I don’t remember any other circumstances, actions, and interests along the way – I know I cherry picked several disparate yet seemingly related events and mashed them together. Rather, the story leaves information out because of a combination of topical relevance and necessity. As Neil (2001) notes in his novel *American Gods*, quoted at the beginning of this chapter – and as many others have pointed out in literature, philosophy, and poetry alike – “the most accurate map possible would be the territory, and thus would be perfectly accurate and perfectly useless” (545). In other words, the scaling back and choices of what is represented and what is left out is necessary in the mapmaking and storytelling industries, otherwise maps and stories would themselves be the territories and experiences, leaving us mapless and storyless in our to-scale realities.

Gregory Bateson (1972) notes:

We say the map is different from the territory. But what is the territory? Operationally, somebody went out with a retina or a measuring stick and made representations which were then put upon paper. What is on the paper map is a representation of what was in the retinal representation of the man who made the map; and as you push the question back, what you find is an infinite regress, an infinite series of maps. The territory never gets in at all. The territory is *Ding an sich* and you can't do anything with it. Always the process of representation will filter it out so that the mental world is only maps of maps of maps, ad infinitum. (p. 460)

Stemming from such notions of representation, I am here broadly interested in the choices, language, and presumed knowledge that result in social representations of people, and in the ways that social representations of people affect the people thus represented. More narrowly, I am interested in how people are represented and, to varying degrees, constituted through medical texts, especially cancer patient information literature. Such literature is offered to newly diagnosed cancer patients at a moment of crisis and significant life change, a moment when patients may most need a map to help guide them through foreign and difficult territory.

Much like a map or a tale, cancer patient information literature uses selective information that is thought to be most helpful to patients regarding their cancers. However, patient information literature is both written for a vulnerable audience, and carries with it varying degrees of social, medical, scientific, and institutional authority. Thus, this literature has the potential to be especially impactful on those who need it, and the selections and choices regarding the type and extent of information that is included or excluded becomes especially important.

This dissertation examines cancer patient information literature published by the American Cancer Society (ACS), and seeks to answer questions regarding how the ACS communicates with patients through this literature. Seven sex-specific detailed patient guides were analyzed to answer questions regarding what is included in the texts, what is excluded from the texts, how these inclusions and exclusions affect the content, message, and potential impact of the literature, and if the tone, content, or message are impacted by whether the text is intended for a female or male audience.

In the following section, I first discuss how scientific knowledge is limited by the parameters of the paradigm in which it is situated. I then discuss how subject positions manifest through texts, as well as how discourse allows for the disruption and renegotiation of such ideological positions. Next, I discuss how paradigmatic knowledge situates subjects in medical contexts, and how gendered discourses are incorporated into medical “fact,” both reinforcing and being reinforced by the social biases from which they were developed. In other words, “scientists do not simply read nature to find truths to apply in the social world. Instead, they use truths taken from our social relationships to structure, read, and interpret the natural” (Fausto-Sterling, 2000, p. 116). I then discuss the authority given to dictionary definitions, which become especially powerful when applied in a medical setting, and especially when the medical subject may be in a state of crisis and more vulnerable to suggestion. Finally, I discuss an example that demonstrates how these elements work together: a medical paradigm of silence constitutes invisible breast cancer patient subjectivity, until one highly visible medical subject comes along and stimulates national social and medical discourse. This discourse disrupts the previously established ideology, and simultaneously renegotiates and redefines a broadly recognized “breast cancer patient” subject position, which ultimately relies on socially situated gender norms, leading to a

similarly situated medical discourse. Cancer patient information literature is developed within such paradigms, and offers vulnerable patients a narrative in which to situate themselves in a moment of disruption and destabilization.

World Maps en Flux

In 1962, physicist, philosopher, and historian Thomas Kuhn applied the notion of “paradigm shifts” to scientific thought, leaving scientific communities awash in controversy and uproar in his wake. Kuhn observed that scientific fields understood themselves, and were understood by the general population, as a knowledge base that developed through the accumulation of data, findings, and evidence. Kuhn challenged that notion when he asserted that, rather than developing through knowledge accumulation, scientific communities periodically undergo “paradigm shifts,” wherein the “facts” and “knowledge” that constitute the present paradigm are challenged by new theories and contradictory facts. Ultimately, the new way of understanding the world is accepted by scientific communities, the old establishment is edged out, textbooks are rewritten, and the knowledge set is replaced. Thus, Kuhn argues, scientific knowledge is not based on a linear accumulation of information; rather, scientific knowledge stems from how scientists perceive the world – and, by extension, the universe – at a given point in time. Thus, as human perception changes, so, too, does scientific knowledge.

To illustrate this concept, Kuhn uses the example of the Copernican Revolution, wherein scientific models of the universe shifted significantly as a result of a change in perspective. The established model at the time placed the Earth at the center of our solar system, with other planets and the sun orbiting around Earth. As western scientists’ observations of planetary movement became more accurate, established models required more and more tweaking to fit what was being observed. Copernicus offered a new model that placed the sun at the center, with

planets orbiting around it. However, Copernicus' new proposal proved "neither simpler nor more accurate than Ptolemy's system" (Kuhn, p. 75, 1962), and was ultimately rejected by his community. The problem with the Ptolemaic and Copernican models can be attributed to the tools – equations, theories, measurements etc. – available within the established paradigm: Copernicus' new model continued to use the scientific tools of Ptolemy's old model, in part because those tools could still more-or-less get the job done, even if the results were messy and, perhaps, ill-fitting. Imagine, for example, nailing a board with a screwdriver, or removing a deck screw with a hammer. Kuhn (1962) notes:

So long as the tools a paradigm supplies continue to prove capable of solving the problems it defines, science moves fastest and penetrates most deeply through confident employment of those tools. [...] As in manufacture so in science – retooling is an extravagance to be reserved for the occasion that demands it. The significance of crises is the indication they provide that an occasion for retooling has arrived. (p. 76)

It wasn't until later, after Galileo Galilei proposed alternative laws of motion, that Johannes Kepler rejected Ptolemaic tools and developed new measurements, equations, and theories, that the Copernican model was finally adopted. Galileo and Kepler's conjectures supported one another, strengthening their individual credibility, and ultimately helping uncover the path to Isaac Newton's development of physics that constitutes our present day understanding of the universe. In other words, the tools developed by and for a dominant paradigm – a dominant belief system – can hinder perception. "The Chinese, whose cosmological beliefs did not preclude celestial change, had recorded the appearance of many new stars in the heavens at a much earlier date" (Kuhn, 1962, p. 117). Indeed, even before new tools were established, the shift in perception was evident in "the very easy and rapidity with which

astronomers saw new things when looking at old objects with old instruments,” indicating that “after Copernicus, astronomers lived in a different world” (Kuhn, 1962, pp. 116-117). As these new interpretations gained credibility and attracted more and more followers, entire scientific communities began to change their overall perspectives, essentially revealing a completely new reality. Importantly, once a new paradigm is accepted, textbooks are rewritten. In so doing, learners are “interpolated” (Althusser, 1971, p. 117) into the paradigm, which hails subjects into the existing discourse

Kuhn’s work regarding science history, thought, and paradigm shifts also aligns with important rhetorical, literary, and social theory. Kuhn (1962) repeatedly addresses how a change in scientific perspective changes the way that scientists understand and thus interact with their worlds, noting, “though the world does not change with a change of paradigm, the scientist afterward works in a different world” (p. 121). Here, Kuhn is describing how paradigms construct boundaries that affect the perspectives and knowledge potential of the people who work within it.

Along a similar line, James Boyd White (1973) introduced the concept of “constitutive rhetoric.” White compares literary and legal texts, demonstrating the power of text to constitute the meanings of concepts and the “characters” in literary and legal stories. Over a decade later, Maurice Charland (1987) analyzed the constitutive power of text in his study of the *Peuple Québécois* in Canada. In his essay, Charland traces how the *Peuple Québécois*, a group of French Canadian pro-separatists in Quebec, came into existence in 1967 when a new political association, the *Movement Souveraineté-Association (MSA)*, declared in Quebec's majority language:

“Nous sommes des Québécois' ('We are *Québécois*') and called for Quebec's independence from Canada. This declaration marked the entry of the term 'Québécois' into the mainstream of Quebec political discourse. Until that time, members of the French-speaking society of Quebec were usually termed 'Canadiens français' ('French-Canadians'). (Charland, 1987, p. 134)

Thus, the subject “Peuple Québécois” was called into existence through the act of its being named. What is especially interesting in this case, is that despite the fact that it did not exist prior to 1967, the term “Peuple Québécois” was endowed with a history and national identity that was articulated in a rhetorical document called a white paper. According to the document, “*Québécois* were an oppressed *peuple* within the confines of Canada's constitution who would be better off with their own country” (Charland, 1987, p. 135). The paper was written as a historical narrative “in which *Québécois* were identified with their forebears who explored New France, who suffered under the British conquest, and who struggled to erect the Quebec provincial state apparatus” (Charland, 1987, p. 135). Thus, immediately upon their conception, the *Peuple Québécois* had a common history, desire, and goals.

When it came time to decide whether or not Quebec should be granted independence, the majority of people voted “no,” and Quebec remains part of Canada today. But the people who wanted independence, those who identified as *Québécois*, stepped into the subject position *peuple Québécois*, adopting the accompanying narrative as their own. Charland notes that “constitutive rhetorics are ideological not merely because they provide individuals with narratives to inhabit as subjects and motives to experience, but because they insert 'narratized' subjects-as-agents into the world” (143). In other words, in addition to providing people with narratives and a guide for how the world should be experienced, constitutive rhetorics allow

individuals to become “characters” within a story, and these “narratized” individuals become agents of the narrative, fighting for the ideals and goals implicit within the given narrative.

Kevin DeLuca (1999), in his explication of Ernesto Laclau and Chantal Mouffe’s conceptualization of articulation theory, highlights facets of social communities and constitutive rhetoric that closely mirror Kuhn’s discussion of scientific communities and paradigms. In his essay, DeLuca describes the formulation and inner workings of social norms and practices in social communities in much the same way that Kuhn describes scientific communities, including common themes of disruption, dissolution, reformulation, and reconstitution of norms and practices. In the realm of articulation theory, these disruptions are called “antagonisms.” DeLuca (1999) notes:

Antagonisms make possible the investigation, disarticulation, and rearticulation of a hegemonic discourse. Antagonisms point to the limit of a discourse. An antagonism occurs at the point of the relation of the discourse to the surrounding life world and shows the impossibility of the discourse constituting a permanently closed or sutured totality. (p. 336)

Importantly, as with scientific communities, the antagonism is a product of the society itself, pushing against and thus challenging the limits constructed by the social. “The limit of the social must be given within the social itself as something subverting it, destroying its ambition to constitute a full presence” (Laclau & Mouffe, p. 127, 1985). Of equal importance, DeLuca notes, is Laclau and Mouffe’s displacement of “the term *ideology* with *discourse*, an action that has important implications for rhetoric” (DeLuca, p. 338, 1999). While the term “ideology” carries implications of stagnant truths and essential subjects, and dichotomizes systems of belief and

infrastructure, the term “discourse” offers an encompassing and more flexible framework capable of evolving with the subjects that both constitute and are constituted by it.

Here, DeLuca’s explanation of ideologies shares parallels with Kuhn’s explanation of the relationship between scientists and scientific paradigms. Similarly, Kuhn’s call to recognize the human aspect inherent in scientific knowledge and endeavors, and to move away from the notion of scientific progress as the accumulation of knowledge, is aligned with DeLuca’s explanation of discourse.

Emily Martin’s (1991) essay “The egg and the sperm: How science has constructed a romance based on stereotypical male-female roles” demonstrates the symbiotic relationship between social and scientific discourses, and explains how both social *and* medical discourses construct and are constructed by the people they represent. For this study, Martin examined widely used textbooks from universities around the country (p. 486). She found that the information offered in the textbooks was heavily based on social stereotypes that implied “not only that female biological processes are less worthy than their male counterparts but also that women are less worthy than men” (p. 485).

Martin found that the textbooks framed women’s menstrual cycles in terms of waste and death, a failure to achieve the female body’s ultimate purpose of conception and reproduction. On the other hand, textbooks viewed the male body’s maturation of several hundred million sperm per day as an impressive feat of productive ability and stamina. Martin quotes a text that makes “the male/female, productive/destructive comparison more explicit: ‘Whereas the female *sheds* only a single gamete each month, the seminiferous tubules *produce* hundreds of millions of sperm each day’” [emphasis mine] (p. 486). Similarly, while male sperm were found to be “produced,” and celebrated for the male body’s continuous production of sperm from puberty to

senescence, female ova were described as a “slowly degenerating and aging” inventory, and inferior because female egg production is finished at birth (Martin, pp. 487-488, 1991). As a result, the male body is exalted for its active and productive existence while the female body is criticized for its static, unproductive, and wasteful state.

The textbooks went on to describe ovulation and fertilization using the same constructions, with power and action attributed to the male body and weakness and passivity attributed to the female body. Ultimately, these medical textbooks constructed a story wherein the mighty and heroic sperm must embark on a treacherous journey where it will overcome untold battles and hardships, fighting its way through the hostile territory of the female body. Only the strongest will survive, and only the mightiest of them all will possess the fortitude to locate the motionless, passive, waiting egg, and overcome its resistant barriers, successfully penetrating and thus saving it from certain demise.

Perhaps most disheartening is Martin’s point that, at the time of Martin’s study, scientific research had proven that the egg is the active cell in the fertilization process (p. 492). Research determined that the “tail” of sperm, previously heralded for its ability to achieve powerful momentum, actually has very weak thrust (p. 492). This change in perspective prompted researchers to ask different questions regarding *how* the sperm “penetrated” the egg, and they found that the sperm does not penetrate the egg, at least not as previously conceptualized. They found that the egg latches onto sperm (p. 493), then selectively binds with a specific sperm based on compatibility (p. 496). However, despite these findings, researchers seem determined to maintain the sperm/active, egg/passive dichotomy. Martin describes the backward application of the lock/key metaphor, wherein a researcher describes the sperm as the active key, and the egg as the passive lock, even though that application does not make sense:

It is as if Wasserman were determined to make the egg the receiving partner. [...] As the diagrams that illustrate Wasserman's article show, the molecules on the sperm are proteins and have "pockets." The small, mobile molecules that fit into these pockets are called ligands. As shown in the diagrams, ZP3 on the egg is a polymer of "keys"; many small knobs stick out. Typically, molecules on the sperm would be called receptors and molecules on the egg would be called ligands. But Wasserman chose to name ZP3 on the egg the receptor and to create a new term, "the egg-binding protein," for the molecule on the sperm that otherwise would have been called the receptor. (p. 496)

Martin points to the historically mutual influences between the social and natural sciences to answer the implicit question, "But, why?" Martin describes how questions in the nineteenth century about how to avoid an increase of the poor was inspirational to Darwin's writing of *Origin of Species*, which, in turn, was used as a model for "Social Darwinism" to justify social order (p. 500). The same phenomenon, Martin argues, is occurring here: questions of gendered social order are answered with scientific models that can then be used to naturalize social inequalities between men and women, essentially "implanting social imagery on representations of nature so as to lay a firm basis for reimporting exactly that same imagery as natural explanations of social phenomena" (p. 500).

Focusing more closely on elements within scientific and social models, the dictionary has been recognized for its role in the naturalization and perpetuation of social inequalities, biases, and perceptions, including representations of sex, gender, sexuality, and sexual and reproductive organs (Braun & Kitzinger, 2001b; Fournier & Russell, 1992; Gershuny, 1977; Metoyer & Rust, 2011). Culturally, dictionaries are considered/act as the authority on the meaning of words, and, combined with the authorlessness of dictionary definitions, carry the notion that dictionary

definitions are objective observations of truth and fact (Braun & Kitzinger, 2001b; Potter, 1996). Furthermore, “dictionaries, in choosing to recognize one set of values over other possible sets of values, give the values they select stability and authority” (Landau, 1985).

In an analysis of 16 English language dictionaries and 12 medical dictionaries, Virginia Braun and Celia Kitzinger (2001b) found that definitions of the clitoris, vagina, and penis were heavily influenced by cultural stereotypes and assumptions regarding women and men; while the penis was defined by its function – especially its sexual function – and as an independent organ, the clitoris and vagina were defined in terms of location and usually in opposition to the penis. The English language and medical dictionaries shared many similarities regarding how they defined bodies as active, passive, sexual, reproductive, prominent, or unknown depending on the assumed gender of those bodies. As a result, “these dictionary definitions of women’s (and men’s) genitals re-present a historical common sense account of traditional male-female sex role stereotypes embodied in the genitals as natural ‘fact’” (Braun & Kitzinger, 2001b, p. 228).

Nearly two decades after Martin’s “The egg and the sperm,” and one decade after Braun and Kitzinger’s “Telling it straight,” Andrea Bertotti Metoyer and Regina Rust (2011) found that many of the same issues regarding medical-scientific paradigms and definitions persist. In a study that followed up on and extended Martin’s work, Metoyer and Rust (2011) examined the most widely used gynecology textbooks among the 132 medical schools in the United States (p. 183). Invoking Kuhn, Metoyer and Rust’s study focused on “how gender stereotypes permeate the dominant medical paradigm” (p. 177). While the heroic sperm saving the damsel-in-distress-egg adventure story was mostly absent, Metoyer and Rust once again found that contemporary medical texts still “framed sperm in primarily active terms while describing the egg in passive terms” (p. 186). Additionally, despite that Metoyer and Rust analyzed gynecology textbooks,

“the terms sperm/spermatozoa appeared 2.6 times more often than egg/ovum/ova/oocyte [...] and 1.25 times more often than cervical mucus” (p. 186). They note that this emphasis might suggest that “science reveres male contributions to the reproductive process more than female contributions,” and that it may also “indicate the cultural obsession with ‘man’s precious fluid’ that Lisa Jean Moore described in her book, *Sperm Count*” (p. 188). Furthermore, despite its integral role in reproductive function, the textbooks described the cervix in terms of place, “as a location, destination, object, route, or opening” (p. 189), and indicated that cervical mucus was something that “sperm would normally overcome, rather than material that protects and transports it” (p. 191).

Metoyer and Rust list three important implications (p. 198). First, they point out that the assumptions present in and perpetuated by medical texts serve to make findings less informative, which in turn means that gynecologists will inevitably leave their patients less informed. Second, the presence of misleading images in regards to contraceptive education may lead physicians to form subconscious ideas about their patients that are similarly negative. Finally, and again invoking Kuhn, Metoyer and Rust note, “because textbooks relay the dominant paradigm to the next generation of scientists (Kuhn 10), these gendered assumptions also affect the types and fervor of questions researchers will ask regarding contraception itself” (p. 198), which, in turn, “might signal that the same dominant ideas found in these medical textbooks affect the research questions social scientists ask and leave unasked” (p. 199).

The socio-medical subject “breast cancer patient” offers an illustration of how the intersections of subject positions (DeLuca, 1999) manifest as a result of the intersection of several subject positions at particular nodal points, subsequently producing a socio-medical script for a subject position that is socially, medically, scientifically, and definitionally

constituted. Tasha Dubriwny marks First Lady Betty Ford's breast cancer diagnosis in 1974 as the formation of the breast cancer subject position. Prior to Ford's diagnosis, breast cancer was an under-diagnosed disease and taboo topic that killed patients quietly outside of the public eye. Through the media coverage that Ford's case received, the topic of breast cancer was brought out from the shadowy realms of taboo and into the spotlight of national importance. It was during this transition that "The Breast Cancer Patient" subject position arose (Dubriwny, 2009).

Present day conceptualizations of breast cancer patienthood are derived from two key aspects of Ford's experience (Dubriwny, 2009). First, Ford's case was framed as a medical success narrative. Within this frame, the breast cancer patient narrative is flattened into a linear model so that there is a beginning (diagnosis), suspenseful arc (treatment and prognosis), and resolution (cure or remission). It is important to note here that while many patients' illnesses end with death, or, alternately, do not have an apparent end in sight, these two scenarios are not accepted as part of the present day breast cancer patient subject position – but more on that later. Second, within this flattened, linear narrative, Ford was articulated as an "ideal patient." Together, "this narrative and the figure of the ideal patient are created within the context of Ford's public persona of First Lady and thus often emphasize[d] the issue of proper womanhood over and above issues such as new medical developments in breast cancer research" (Dubriwny, 106).

Because of Ford's case, breast cancer research increased, and the research revealed devastating facts and figures regarding breast cancer patient prognosis. However, as Ford's treatments and medical research occurred simultaneously, media coverage on medical research was usually begun, ended, or paired with Ford's individual medical success narrative. These success narratives highlighted Ford's fulfillment of her role as wife and mother, and focused on

her upbeat attitude, physical stamina, and mundane daily activities. The inclusion of Ford's upbeat success narrative with every article on breast cancer research cushioned the frightening realities revealed by the research. Consequently, the information provided through breast cancer research became further and further removed from the perceived reality of what a breast cancer patient *was*; in other words, the media's positive depiction of Betty Ford as a breast cancer patient overshadowed the negative depiction of the disease presented by medical research, ultimately resulting in the aestheticization of breast cancer (Dubriwny, 2009).

Today's breast cancer narrative is a cheerful, strangely beautiful, and heartwarming story of survivorship, in which corporations and philanthropic masses raise and donate billions of dollars every year to find new and better treatments for those afflicted with the disease, and where cause and prevention are rarely mentioned. In this narrative, breast cancer is conceptualized as an enriching experience, and breast cancer patients must be enthusiastically concerned with the bright side of the cancer patient experience (King, 2006; Dubriwny, 2009).

The Importance of Maps: Patient Information Literature

The doctor's voice came stumbling into the room. "This... this isn't good. This is bad. This is cancer." Like many patients, the pronouncement of cancer pushed me off balance. Through their synthesis of published qualitative research, Germeni & Schulz (2014) found that "even when expected, the announcement of cancer diagnosis caused a kind of shock reaction" among patients (p. 1375). This finding rings true in my own diagnosis experience; even though medical institutions at large were generally dismissive of my health concerns, logically, I knew I had cancer; there were too many clues leading up to the diagnosis for me to think otherwise. Physically I knew because the mass had grown in size, and at the point of diagnosis, I could see it under my skin. My first medical affirmation came after my initial ultrasound when the

technician locked eyes with me and said, “I’m not supposed to say anything, but they’re going to want you to get this checked out. You need to get this checked out.” My suspicions were all but confirmed during my first visit with my diagnosing doctor: Toward the beginning of my first appointment, I asked a question about the biopsy, and my Lewis Black-esque doctor chuckled dismissively, much like the doctors before him when I’d asked for referrals for an ultrasound. He said something about not getting ahead of myself and probably not needing a biopsy, and that even if I did get a biopsy, he was booked for weeks; he was priming me for more waiting.

Then he hung the ultrasound films on the light board, and upon seeing the films for the first time, his demeanor changed completely. Suddenly, not only did I definitely need a biopsy, but I definitely needed it right away; the very busy doctor that I’d had to wait three weeks to see made a space for me the following day, a Wednesday, and when they called on Thursday and asked me to come to the office by 5 pm, I knew; they weren’t opening up their schedules for my convenience to tell me I was fine.

Yet, when the doctor said it, when he said “This is cancer,” any logical understanding I’d had of my situation dissolved into a kind of madness, an internal struggle between acceptance and denial of what I *knew*, and a fight between laughing and crying because of the affirmative diagnosis. I honed in on the absurdity of the situation, locating my own comic relief within the minutia of the interaction. I can still hear his words, still see the way his head shook and hands jerked as he said them. I can watch him walk toward me, looking at his clipboard as he speaks; I can hear his scratchy, uneven voice spilling my fate into the room, perhaps accidentally; I can feel the rush of embarrassment as I stretch to look around him through the closing door, worried that someone might have overheard; I can see the way he blinks as he looks up at me, the way he hesitates when he meets my eyes, then looks down again, carrying on with the clipboard; I can

feel the anticipation as I wait for him to admit it's a joke; I can feel the struggle as I physically fight myself to keep from laughing; and I can feel my chest tighten, throat clench, and eyes burn as I realize that I must tell my little brother that I have cancer. Like pressing play on a familiar film, the scene always plays out exactly the same way, the sounds, expressions, movements, and feelings vivid and well known.

Within that scene, the doctor divulged significant information. He explained my results, told me what tests I would need next, discussed different treatment options, explained the treatment option he recommended, and explained my general cancer treatment timeline. However, the only things I clearly remember him saying were at the very beginning and very end of that interaction: first, that I had cancer, and, at the end, that he was going to get me some literature. Everything in between was a blur, a communication event fraught with one-sided struggle and uncertainty: struggle to maintain composure, struggle to comprehend meaning, uncertainty about the seriousness of the situation, and uncertainty about hurting my brother. In that moment, I was alone in discord.

Popular media representations of cancer diagnoses use sound and camera effects to depict the state of confusion, disbelief, and shock that many people describe when they reflect on their cancer diagnosis stories. Two recent examples include the movie *50/50* (2011), a movie about a young man who is diagnosed with a rare cancer and has a 50% chance of survival, and *Breaking Bad*, a five-season television series depicting a lung cancer patient's rise (or descent) from a passive father, husband, and teacher to a drug kingpin.

Conceptualized by friends Will Reister and Seth Rogan after Reister's real-life diagnosis with a rare spinal cancer, the movie *50/50* highlights cancer patients' experiences and relationships through a mix of drama and humor. The diagnosis scene opens with a shot of Adam

(Joseph Gordon-Levitt) walking up a long, concrete ramp toward a glass and steel office building. The scene cuts to Adam sitting in a chair at a desk as he reads a pamphlet titled “Living With Incontinence.” On the other side of the desk is a computer and office chair – the doctor’s side of the desk. As the doctor enters the room, he does not make eye contact with Adam or address him in any way. As the doctor walks behind Adam and around to his side of the desk, he begins dictating the results of Adam’s MRI into a recorder. By not addressing or even looking at Adam, the scene conveys a sense of isolation and alternate reality, causing the viewer to wonder, “Who does that?” Adam tentatively raises his hand, at which point the doctor, now sitting across from Adam, hesitates and then stops recording. Adam apologizes for not understanding the medical jargon, and asks if something is wrong with him. The doctor turns the computer screen toward Adam and points to digital images of his MRI results. Using medical jargon, the doctor names Adam’s condition. Adam again apologizes for not understanding and the doctor interrupts, telling Adam it’s a malignant tumor.

Adam smiles and laughs in disbelief as he tells the doctor, “That doesn’t make any sense. I don’t smoke. I don’t drink. I recycle,” (Reister & Levine, 9:08, 2011). The doctor responds to Adam’s points by telling him that his case is fascinating because it’s incredibly rare. As the doctor explains, Adam’s face begins to sink, and a high-pitched buzzing noise reminiscent of ears ringing begins to drown out the doctor’s voice (9:23) as the screen blurs the doctor’s figure. The doctor’s voice echoes in the background, pieces of words like “neuro” fading in and out of the intensifying ringing sound. The single word that clearly makes it through the noise is “chemotherapy.” The ringing, echoing voice and blurred vision continue for nearly 20 seconds, emphasizing the shock and confusion the viewer could see on Adam’s face, and indicating that

Adam is preoccupied with other thoughts. As the buzzing and blurriness clear, the doctor's monotone voice fades back into coherence, and Adam stands and walks to the window.

When the doctor begins to explain the potential effects of treatment on fertility, Adam, unconcerned about his fertility in the face of potential death turns and asks, "But I'm gonna be ok?" (Reister & Levine, 9:53, 2011). The doctor pauses for a moment and then begins, "If you need someone to talk to, we have an excellent staff here at the hospital..." (Reister & Levine, 9:58, 2011), and as he continues, Adam turns toward the window and the doctor's voice fades into the background. The camera angle changes, and viewers find themselves looking in on Adam from outside the building, city noises in the background muffling the doctor's voice. The camera pulls back and angles up from the sidewalk below, making Adam appear small, barely noticeable behind the glare of the top floor window. The music rises and the diagnosis scene ends. The viewer is left with the sense that Adam feels isolated, alone, and distracted. In the next scene, Adam's *WebMD* research reinforces the notion that Adam requires additional information to explain his diagnosis, potential treatment options, and prognosis.

In the pilot episode of AMC's hit series *Breaking Bad* (2008), protagonist Walter White (Brian Cranston) is diagnosed with terminal lung cancer early in the episode. Similar to the diagnosis scene in *50/50*, sound and camera angles create a sense that the individual being diagnosed is shocked and unable to pay attention to the doctor's diagnosis.

The diagnostic sequence begins with Walter in an ambulance. The first responder in the vehicle asks Walter if he is a smoker. Walter responds in the negative, seemingly surprised. In the following scene, the viewer sees Walter wearing a gown in an MRI machine. Deep bass notes precede the cacophony of the MRI machine, lending an ominous tone. The cacophony fades into a ringing sound that bleeds into the following scene where Walter is sitting in his diagnosing

doctor's office. With the camera focused on Walter's face, the ringing noise rises as a slowed, slurred human voice becomes audible. The camera angle changes to Walter's perspective, and the camera focus is on the mouth of a middle aged white male doctor. As the doctor's mouth moves in slow motion, layered tracks of the doctor's speech play at different speeds in conjunction with the ringing sound. Walter's focus moves to a small mustard stain on the lapel of the doctor's white coat. After a pause with the mustard stain, the camera angle changes again, focusing on Walter. The doctor's voice comes across clearly when he asks, "Mr. White?" recognizing that Walter appears distracted.

The combination of sound effects, voice alteration, overlapping speech, slow motion picture, and camera angle give the scene a surreal quality, and even as the doctor's voice becomes intelligible, the ringing sound persists until Walter finally responds to the doctor's prompt. As the scene progresses, the viewer gets the sense that Walter is in a state of shock.

Doctor: You understood what I've just said to you?

Walter: Yes. Lung cancer. Inoperable.

Doctor: I'm sorry, I just need to make sure you fully understand.

Walter: Best-case scenario, with chemo, I'll live maybe another couple years.

[long pause]

Walter: It's just... you've got, *mustard*, on your, right there. You've got, mustard. There. Right there.

While Walter's summary indicates that he registered the doctor's diagnosis, his sustained preoccupation with the mustard stain on the doctor's white coat indicates that Walter is distracted, in shock, and does not fully comprehend the gravity of the situation.

Each of these popular culture depictions of cancer diagnoses offer viewers the sense that the diagnosis event itself is overwhelming. Furthermore, while the viewer is not privy to what Adam and Walter are thinking about during the scenes, the questions and life circumstances of each character offer an idea: In *50/50*, when Adam interrupts the doctor's explanation of potential effects on fertility to ask, "But I'm gonna be ok?" (Reister & Levine, 9:53, 2011), the viewer understands that Adam is more concerned about whether or not he will "be ok" than he is with family planning; and in *Breaking Bad*, before Walter is diagnosed with lung cancer, viewers learn of the White family's precarious financial situation and the impending birth of Walter's second child, 16 years younger than his son. Thus, in each instance, the patients are preoccupied by the impact of the diagnosis on their lives, making the actual diagnosis .

Both diagnosis scenes in *50/50* and *Breaking Bad* are reflective of my own experience in some way: Much like Adam, the notion that I had cancer seemed impossible; much like Walter, I was concerned about my family and financial situation; and I felt distant, distracted, and I did not fully hear or comprehend everything the doctor told me about potential surgeries, treatments, and side effects. If my diagnosis story were translated into a scene in a movie or television series, it would look something like this:

The patient and her sister sit in the patient room chatting idly. Suddenly, the door swings open. The sisters stop speaking and both look toward the door as the doctor sweeps into the room and immediately begins speaking. Looking down at his clipboard, he makes the diagnostic pronouncement: "This [pause], this isn't good. This is *bad*. This is *cancer*." The doctor's voice begins to fade and the camera angle changes to look in through the closing door as the patient leans to peer around the doctor, worried that someone outside the room may have heard. Back inside the room, the patient sits up and directs her attention back to the doctor as an ear-ringing

noise begins to rise. The doctor's speech is slowed and layered to depict conceptual time interference by playing past, present, and future speech simultaneously. The scene is playing in slow motion and we're looking at the doctor from the patient's point of view. The camera focuses on the doctor's face, clipboard, and jerky movements, then goes out of focus as the ear-ringing noise continues to rise, almost completely overpowering the doctor's voice. The camera angle changes to a view of the patient, who is gripping the edge of the table she's sitting on and contorting her face as she mostly unsuccessfully tries to keep from smiling. The angle switches again, focusing on the doctor's twitchy facial expressions, his seemingly random hand movements, and, of course, the clipboard. The camera angle goes wide again and resumes normal speed. The doctor pauses, his face conveying confusion as he looks at his patient's seemingly amused expression, and the ear-ringing noise lowers. We can clearly hear the doctor as he tells the patient that he's going to get her some information, and we understand that this doctor recognizes that his patient is not fully present.

In addition to demonstrating patients' need for information, each diagnosis scene also provides a unique depiction of patient information acquisition. In *50/50*, the scene following Adam's diagnosis shows Adam searching *WebMD* for information about his cancer; in *Breaking Bad*, Walter does not seek cancer information, although he does begin seeking information about methamphetamine production; and my character sought additional information through the patient information literature provided by the doctor at the diagnosing medical institution.

Adam's Internet search is demonstrative of the wide use of online resources for information acquisition. With approximately 2.8 billion Internet users worldwide and 254.3 million users in the United States (US), the Internet has proven to be a pervasive and revolutionary force in commerce, communication, and information technologies. The US ranks

28th for Internet pervasiveness with 81% of its population using the Internet. A 2010 study showed that 80% of breast cancer patient participants had access to the Internet, with 63% searching the Internet specifically for cancer related information (Castleton et al., 2010)). Of those surveyed, 76% said that they used the Internet to acquire additional information about their disease after the initial diagnosis (Castleton et al., 2010). In addition to the prevalence of Internet as a research tool, Adam's age (27 years old), implied socioeconomic status, and level of education all point to an increased likelihood of Internet use for information acquisition (Carlsson, 2000; Walsh et al., 2010; Ybarra & Suman, 2008). While Adam's search on *WebMD* may initially come across as comical considering the popular joke that "all *WebMD* searches lead to cancer," studies indicate that *WebMD* is widely utilized by cancer patients as a research tool (Castleton et al., 2011; Maloney et al., 2013). One study found that *WebMD* was utilized by 42.5% of study participants, second only to the American Cancer Society at 78.4%, and utilized more frequently than the National Cancer Institute website (36.5%) (Castleton et al., 2011).

On the other hand, 50-year-old Walter White from *Breaking Bad* is not shown seeking any cancer related information beyond the verbal information he receives from his doctor. While Walter is portrayed as actively dismissal of medical advice and care from medical professionals based on his preoccupation with money and his initially genuine desire to leave his family financially secure when he dies, he eventually submits to a treatment schedule decided on by his family and doctors. Although the plot is focused on Walter's transition from a passive employee, teacher, and family man to an aggressive and dangerous producer and distributor of methamphetamines, Walter's initial patient subjectivity highlights some important factors. Walter does not initially seek additional cancer related information, despite his advanced degree, relatively young age at diagnosis (50 years old), and middle-class socioeconomic status, all

indicative of higher information acquisition rates and types (Carlsson, 2000; Castleton et al., 2011; Walsh et al., 2010; Ybarra & Suman, 2008). However, Walter's character echoes several key aspects of patient information seeking behavior.

Patients who reportedly avoid further information acquisition after diagnosis do so for a range of often intersecting reasons (Germeni & Schultz, 2014). In addition to Walter's status as a male patient, which automatically reduces the likelihood of patient information acquisition (Carlsson, 2000; Castleton et al., 2011; Finney Rutten, Squiers, & Hesse, 2006; Walsh et al., 2010; Ybarra & Suman, 2008), the study indicates that Walter might avoid additional information for four reasons. First, Walter might avoid seeking cancer information as a way to cope with fear/maintain hope (fear of failing his family, hope that they'll be ok when he's gone). Second, Walter seems to implicitly trust the diagnostic tests and the medical expertise offered by the diagnosing doctor. Third, at the time of diagnosis, Walter is dealing with concurrent life events including financial insecurity and the impending birth of his daughter. Fourth, beginning in the pilot episode, Walter demonstrates a need to maintain control in his life. While Germeni & Schultz's study links patients' medical information acquisition tendencies to a desire to regain control in their lives, Walter's absolute acceptance of the medical expertise offered by the diagnosing doctor fixes the locus of Walter's quest for control within another concurrent life event: financial insecurity. Ultimately, it is this desire for control that drives the character transformation of the terminally ill Walter White. Finally, Walter's reliance on medical staff and family regarding his acceptance of treatment reflects findings that patients often rely on medical professionals and friends/family when making medical decisions (Carlsson, 2000; Kelly et al., 2010; Hesse et al., 2005; Roscoe, Malphurs, Dragovic, & Cohen, 2001; Walsh et al., 2010;

As a young, middle class, female breast cancer patient, my information acquisition

tendencies reflected study findings that breast cancer patients have high information needs (Satterlund, 2003; Ussher, Perz, & Gilbert, 2012; Ussher, Perz, & Gilbert, 2014). However, while I sought multiple opinions from a variety of medical professionals in different fields and carefully studied patient information literature, I held closely the words and literature offered by doctors and well-known institutions, ultimately rejecting the Internet as a resource.

The diagnosis event is but one in a series of interactions between doctors and patients, something oncologists are acutely aware of (Roscoe, Tullis, Reich, & McCaffrey, 2013). As a result, patient information literature becomes part of the ongoing conversation that occurs between patients and medical professionals. The patient information literature I received at almost every medical visit or interview at the beginning of my cancer experience gave me a sense of who I needed to be in order to survive the disease. The literature told me what to expect, what to ask, how to respond, what was important and, by omission, what was not important, what I did not need to/should not ask, and what I did not need to think about concerning my cancer and treatments. My doctors and surgeons often reiterated what I read in the patient literature, and what my doctors and surgeons said was often reiterated in the patient literature I went home with. Essentially, my doctors and the patient literature their institutions supplied cultivated my understanding of my disease and informed my patienthood. Ultimately, the information I received as a patient acted as a map to the new world I suddenly found myself in.

At an essential level, we live our lives are through the model of the tale that Gaiman (2001) points to, with questions such as “How did it go?” and “How did you meet?” requesting and requiring that the answerer offer the “tale” version and *not* the lived experience version, so that unrelated and unnecessary details are omitted from our explanations. It is through these tellings that narratives are created. The patient information literature routinely offered to cancer

patients at diagnosis and throughout their cancer patienthood is designed to help guide patients through their cancer experiences, with the most comprehensive literature covering a wide array of information. As may be expected, narratives develop within this literature, and as may also be expected, “narratives that might make sense of recent or dramatic events tend to be evaluated as more important than those that seem peripheral to immediate concerns” (Loseke, 2007, 665). This dissertation examines some of these important documents. Specifically, this dissertation examines the American Cancer Society’s (ACS) aptly named “Detailed Guides.” In the next chapter, I will discuss the history and role of the American Cancer Society in cancer research and development, as well as the literature selected for this study, and the method used to analyze the data. In chapters 3 and 4, I will analyze the selected detailed guides, and in chapter 5 I will discuss some implications and ways they can be addressed.

CHAPTER 2: METHODS

“We nourish ourselves with the stories we hear and read; we metabolize them and incorporate them into our tissues, derive energy from them, become more of who we are by virtue of their fuel. [...] We do what we do as readers not only for our own good but also because our lives depend on it.”

Rita Charon, 2008

The American Cancer Society

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In 1913, a small group of doctors and businessmen founded the American Society for the Control of Cancer (ASCC) in New York, NY. The mission of the 10 doctors and 5 businessmen was to raise public awareness of cancer as a means of lifting the shroud of mystery and fear that kept cancer a taboo subject, with the goal of researching and understanding cancer – at the time, a death sentence – in order to prevent, treat, and cure the disease. Thanks to the dedication of the Women’s Field Army, nationwide partnerships with the ASCC rose from 15,000 to 150,000 participants between 1935 and 1938. After World War II, the ASCC seized upon the opportunity to bring renewed attention and interest to their movement, and in 1945 they reorganized as the American Cancer Society (ACS). The following year, \$4 million was donated to the ACS, and they dedicated \$1 million to establishing and funding their world-class research program.

Today, the ACS is the largest voluntary health organization in the United States. With over 2.5 million dedicated volunteers and an impressive cancer research resume, the ACS prides itself on its position as “a global leader in the fight against cancer” (Our History, 2015). To date, the ACS has invested over \$4 billion in cancer research, and has “recognized and provided the funding 47 researchers needed to get started and go on to win the Nobel Prize” (Our History,

2015). As a result of their dedication to cancer research, the ACS has been at the forefront of cancer-related policy and law changes at state and federal levels. The ACS was integral to the Surgeon General's report on the link between smoking and cancer as well as the resulting changes in policy and federal investment; the ACS contributed to the passage of the National Cancer Act in 1971, which expanded the reach of the National Cancer Institute (NCI); and the ACS has stepped up to fill gaps both in the NCI's focus on cancer prevention and education, and to fill gaps in research funding left by decreased funding from the National Institutes of Health. Furthermore, the ACS has developed clinical guidelines for cancer screening tests and nutritional and physical activity to aid in cancer prevention.

In addition to having a significant presence in and effect on cancer research and government policy, the ACS has a significant presence in and effect on cancer information, services, and assistance for the general public. The ACS offers free information to anyone who wants it, including a toll-free phone line staffed by trained Cancer Information Specialists 24/7, an online chat feature available 7am-7pm CST Monday-Friday, and a broad range of pamphlets, literature, and DVDs. Information material published by the ACS is made widely available to patients, not only through medical offices and institutions, such as the H. Lee Moffitt Cancer Center and Research Institute in Tampa, Florida, but also online in HTML and PDF format; by request through the ACS website, Cancer.org; email; or by calling the ACS 24/7 phone line. All of the ACS published patient information material is available free of charge. In 2014 alone, the ACS filled over 800,000 requests for information via phone, email, and online chats. Additionally, the ACS provided 1-on-1 guidance for 56,000 patients, helping them understand their diagnoses and connecting them with needed resources.

Finally, holding to its foundational notion that public awareness is key to effectively fighting cancer, the ACS runs Relay For Life®, the “worlds largest movement to end cancer,” with 4 million people participating in 6,000 Relay For Life® events throughout the world every year (Fact Sheet, 2015). The ACS is also a leader in breast cancer awareness, with their Making Strides Against Breast Cancer® event uniting nearly 300 communities throughout the US to raise awareness and money “to finish the fight against the disease” (Fact Sheet, 2015).

Patient Detailed Guides of the American Cancer Society

Considering the American Cancer Society’s (ACS) rich historical background and substantial reach concerning public awareness, research, government decision making, federal policy, clinical guidelines, and distribution of patient information material, the influence and importance of the patient information material they provide must not be understated. Rather, it is important to understand that the patient information distributed by the ACS is imbued with authority. In addition to the ACS’s medical authority, ACS information is granted additional authority when handed or referred to patients by a medical professional. Because of these layers of medical authority, patients are automatically more likely to not only trust the information provided to them, but also to believe assertions made through the information and to follow suggestions offered by the informational source. In other words, the well-established research and medical authority of the ACS, combined with the authority of the medical professional or medical institution that provides the information to the patient, gives patients the sense that the information provided by the patient detailed guides (DG) is trustworthy. Additionally, the medical authority present in the DGs, combined with the notion of the DG as a purveyor of objective fact, makes the reader more likely to be influenced by assertions made in these texts, even if the patient previously recognized the assertion as a value judgment or opinion. For

example, if a patient reads a cancer blog and subsequently developed the belief that a strict diet of raw foods, including fruits, vegetables, and fish, would result in the best treatment and recovery outcomes, but that patient then read in an ACS publication that raw foods carry a substantial risk of bacterial infection to patients with compromised immune systems, the socio-medical authority imbued in the ACS publication would encourage the patient to read the nutritional information as fact based, leading them to question their previously held beliefs (Braun & Kitzinger, 2001; Metoyer & Rust, 2011; Mukherjee, 2010).

Thus, the type of information offered in ACS DGs, as well as the way that information is presented to patients, has the potential to strongly influence patient subjectivity and patient notions of health and health responsibility. Therefore, ACS DGs must be closely scrutinized in order to ensure that patients are comprehensively and responsibly served. This dissertation seeks to examine the nature and presentation of information offered to patients through American Cancer Society's cancer patient detailed guides, which are presented as comprehensive guides meant to inform patients about cancer basics, including cancer anatomy, prevalence, risk factors, prevention, detection, available treatments, associated side effects, and post-cancer expectations and recovery. More specifically, this dissertation seeks to examine the nature of the informational content offered by ACS' DGs, and how that content is contextualized, organized, and delivered. Prompted by my own involvement with cancer patient information literature and my own experiences in clinical settings, I became interested in representations of gender, sex, and sexuality in cancer patient information literature. A preliminary examination of some of the guides indicated that the detailed guides "speak" to patients differently based on their perceived gender, which led to an increased interest in exploring these differences. As a result, this dissertation is concerned with how medical and social ideologies surrounding gendered bodies

are perpetuated through literature produced by medical institutions. Specifically, this dissertation examines the constitutive rhetoric present in American Cancer Society cancer patient detailed guides, and analyzes how those ideologies impact the interpretation of information, which in turn reinforces gendered ideologies and patient subjectivities.

Data Sources

The American Cancer Society (ACS) cancer patient detailed guides discussed in this dissertation range between 43 – 85 pages in length. The 7 guides examined in this dissertation are written for sex-specific cancers – ovarian, vaginal, uterine, cervical, endometrial, penile, prostate, and testicular. These guides were chosen because they are directed at strictly male and female audiences, thus allowing for an examination of how the guides “speak” to patients based on their perceived gender and an exploration of similarities and differences in literary, linguistic, and structural components. While the breast cancer DG was initially included in the sample, the size and scope of the breast cancer DG analysis was sufficient for its own dissertation, and required a significant amount of analysis beyond the scope of this project, including examinations of the breast cancer movement, rhetoric surrounding the disease, and the subject position already available to and imposed upon breast cancer patients.

Of the 7 guides, 3 are available in print and PDF format, and 4 are available only through the ACS’s website in PDF format. While there is a palpable difference between holding the bound guides with thick, glossy covers and pages and holding a stack of thin, flat, unbound papers, the layout of the information does not change between the bound guides and their PDF versions. For the purpose of this dissertation, I will refer to the informational unit as “guide(s)” or “patient guide(s)” regardless of whether they are in bound or PDF format, except for when the differences in presentation and patient access are relevant to the discussion.

A close reading of 7 American Cancer Society (ACS) patient detailed guides (DGs) was conducted. The DGs analyzed are listed below and include the type of cancer each document addresses, the length in pages of each document, the last date the document went under medical review, and the last date the document was revised.

Table 1: Sample Selection

Cancer Type	Number of Pages	Last Medical Review / Last Revised (MM.DD.YY)
Cervical	58	01.18.12 / 01.17.13
Endometrial (Uterine)	51	7.25.12 / 01.17.13
Ovarian	62	03.21.13 / 03.21.13
Penile	47	05.02.12 / 01.17.13
Prostate	85	02.27.12 / 09.04.12
Testicular	46	05.04.12 / 5.14.12
Vaginal	43	01.30.13 / 01.30.13

As previously noted, each DG has the same basic structure outlined above, with the same or similar section titles throughout. This structure helps to guarantee that a wide breadth of topical information is addressed, and that continuity across patient communities is maintained so that the common concerns and questions posed by patients are answered in a way that is specific to each cancer type. Thus, while the DGs share common section titles that address a wide range of questions and concerns, the content of each section is tailored to the specifics of each cancer type.

All guides are organized using the following format:

Section title

Level 1 heading

Level 2 heading

Level 3 heading

Bullet points are used to separate distinct points within section levels. An example of how guides are laid out using titles, headings, and bullet points can be seen in the images from the PDF version of the ACS ovarian cancer guide below.

Section title	→	How is ovarian cancer staged? <p>Staging is the process of finding out how widespread a cancer is. Most ovarian cancers that are not obviously widespread are staged at surgery. One of the goals of surgery for ovarian cancer is to take tissue samples for diagnosis and staging. To stage the cancer, samples of tissues are taken from different parts of the pelvis and abdomen and examined under the microscope.</p> <p>Staging is very important because ovarian cancers have different prognoses at different stages and are treated differently. The accuracy of the staging may determine whether or not a patient will be cured. If the cancer isn't accurately staged, then cancer that has spread outside the ovary might be missed and not treated. Once the cancer has been given a stage it does not change, even when it comes back (recurs) or spreads (metastasizes) to new locations.</p> <p>Ask your cancer care team to explain the staging procedure. After surgery, ask what your cancer's stage is. In this way, you will be able to make informed decisions about your treatment. One of the reasons it is important to be operated on by a gynecologic oncologist is that you are more likely to be staged accurately.</p> <p>Ovarian and fallopian tube cancer is most often staged using the <i>FIGO system</i>. This system relies on the results of surgery to determine the extent of the primary tumor (often described by the letter T), the absence or presence of metastasis to nearby lymph nodes (described by the letter N), and the absence or presence of distant metastasis (described by the letter M). This information is combined to determine the final stage. Primary peritoneal cancer (PPC) is staged in a similar way, but there is no stage I.</p> <p>The American Joint Committee on Cancer has another way to stage ovarian, fallopian tube, and primary peritoneal cancers. This also uses T, N, and M categories, however this staging is slightly different from the most recent FIGO staging.</p>
Level 1 heading	→	Stages of ovarian and fallopian tube cancer <p>Once a patient's T, N, and M categories have been determined, this information is combined in a process called <i>stage grouping</i> to determine the stage, expressed in Roman numerals from stage I (the least advanced stage) to stage IV (the most advanced stage). Many stages are divided into substages designated by adding letters and sometimes additional numbers to the Roman numerals.</p>
Level 2 heading	→	Stage I <p>The cancer is only within the ovary (or ovaries) or fallopian tube(s). It has not spread to organs and tissues in the abdomen or pelvis, lymph nodes, or to distant sites.</p> <p>Stage IA (T1a, N0, M0): Cancer has developed in one ovary, and the tumor is confined to the inside of the ovary; or the cancer has developed in one fallopian tube, and is only inside the fallopian tube. There is no cancer on the outer surface of the ovary or fallopian</p>

Figure 1: Sample page from ACS ovarian cancer detailed guide demonstrating headings and seriation.

		tube. Laboratory examination of washings from the abdomen and pelvis did not find any cancer cells.
Level 3 heading	→	Stage IB (T1b, N0, M0): Cancer has developed in both ovaries or fallopian tubes but not on their outer surfaces. Laboratory examination of washings from the abdomen and pelvis did not find any cancer cells.
Level 3 heading	→	Stage IC (T1c, N0, M0): The cancer is present in one or both ovaries or fallopian tubes and any of the following are present: <ul style="list-style-type: none"> • The tissue (capsule) surrounding the tumor broke during surgery, which could allow cancer cells to leak into the abdomen and pelvis (called <i>surgical spill</i>). This is stage IC1.
Bullet points as necessary	→	<ul style="list-style-type: none"> • Cancer is on the outer surface of at least one of the ovaries or fallopian tubes or the capsule (tissue surrounding the tumor) has ruptured (burst) before surgery (which could allow cancer cells to spill into the abdomen and pelvis). This is stage IC2 • Laboratory examination found cancer cells in fluid or washings from the abdomen. This is stage IC3.
Level 2 heading	→	Stage II The cancer is in one or both ovaries or fallopian tubes and has spread to other organs (such as the uterus, fallopian tubes, bladder, the sigmoid colon, or the rectum) within the pelvis. It has not spread to lymph nodes or distant sites. Stage IIA (T2a, N0, M0): Either <ul style="list-style-type: none"> • Cancer that started in the ovaries has spread to or has invaded (grown into) the uterus or the fallopian tubes, or both, OR <ul style="list-style-type: none"> • Cancer that started in the fallopian tubes has spread to the ovaries, the uterus or both. Stage IIB (T2b, N0, M0): The cancer has grown into other nearby pelvic organs such as the bladder, the sigmoid colon, or the rectum.
Level 2 heading	→	Stage III The cancer is in one or both ovaries or fallopian tubes, and one or both of the following are present: <ul style="list-style-type: none"> • Cancer has spread beyond the pelvis to the lining of the abdomen • Cancer has spread to lymph nodes in the back of the abdomen (retroperitoneal lymph nodes)

Figure 2: Sample page from ACS ovarian cancer detailed guide demonstrating headings and seriation.

All guides follow the same general outline for cancer information, although some section titles contain slight variations in wording between some guides, and some guides contain titles

that others do not or that are subsumed within other titles. Below is a list of the section titles shared among guides. The blank spaces inserted into the titles listed below are representative of the 8 sex specific cancer types discussed in this dissertation (vaginal, penile, ovarian, prostate, vulvar, endometrial, testicular, cervical) etc.). The spaces are left blank in as a means of representing all cancer types and to avoid presenting inaccurate depictions of the guides. The footnotes after certain titles listed below detail the following: differences in how a title is worded in certain guides; titles that may appear only in one or two guides; or titles that may appear as first level headings in some of the guides.

- What is cancer?
- What is _____ cancer?
- What are the key statistics about _____ cancer?
- What are the risk factors for _____ cancer?
- Do we know what causes _____ cancer?
- Can _____ cancer be prevented?
- Can _____ cancer be found early?
- Signs and symptoms of _____ cancer¹
- How is _____ cancer diagnosed?
- How is _____ cancer staged?
- How is _____ cancer treated?²
- Clinical trials for _____ cancer³
- What should you ask your doctor about _____ cancer?
- What happens after treatment for _____ cancer?⁴
- If treatment for _____ cancer stops working^{5,6}
- What's new in _____ cancer research and treatment?

¹ The title of this section varies in the vulvar cancer guide; it reads: "Signs and symptoms of vulvar cancers and pre-cancers."

² Following the "How is ____ cancer treated?" section, the vaginal and vulvar cancer guides each contain a section specifying stage based treatments. In the vaginal cancer guide, this section is titled: "Treatment options by stage and type of vaginal cancer." In the vulvar cancer guide, this section is titled: "Treatment options for squamous cell vulvar cancer by stage."

³ This section is only present as a titled section in the cervical cancer guide. In all other guides analyzed for this dissertation, "Clinical trials for ____ cancer" appears as a level 1 heading under the "How is ____ cancer treated?" section.

⁴ The title of this section varies in the ovarian, endometrial, and vulvar cancer guides; it reads: "What will happen after treatment for ____ cancer?"

⁵ The title for this section varies in the ovarian and prostate cancer guides; it reads: "If ____ cancer treatment stops working."

⁶ The section title "If treatment for ____ cancer stops working" appears in the testicular cancer guide as a first level heading in the section "What happens after treatment for ____ cancer?"

Method of Analysis

Close Reading

The method of analysis employed for this project is situated in the literary tradition of “close reading,” wherein a reader engages deeply with a text and scrutinizes the elements that determine how the story is told. Specifically, my analysis is guided by Rita Charon’s (2008) discussion of close reading as situated within her applied theory of narrative medicine. Charon asserts “a reading theory of the clinic encompasses the dynamics of the relationship between two people, the teller and the listener, but also conceptualizes the narrative itself as a dynamic partner in their intercourse, able of its own to alter what happens between them” (Charon, p. 108, 2008). Like the doctor and patient Charon points to above, patient information literature plays a significant role in the construction of medical narratives, and must be similarly considered. The 7 ACS patient detailed guides examined for this dissertation act both as literary texts and as authoritative participants in medical discourse.

Charon’s discussion of close reading is especially aimed at medical practitioners as readers of patients’ narratives, and works to translate the practice of literary close reading into the setting of medical practice. In my capacity as a researcher, I am positioned to read the 7 American Cancer Society patient detailed guides chosen for this project by Charon’s guidelines for practitioners.

Much like great literary works, medical literature tells a story, and the story told in the guides at hand are situated in the present. Like many suspense novels and dramas, the story begins with an introduction to an antagonist, and like many epic fantasy and adventure novels, these stories offer a map of the world in which the story is set within the first few pages. In the facts and figures section, the reader learns some of the key parameters of this world; soon after,

in the risk factors section, the reader discovers that this is a story of fate, predestined or self-determined, depending on the reader. The world continually expands, offering many potential paths and posing countless challenges and obstacles for the protagonist. In this story, the protagonist and the reader are usually one-and-the-same, and, in an unhappy twist, the story villain is made by, from, and lives within the protagonist.

Considering these similarities, it makes sense to apply a close reading technique to these medical texts. However, it is the differences between medical and literary texts that makes this literary method of analysis so important; while these texts may tell a story, they are read as objective, factual information, and readers do not approach them with the same notions of subjectivity and wonder that they might approach Mary Shelly's *Frankenstein* or William Gibson's *Neuromancer*. Rather, readers approach these medical texts seeking answers, suggestions, and direction, and they are not expecting personal or cultural biases to play a part in whatever information is included, how the information is conveyed, or how side effects might be explained. Indeed, in my own experience, I read the cancer patient information literature given to me by the medical institutions I visited as though they were a comprehensive selection of medical options – an explanation of medical standards overall.

Thus, I consider throughout my analysis how these texts might be affective in patient narratives. In this way, I have worked “to strengthen those cognitive and imaginative abilities that are required for one person to take in and appreciate the representation—and therefore the reality—of another” (Charon, p. 113, 2008).

Charon points out that medical practitioners engage in close reading when they examine chest X-rays: “The reader has learned to pay attention to various features of the visual text, moving sequentially through a drill of specific aspects so as to capture all the news that the chest

X-ray has to offer” (p. 113). Similarly, Charon has developed a drill for the close reading of medical narratives, wherein the reader “examines five aspects of the narrative text—frame, form, time, plot, and desire” (p. 114). Using Charon’s proposed framework as a guideline, a close reading of the 7 chosen ACS DGs was conducted, scrutinizing the frame, form, time, plot, and desire of the texts, as outlined below.

Frame. The first and, perhaps, most important step in a close reading is to determine the frame of the text under examination. The frame of a text contextualizes the content, giving readers an understanding both for how they are to read the text, and for how they are meant to interpret its meaning. Invoking the notion of an actual frame, Bateson (1972) explains, “The picture frame tells the viewer that he is not to use the same sort of thinking in interpreting the picture that he might use in interpreting the wallpaper outside the frame” (p. 187). In other words, as mentioned above, the frame will determine how a reader will interpret the context within it; concerning the text at hand, readers are expected to understand the text as a fact and evidence based informational source, and *not* as a science fiction piece such as Gibson’s *Neuromancer*, because “the messages enclosed within the imaginary line are defined as members of a class by virtue of their sharing common premises or mutual relevance,” (Bateson, p. 188, 1972). The DGs under discussion share a common premise with texts such as the dictionaries and medical textbooks discussed earlier. The DGs also share commonalities with medical pamphlets or brochures, as well as with in-office doctor consultations. Thus, the DGs are understood to be firmly situated within a frame of medicine, comprised of unbiased, fact based, scientific truths offering helpful and life-saving information.

Once the frame is established, participants will understand how to engage with the content: “a frame is metacommunicative. Any message, which either explicitly or implicitly

defines a frame, *ipso facto* gives the receiver instructions or aids in his attempt to understand the messages included within the frame” (Bateson, p. 188, 1972). Concerning the texts at hand, the frame instructs readers to interpret the presumably factual content at face value. The medical-centric frame also encourages readers to engage with the text as they might engage with a doctor during an in-office visit – patients are encouraged to wait patiently, listen, and comply with prompts given by each medical professional they encounter during a visit. While the ACS DGs primarily offer information, they also offer behavioral suggestions regarding lifestyle choices, doctor encounters, information seeking/gathering, etc.

Crucial to the analysis of the ACS DGs I examine here is Bateson’s (1972) point that frames are both exclusive and inclusive, because while certain messages are included, certain other messages are excluded, and vice versa (p. 187). “The frame around a picture, if we consider this frame as a message intended to order or organize the perception of the viewer, says, ‘Attend to what is within and do not attend to what is outside’” (Bateson, p. 187, 1972).

Similarly, Charon (2008) states “the spatial meaning of the word ‘to frame’ is also salient for the reader” (p. 115). Like Bateson (1972), she posits that just as important as what is present in the text is that which is not present in the text, and encourages readers to examine how authors “draw borders around events, people, time periods, or emotions in determining the purview of the work,” noting that “the reader who adequately inspects the frame of the text will actively wonder about what’s left out and will supply—if only in hypotheses—that which leaves, at best, a shadow or a trace” (p. 115). The ACS cancer patient detailed guides are considered informational in nature, and, as such, the reader expects that all relevant information will be included. Thus, as my analysis considers what the messages included within the text are saying and doing, my discussion will also consider what messages are excluded, and what that exclusion

says and does as a result. This frame analysis requires individual application, and is practiced throughout the analyses conducted for this dissertation.

Finally, Charon (2008) notes that readers must determine elements such as the authors of the text (who is speaking?), the intended readers (who is listening?), what the text is answering, and how the text changes the meaning of other texts (p. 114).

Concerning the authors and intended readers of the texts in question, the second consideration allows for a quick and straightforward response: the intended readers of the guides examined here are most frequently recently diagnosed cancer patients, and possibly patients who are undergoing diagnostic testing and may soon become cancer patients. Additional anticipated readers may include family members, caretakers, friends, etc. Identifying the author of the text – who is speaking – requires deeper consideration. Individual authors of the 7 texts remain unnamed, implicating the American Cancer Society at large as the author. Through the omission of individual author names, the potential for individual error and accountability is negated, instead imprinting the institutional, medical, and social authority of the ACS on the informational content. In other words, if there is not an individual author, then there cannot be authorial bias or error, thus imbuing the texts with a “natural” authority that is enhanced by the credibility and authority accrued by the ACS throughout the past century.

The ACS DGs in question are intended to provide sufficiently detailed information regarding specific cancers, including risk factors, diagnostic procedures, potential treatment options, side effects, and additional available resources. The guides are written and intended to be read as informational guides that answer questions common among cancer patients. As such, the guides have the potential to reinforce or negate other sources of information. For example, a

patient may find a doctor more credible if the doctor offers treatment options and information congruent with the information provided through the ACS DGs.

Form. The form of a text includes genre, visible structure, narrator, metaphor, allusion, and diction. Charon states that these elements “are among the more important elements of literary form” (p. 116).

Genre. As previously indicated, the patient detailed guides under examination are of an informational and reference genre. The guides offer information, definitions, citations of studies, and additional resources. As such, they are authoritative by nature, similar to a dictionary, encyclopedia, or telephone book.

Visible structure. Charon notes, “explicitly examining the visible structure of the text allows the reader to query the meaning of the breaks, the impact of the tempo, and the message of the rhythm of the work. Even the relative length of sections can give a clue to their importance or weight” (p. 117). As previously discussed, the general outline and section headers of all 7 guides are very similar. However, subsections and the length of sections differ between guides. These visible structural components are noted in each individual guide, and will be discussed in more detail in the following chapters.

Narrator. As Charon asserts, identifying the narrator of a text allows readers to identify the point of view of the text. “The practice one accumulates in identifying narrators and focalizers in narrative fiction is of enormous benefit when one then reads such clinical texts as progress notes or admission write-ups” (p. 118). Concerning ACS’ cancer patient detailed guides, the narrator and the author are the same entity. Due to the nature of the guides as informational, the guides are generally considered objectively factual artifacts. Thus, the narrator might be considered “Truth,” “Science,” or “Fact.”

Metaphor. The American Cancer Society cancer patient detailed guides are rife with metaphor. In the example analysis below, we can see how the guides tie female bodies so closely to reproductive function that they are represented as literally one-and-the-same; in the example below, the uterus *is* the “womb,” the vagina *is* the “birth canal,” and their singular function is to facilitate the growth and birth of “a baby.”

However, while such metaphors are used throughout all 7 guides, the informational nature of the guides works to disguise the metaphors as facts. In other words, while the uterus and vagina have multiple functions, the informational presentation of the uterus as the “womb” and the vagina as the “birth canal” associates those parts of the body strictly with reproductive function. Because the guides are presumably conveying objective facts, the metaphors used in the informational context of the guide are likely to be taken not as metaphor, or even as potentialities, but, rather, as objective truth and scientific fact: “Yes, the scientific truth is that the vagina *is* the birth canal – a passage for the birth of a baby *is* its function. Everything else is tangential.” The DGs’ focus on reproductive function demands that readers consider themselves as reproductive entities; as such, women who are post-menopausal are asked to frame their bodies as functionless, and women who must have their affected organs removed are asked to frame their loss as a loss of function. Furthermore, the strong and, often, irrational focus on the reproductive function of women’s organs (vagina, uterus, and cervix) and glands (ovaries) eclipses the other important functions that these parts play, ultimately misinforming readers about the changes and side effects that can or will occur regarding sexuality, hormone production, and the excretory system. Such changes have significant effects on women’s sense of self that can persist years after treatment (Abbott-Anderson & Kwekkeboom, 2012) and include a broad range of factors including sexuality, feelings of bodily emptiness, perceived change in

partner attraction, and vulnerability (Abbott-Anderson & Kwekkeboom, 2012; Ratner et al., 2011; Sekse, Gjengedal, & Råheim, 2012). Individually, such changes necessarily lead to changes in lifestyle and require personal and relational adjustments, and in the case of cervical cancer where spread can require the removal of the cervix, uterus, vagina, and bladder, patients' must face lifestyle and relationship adjustments far beyond the notion of reproductive function.

Allusion. Charon notes, “all texts speak to other texts—they cannot help it” (p. 119). Similarly, the ACS' DGs speak to other mediated cultural artifacts. When the guides under discussion and cultural artifacts such as movies, television, music, and advertisements use the same language and advance the same assumptions – in this case, gendered language and assumptions – they speak to one another, ultimately working together to reinforce and naturalize gendered biases.

Additionally, the ACS cancer patient detailed guides in question literally point to other patient information literature, as well as medical research, through direct resource references and academic citations. These sources – especially the medical research articles – serve to reinforce the information presented in the guides, while the references to additional resources points away from the information within the guides to other information that is not offered or is not discussed in detail in the guides.

Diction. While the guides take care to inform the reader that the treatment information provided by the ACS authorial board are derived from their own interpretations, and that medical opinions and reasoning may vary among professionals and on a case-by-case basis, the rest of the information in the guides – such as risk factors, definitional sections, etc. – are not preceded by such disclaimers. Thus, the majority of the guides are assumed to be written from an objective

standpoint, which lends to a tone that is ultimately authoritative in nature. There are several factors that make the tone of the guides informative and hierarchical:

First, italicized and parenthetical terms appear throughout the guides. The italicized terms are akin to vocabulary words in textbooks, and are usually accompanied by explanations or definitions, while parenthetical terms usually offer a synonym for an adjacent term. In the analysis example below, the term “vagina” is followed by parenthetical term “birth canal,” appearing as: “vagina (birth canal).” In this example, the parenthetical term demands that the reader to define the vagina by its reproductive potential and to situate the vagina as a passage. The commanding tone of the guides asks readers to understand this finite reproductive context as encompassing and inevitable, and the informational nature of the guides situates this reproductive definition as natural and complete. As discussed under the “metaphor” section above, the tendency of the female affiliated DGs to describe and discuss women’s bodies as though reproduction is their sole function is incorrect, incomplete, and will lead to misinformed and ultimately confused and frightened patients.

Second, the guides provide lists of suggested questions for patients to ask their doctors. While the guides frame their suggestions in the context of “Among the questions you might want to ask are,” and encourages readers to ask all of their questions regardless of how small the question may seem, the guides are in a position to make serious recommendations for action. Considering questioning from a communication standpoint, the asker of a question is generally considered to occupy a position of power relative to the person who is made to answer. In this way, the ACS DGs encourage patient autonomy and self-advocacy, and the suggested questions offer readers a foundation for formulating their own questions. However, there is extraordinary power in providing the background, basis, and framework for what questions patients are

encouraged to ask. While the suggested list of questions may simply serve as a broad overview for the kinds of questions patients should consider asking their doctors, the informational content and structure throughout the rest of the guides provides an authoritative framework for the types and content of questions patients should ask.

Finally, the DGs also offer sympathetic and deferential tones, consistently recognizing the difficulties of cancer and cancer treatments, and reiterating the notion of options and the active role of patients in the doctor/patient relationship. As discussed earlier, patient information acquisition habits are often born from a desire to regain a sense of control. The combination of a sympathetic tone with the reassurance that patients are still autonomous and have choices creates a space for patients to feel cared for, understood, and, to an extent, in control of their lives. As a result, patients may consider the DGs as empowering allies, making patients more likely to take the information offered by the guides at face value.

Time. Charon asserts that medical readers who are attuned to narrative time will be similarly attuned to illness time (p. 121). This attunement is key, because while clinical time is highly regimented, illness time for patients is often synchronous, past and future considerations mattering only insofar as the present is concerned (p. 121). The DGs under examination seem attuned to the patient time orientation Charon discusses, as the text seems to honor the present – past and future coming together in and going only as far as the here and now. This form of writing demonstrates a careful orientation to patient needs, and can certainly be interpreted as desire on the part of the American Cancer Society to honor and assist patients by meeting them where they are during a tumultuous and arguably traumatic time. However, as with so many of the individual elements of these guides, this understanding of illness time and subsequent form of written communication is imbued with significant power, and requires careful attention when

communicating with patients. This is perhaps most clearly demonstrated in the “Risk Factors” sections of the guides, wherein patients learn of the potential factors that might contribute to the development of their cancers, including both hereditary/genetic and life-style factors. Charon notes:

“Everything that has happened to our bodies is with us still—scars, infarcts, stenosis, adhesions. Kathryn Montgomery once told me that you could accomplish an entire medical interview by asking a patient, ‘Tell me about your scars.’ Our bodies are texts, then, clerking the records of what we have been through, hoarding evidence of past hurts, remembering as only bodies can the corporeal stabilities that keep us alive” (Charon, p. 122, 2008).

Considering the ever-present nature of human bodies, the past can have a significant impact on patients experiencing illness. On the one hand, understanding that generations of genetic replication led to the inevitability of one’s cancer – the culmination of hundreds of years of biological history happening now, in the present – can offer a patient relief from the nagging question, “What if I had only done something different?” On the other hand, understanding that life choices ultimately led to the development of their cancer – years of dipping leading to jaw cancer, for example – can weigh heavily on a patient, perhaps causing him guilt at the thought of putting himself and his family through a harrowing experience of illness. Should this imaginary jaw cancer patient survive his disease, however, then taking responsibility for his choices and the consequences he suffered is an important step in making healthier choices in the future.

The “Risk Factors” sections of the ACS DGs often call on patients to account for their pasts and how the past may have contributed to their present, and will shape their future. Some questions to consider here are: when is guilt and shame useful; when is it harmful; and who

“deserves” to be held responsible for their cancer? Due to the differences between guides, these questions will be considered on an individual basis and will be addressed in subsequent chapters.

Plot. The plot is “what happens” in any given story, “quite beyond the language used or the style adopted” (Charon, p. 123, 2008). While the plot of the ACS DGs might at first seem more akin to a choose-your-own-adventure story than to George R.R. Martin’s *A Song of Ice and Fire* epic fantasy novels, in both instances, readers bring their own perceptions and backgrounds to the stories, working with what the authors have offered in order to make sense of a world that was, perhaps, previously foreign to them. In the cancer DG, readers will approach the literature with varying levels of experience in the realms of cancer and medicine, the notion of patienthood registering in different degrees of familiarity; in Martin’s novels, readers will approach the literature with varying experiences in the realms of fantasy, having no or many pre-conceived understandings of how dragons and magic might operate in a fantasy world. Peter Brooks notes, “Plot . . . thus comes to appear one central way in which we as readers make sense, first, of the text, and then, using the text as an interpretive model, of life” (as cited in Charon, p. 123, 2008). In the case of ACS DGs, the “what happens” of treatment and prognosis is determined by diagnostic assessment, while the question of “what happened” is mostly left for the reader to determine on her own.

Thus, the information that is present in the guides – and, to an equal degree, the information that is not present in the guides – has the distinct potential to shape the plotline of a reader’s cancer story and experience; just as the guides draw attention to or away from various aspects of cancer, risk factors, treatment, etc., so, too, might the patient reader/narrator.

Desire. Charon asserts that close readers can determine what a text has accomplished by identifying the desires, needs, or longings that have been satisfied by a reading (p. 126). She

urges close readers to ask, “What appetite is satisfied by virtue of the reading act?” and “What hunger seems to have been fulfilled in the teller by virtue of his or her writing act?” (Charon, p. 124, 2008). While the guides examined for this dissertation entertain a variety of topics that have the potential to fulfill a variety of desires, needs, or longings, one of the primary accomplishments of the guides overall is to fulfill informational needs. As discussed earlier, patient information acquisition needs and tendencies are often derived from a desire, need, or longing to gain a sense of control in a seemingly out-of-control situation.

Additional desires, longings, and needs fulfilled by the guides might be generally categorized as informational in nature, although what is being accomplished in the sections of these guides varies between guides and sections. As a scholar and close reader, I seek to understand and acknowledge the longings, desires, and needs satisfied after each close reading; and as a scholar and patient, I seek to explore the potential longings, desires, and needs fulfilled for other patient readers, as well as to consider potentially unfulfilled longings, desires, and needs.

A sample demonstration of close reading is included on the following page.

Example of Close Reading

Below is an example of how the close reading was applied to the American Cancer Society’s cancer patient detailed guides. The “What is cervical cancer?” section of the Cervical Cancer DG was used for this example.

<p>What is cervical cancer?</p>	<p>Pg. 2</p>
<p>The cervix is the lower part of the uterus (womb). It is sometimes called the <i>uterine cervix</i>. The body of the uterus (the upper part) is where a baby grows. The cervix connects the body of the uterus to the vagina (birth canal). The part of the cervix closest to the body of the uterus is called the <i>endocervix</i>. The part next to the vagina is the <i>exocervix (or ectocervix)</i>. The 2 main types of cells covering the cervix are <i>squamous</i> cells (on the exocervix) and <i>glandular</i> cells (on the endocervix). The place where these 2 cell types meet is called the <i>transformation zone</i>. Most cervical cancers start in the transformation zone</p>	<p>1-9</p>
<div data-bbox="440 837 1068 1327" data-label="Image"> <p>The diagram illustrates the female reproductive system within a female torso outline. Labels include: Fallopian tubes, Ovaries, Endocervix, Cervix, Exocervix, Body of uterus, and Vagina. The cervix is shown as the lower neck of the uterus, connecting to the vagina.</p> </div> <p>Most cervical cancers begin in the cells lining the cervix. These cells do not suddenly change into cancer. Instead, the normal cells of the cervix first gradually [...]</p>	<p>Pg. 3</p>

Figure 3: Analysis exemplar excerpt

In the first sentence of the definition, the text defines the cervix as “the lower part of the uterus,” which is then defined in parentheses as the “womb.” Thus, the cervix is defined as part of the reproductive space “womb.” The second sentence offers an alternate term for this portion of the cervix, “uterine cervix,” which solidifies the cervix as part of the uterus/womb.

The third and fourth sentences situate the cervix as a connection between reproductive areas. The third sentence explains that the “body of the uterus (the upper part) is where a baby grows,” and the fourth sentence informs the reader that “the cervix connects the body of the uterus to the vagina (birth canal).”

After firmly situating the cervix, uterus, and vagina as spaces that exist within a framework of reproduction, the text continues to describe each in terms of place. Below, the terms and phrases that situate the cervix, uterus, and vagina as spaces or places have been excerpted and bolded. They are listed in order of occurrence:

“the **lower part... body** of ... (the **upper part**) is **where...** cervix **connects the body** of... to the... (birth **canal**). The **part** of the cervix **closest** to the **body** of... The **part next to** the... cells **covering** the... (**on the** exocervix)... (**on the** endocervix). The **place where** these... **meet...** the *transformation zone*... in the **transformation zone**”

Thus, the cervix is defined as a connective space – like a hallway – between two reproductive spaces.

The accompanying diagram serves to reinforce the notion that the uterus, cervix, and vagina are connected reproductive spaces, a home (womb) “where a baby grows” and is eventually sent into the world through the “birth canal.” The diagram depicts the vagina, cervix, and uterus as a contiguous open space that begins as a hollow space (the uterus), narrows in the center (the cervix), and dumps out thorough a wide, open tunnel at the bottom (the vagina or “birth canal”).

Summary and Overview

The analysis of the excerpt above illustrates some of the gendered issues previously highlighted by scholars like Martin (1991), Braun & Kitzinger (2001), and Metoyer & Rust

(2011). The definitional information provided in the excerpt above is shallow and incomplete, and its focus eclipses related information that may be crucial for patients to understand and cope with the disease they are facing. Studies have shown that cultural taboo and shame often leave gynecological cancer patients mis- or uninformed regarding their health, disease, treatments, and side effects (e.g., Calvo et al., 2012; Wray, Markovic, & Manderson, 2007).

This analysis will help to garner a deeper understanding of what the DGs accomplish, what information is obscured, what information the texts leave out, if information is gendered in significant ways, and, if so, what consequences may arise from the use of gendered language in patient information literature. Furthermore, the American Cancer Society could potentially use this analysis to guide their organization's consideration of how the information present in the DGs either fulfills or falls short of the ACS's goals. Through this analysis, I seek to highlight the importance of patient information literature and advance the body of research that examines this topic. My hope is that this research will help to improve the scope and quality of patient information literature.

Chapter 3 will analyze and discuss female oriented DGs, with a specific focus on the cervical and vaginal DGs and including excerpts from the ovarian and uterine DGs. Chapter 4 will analyze and discuss male oriented DGs, with a specific focus on the penile DG and including excerpts from the testicular and prostate DGs. Finally, Chapter 5 will provide a comparative analysis of the female and male DGs, and discuss similarities, differences, and potential implications for patients.

CHAPTER 3: ANALYSIS

It's a Girl!:

Analyzing Women's Cancer Patient Detailed Guides

In this chapter, I analyze the vaginal, cervical, ovarian, and uterine cancer patient detailed guides (DG) produced by the American Cancer Society (ACS). I first examine the definitional sections of each DG, and then move on to examine the risk factors and side effects sections. Through this process of examination, we can begin to understand how the definitional frame goes on to influence how patients are instructed to understand their disease, their bodies, and the potential side effects they may face with different treatment options.

Defining the Female Body

I will begin by analyzing the ACS definitions of the vagina and cervix, and then move on to the definitions of the uterus/endometrium and ovaries in the opening sections of their respective DGs. Each section of analysis will begin with a replicated excerpt from the associated ACS DG. Each excerpt is accompanied by a column to the right that indicates page numbers and sentence groups.

Vaginal Cancer

What is vaginal cancer?: The vagina. The vaginal cancer introductory section, “What is vaginal cancer?” demarcates a subsection dedicated to offering a full definition of the vagina.

The excerpt below is mimics the original format:

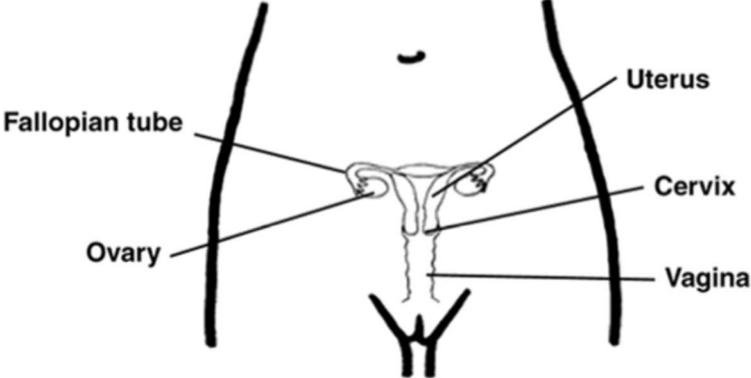
<p>What is vaginal cancer?</p>	<p>Pg. 2</p>
<p>The vagina</p>	
<p>The vagina is a 3- to 4-inch (7 ½- to 10-cm) tube. It is sometimes called the <i>birth canal</i>. The vagina goes from the cervix (the lower part of the uterus) to open up at the vulva (the external genitals). The vagina is lined by a layer of flat cells called <i>squamous</i> cells. This layer of cells is also called <i>epithelium</i> (or <i>epithelial lining</i>) because it is formed by epithelial cells.</p>	<p>1-5</p>
<p>The vaginal wall underneath the epithelium contains connective tissue, muscle tissue, lymph vessels, and nerves. The vagina is usually in a collapsed state with its walls touching each other. The vaginal walls may have many folds that help the vagina open and expand during sexual intercourse or the birth of a baby. Glands near the opening of the vagina secrete mucus to keep the vaginal lining moist.</p>	<p>6-9 Pg. 3</p>
 <p>The diagram is a simplified anatomical illustration of the female reproductive system. It shows a central pear-shaped organ labeled 'Uterus'. Two fallopian tubes extend from the upper corners of the uterus, each ending near an oval-shaped 'Ovary'. The lower part of the uterus is labeled 'Cervix', which leads into a canal labeled 'Vagina'. The diagram is symmetrical and uses simple black lines on a white background.</p>	

Figure 4: Vaginal cancer definitional section excerpt

The first sentence of this section describes the vagina as a tube, implying emptiness and spatial or transport functionality similar to a hallway or tunnel. The alternative definition “birth canal” offered in the second sentence assigns reproductive function to the vagina and situates the vagina as an exit. The following sentences describe the structural components of the tube, and the description of the vagina as “opening up” at the vulva reinforces the notion of the vagina as an exit.

The next paragraph describes the vagina as a place with walls that contain tissues, nerves, and lymph vessels, similar to how the wall of a home might be described as containing electrical

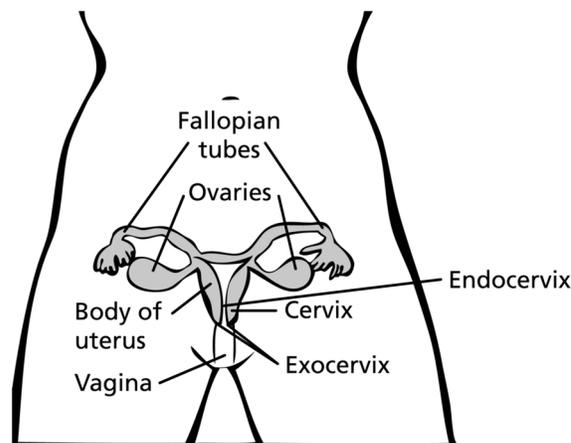
wiring, plumbing, and support beams. The second sentence of this paragraph states that “the vagina is usually in a collapsed state with its walls touching each other,” with the fourth sentence further explaining that the vagina opens and expands “during sexual intercourse or the birth of a baby.” This description firmly situates the vagina as having the specific function of a passage: an entrance for men to go into the female body, and an exit for babies to leave from the female body. Notably, the first mention of sexual function occurs in the fourth sentence, and is coupled with reproduction function, linking the act of “sexual intercourse” with the “birth of a baby.” When the vagina is not being used for one of its dedicated functions (sexual intercourse or birth), it falls into a “collapsed state” of disuse. The final sentence, framed by the preceding explanation and description of the vagina, invites the reader to consider the vagina’s moisturizing mucus as an assistive function for the entering penis or exiting baby.

Cervical Cancer

What is cervical cancer? The cervical cancer introductory section, “What is cervical cancer?” does not have a separate “About the cervix” subsection. Instead, the “What is cervical cancer?” section begins with a paragraph dedicated to defining and describing the cervix (sentences 1-9), and merges into a discussion of cervical cancer (sentences 10-36). All formatting, emphasis, and punctuation is true to the original document, including sentences 9 in the first paragraph, which ends without punctuation.

What is cervical cancer?

The cervix is the lower part of the uterus (womb). It is sometimes called the *uterine cervix*. The body of the uterus (the upper part) is where a baby grows. The cervix connects the body of the uterus to the vagina (birth canal). The part of the cervix closest to the body of the uterus is called the *endocervix*. The part next to the vagina is the *exocervix (or ectocervix)*. The 2 main types of cells covering the cervix are *squamous* cells (on the exocervix) and *glandular* cells (on the endocervix). The place where these 2 cell types meet is called the *transformation zone*. Most cervical cancers start in the transformation zone



Most cervical cancers begin in the cells lining the cervix. These cells do not suddenly change into cancer. Instead, the normal cells of the cervix first gradually develop pre-cancerous changes that turn into cancer. Doctors use several terms to describe these pre-cancerous changes, including cervical intraepithelial neoplasia (CIN), squamous intraepithelial lesion (SIL) and dysplasia. These changes can be detected by the Pap test and treated to prevent the development of cancer (see “Can cervical cancer be prevented?”).

Cervical cancers and cervical pre-cancers are classified by how they look under a microscope. There are 2 main types of cervical cancers: *squamous cell carcinoma* and *adenocarcinoma*. About 80% to 90% of cervical cancers are squamous cell carcinomas. These cancers are from the squamous cells that cover the surface of the exocervix. Under the microscope, this type of cancer is made up of cells that are like squamous cells. Squamous cell carcinomas most often begin where the exocervix joins the endocervix.

Most other cervical cancers are adenocarcinomas. Cervical adenocarcinomas seem to have become more common in the past 20 to 30 years. Cervical adenocarcinoma develops from the mucus-producing gland cells of the endocervix. Less commonly, cervical cancers have features of both squamous cell carcinomas and adenocarcinomas. These are called *adenosquamous carcinomas* or mixed carcinomas.

Figure 5: Cervical cancer definitional section excerpt

<p>Although cervical cancers start from cells with pre-cancerous changes (pre-cancers), only some of the women with pre-cancers of the cervix will develop cancer. The change from cervical pre-cancer to cervical cancer usually takes several years, but it can happen in less than a year. For most women, pre-cancerous cells will go away without any treatment. Still, in some women pre-cancers turn into true (invasive) cancers. Treating all pre-cancers can prevent almost all true cancers. Pre-cancerous changes and specific types of treatment for pre-cancers are discussed in the sections, “How are cervical cancers and pre-cancers diagnosed?” and “Treating pre-cancers and other abnormal Pap test results.”</p>	26-31
<p>Pre-cancerous changes are separated into different categories based on how the cells of the cervix look under a microscope. These categories are discussed in the section, “How are cervical cancers and pre-cancers diagnosed?”</p>	Pg. 4 32-33
<p>Although almost all cervical cancers are either squamous cell carcinomas or adenocarcinomas, other types of cancer also can develop in the cervix. These other types, such as melanoma, sarcoma, and lymphoma, occur more commonly in other parts of the body.</p>	34-35
<p>This document discusses the more common cervical cancer types, and will not further discuss these rare types.</p>	36

Figure 5: Cervical cancer definitional section excerpt continued

Beginning with the first sentence of this section in the ACS cervical cancer DG, the text strongly encourages the reader to consider the female body as a reproductive entity. Using anatomically correct terms of body parts followed by socially informed parenthetical definitions after, the cervical cancer DG encourage readers to understand the cervix, uterus, and vagina as reproductive entities.

The first sentence of the “What is cervical cancer?” section of the ACS cervical cancer DG immediately aligns female anatomy with reproduction when it states, “The cervix is the lower part of the uterus (womb).” The DG defines the cervix as “the lower part of the uterus,” which is simultaneously defined as “(womb).” Thus, the DG defines the cervix as *the* lower part of the uterus, and while the term “uterus” is medically accurate, the use of the parenthetical term “womb” urges readers to consider the uterus and cervix specifically in terms of reproductive function. The following sentence scientifically connects the terms “cervix” and “uterus” when it notes, “it is sometimes called the *uterine cervix*” [original emphasis].

The third and fourth sentences of this section work to further align the female body strictly with reproductive function. The third sentence states, “The body of the uterus (the upper part) is where a baby grows.” The phrase “where a baby grows,” assumes that a baby can and should “grow” in the space of the uterus. The following sentence states, “The cervix connects the body of the uterus to the vagina (birth canal).” Through this wording, the vagina is described as a passage from which the assumed baby emerges, and the text once again requests that readers frame women’s bodies in terms of reproduction. The remainder of the paragraph explains where the cervix is located and offers some general information regarding cellular makeup.

Throughout this first paragraph, the uterus is described as a place, space, or passage of reproduction. Words and phrases such as “lower part,” “upper part,” “canal,” “womb,” “part [...] closest to the body of,” “part next to,” “place where,” “parts covering,” etc., describe the cervix, uterus, and vagina as a place. This simultaneous reference to these internal organs as places and the text’s alignment of the female body with reproduction results in the cervix, uterus, and vagina being firmly situated as spaces of reproduction. Thus, the reader is invited to understand the function of the vagina, uterus, and cervix as strictly reproductive. As a result of this focus on reproduction, other potential functions are excluded.

Importantly, the infantilizing language used throughout this definitional paragraph serves to cultivate attitudes regarding the cervix as well as the people who have them. First, the language establishes the notion that the cervix is a simplistic and essentially purposeless structure. The text does not ascribe purpose to the cervix, instead focusing on its location and what different ends of the cervix are called.

Endometrial Cancer

Similar to the vaginal and cervical cancer DGs, the endometrial cancer DG situates the uterus, vagina, cervix, and ovaries as strictly reproductive.

What is endometrial cancer? The first sentence of the “What is endometrial cancer?” section defines cancer as “a cancer that starts in the endometrium, the inner lining of the *uterus* (womb).” Like the cervical cancer DG, the use of anatomically correct terms followed by socially informed parenthetical definitions, readers are encouraged to understand the uterus as strictly reproductive in nature.

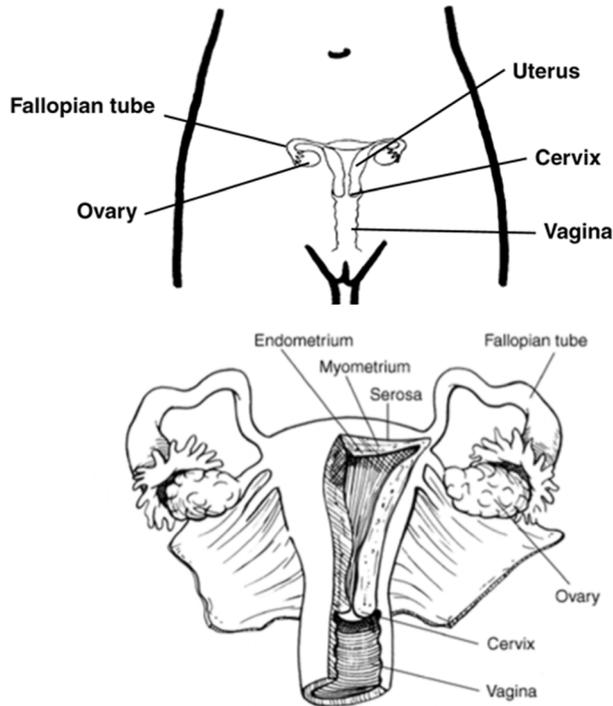
About the uterus and endometrium. In the subsection, “About the uterus and endometrium,” the text reinforces notions of reproduction by focusing on the reproductive function of muscles, hormones, and glands, and using language that assumes pregnancy and birth. The first paragraph (sentences 1-5) in this subsection offers a basic description of the uterus:

The uterus is a hollow organ, about the size and shape of a medium-sized pear. The uterus is where a fetus grows and develops when a woman is pregnant. The uterus has 2 main parts (see picture above). The lower end of the uterus extends into the vagina and is called the *cervix*. The upper part of the uterus is called the body and is also known as the *corpus*. (*Corpus* is the Latin word for body.)

Similar to the vagina, the uterus is described as empty, indicating that it is an unoccupied space. However, unlike the vagina or cervix, this definition acknowledges the uterus as an organ, endowing it with a level of individual importance not seen in the definitions of the vagina or cervix. The second sentence reinforces the notion of the uterus as a place while also reinforcing its reproductive function established through the DG’s previous definition of the uterus as the

What is endometrial cancer?

Endometrial cancer is a cancer that starts in the endometrium, the inner lining of the *uterus* (womb). The picture below shows where the uterus is located.



Pg. 2

1-2

Pg. 3

About the uterus and endometrium

The uterus is a hollow organ, about the size and shape of a medium-sized pear. The uterus is where a fetus grows and develops when a woman is pregnant. The uterus has 2 main parts (see picture above). The lower end of the uterus extends into the vagina and is called the *cervix*. The upper part of the uterus is called the body and is also known as the *corpus*. (*Corpus* is the Latin word for body.)

1-5

The body of the uterus has 2 layers. The inner layer or lining is called the *endometrium*. The outer layer of muscle is known as the *myometrium*. This thick layer of muscle is needed to push the baby out during birth. The tissue coating the outside of the uterus is the *serosa*.

6-10

Hormone changes during a woman's menstrual cycle cause the endometrium to change. During the early part of the cycle, before the ovaries release an egg (ovulation), the ovaries produce estrogens. The hormone called *estrogen* causes the endometrium to thicken so that it could nourish an embryo if pregnancy occurs. If there is no pregnancy, estrogen is produced in lower amounts and more of the hormone called *progesterone* is made after ovulation. This causes the innermost layer of the lining to prepare to shed. By the end of the cycle, the endometrial lining is shed from the uterus and becomes the menstrual flow (period). This cycle repeats throughout a woman's life until menopause (change of life).

11-17

Figure 6: Endometrial cancer definitional section excerpt

“womb.” The rest of the paragraph continues to describe the “parts” of the uterus, using the directional terms “lower” and “upper” that correspond with the accompanying diagrams. In sentence 4, the cervix is acknowledged as “the lower end of the uterus.” While this sentence necessarily indicates that the cervix is included in the “organ” as a whole, it also upholds the ACS’ definition of the cervix in the cervical cancer DG. “The lower end of the uterus” is indicative of place – and, potentially, of “low” quality – while “extends into the vagina” simultaneously asserts the image of a passage and the notion of unclear boundaries. Sentence 5 informs readers “The upper part of the uterus is called the body and is also known as the *corpus*. (*Corpus* is the Latin word for body.)” This sentence describes the corpus as a “part” rather than an “end,” giving the corpus a higher level of distinction and importance than is given to the cervix. The really important part, here, is the body, or the “upper part.”

The middle paragraph (sentences 6-10) offers additional information about the body of the uterus, reinforcing its importance:

The body of the uterus has 2 layers. The inner layer or lining is called the *endometrium*. The outer layer of muscle is known as the *myometrium*. This thick layer of muscle is needed to push the baby out during birth. The tissue coating the outside of the uterus is the *serosa*.

Sentence 6 further reinforces the notion of the uterus as a complex organ; it is an organ that has two parts, one of which has 2 layers. Sentence 7 briefly introduces the endometrium – the subject of the DG, where the potential or discovered cancer is located – but is quickly abandoned when sentence 8 introduces the myometrium. Sentence 9 defines the myometrium, stating “This thick layer of muscle is needed to push the baby out during birth.” This wording indicates that the sole

function of the myometrium is to push “the” assumed baby out, denying this muscle the potential of any other function.

The final paragraph (sentences 11-17) describes the menstrual cycle and the purpose of hormones:

Hormone changes during a woman’s menstrual cycle cause the endometrium to change. During the early part of the cycle, before the ovaries release an egg (ovulations), the ovaries produce estrogens. The hormone called *estrogen* causes the endometrium to thicken so that it could nourish an embryo if pregnancy occurs. If there is no pregnancy, estrogen is produced in lower amounts and more of the hormone called *progesterone* is made after ovulation. This causes the innermost layer of the lining to prepare to shed. By the end of the cycle, the endometrial lining is shed from the uterus and becomes the menstrual flow (period). This cycle repeats throughout a woman’s life until menopause (change of life).

While this paragraph frames the endometrium, ovaries, and production of hormones as reproductive by nature, its focus on the menstrual *cycle* prevents it from assuming the occurrence of pregnancy and childbirth. However, readers’ attention is continuously drawn to the reproductive function of each biological element the DG mentions, with the final sentence situating the lives of women and the purpose of their bodies firmly in the context of reproduction. Sentence 17 states “This cycle repeats throughout a woman’s life until menopause (change of life).” The phrase “throughout life” – whether a woman, man, or dog’s life – indicates the entirety of that life, from birth death. While the modification “until menopause” offers an end point, the text does not offer a beginning point, and with the addition of the alternate definition of menopause, “change of life,” the life in question can be understood as ending at menopause.

Similarly, at the end of this life, the function, importance, and purpose of women’s bodies perishes in the “change of life.”

Ovarian Cancer

The ovarian cancer DG introductory section does not contain subsections for defining the ovaries and introducing ovarian cancer. Instead, the DG begins the “What is ovarian cancer?” section by defining the ovaries Below are sentences 1-6:

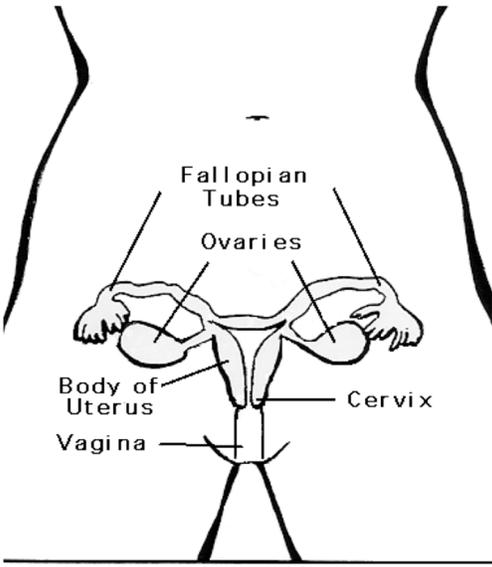
<p>What is ovarian cancer?</p>	<p>Pg. 2</p>
<p>Ovarian cancer is cancer that begins in the ovaries. Ovaries are reproductive glands found only in females (women). The ovaries produce eggs (ova) for reproduction. The eggs travel through the fallopian tubes into the uterus where the fertilized egg implants and develops into a fetus. The ovaries are also the main source of the female hormones estrogen and progesterone. One ovary is on each side of the uterus in the pelvis.</p>	<p>1-6</p>
<div style="text-align: center;">  </div>	<p>Pg. 3 7</p>
<p>The ovaries are made up of 3 main kinds of cells:</p>	<p>8</p>
<ul style="list-style-type: none"> • Epithelial cells, which cover the ovary 	<p>9-10</p>
<ul style="list-style-type: none"> • Germ cells, which are found inside the ovary. These cells develop into the eggs (ova) that are released into the fallopian tubes every month during the reproductive years. • Stromal cells, which form the supporting or structural tissue holding the ovary together and which produce most of the female hormones estrogen and 	<p>11</p>

Figure 7: Ovarian cancer definitional section excerpt

progesterone.	12-13
Each of these types of cells can develop into a different type of tumor. There are 3 main types of ovarian tumors:	14-15
<ul style="list-style-type: none"> • Epithelial tumors start from the cells that cover the outer surface of the ovary. Most ovarian tumors are epithelial cell tumors. 	16
<ul style="list-style-type: none"> • Germ cell tumors start from the cells that produce the eggs (ova). 	17
<ul style="list-style-type: none"> • Stromal tumors start from structural tissue cells that hold the ovary together and produce the female hormones estrogen and progesterone. 	18-19
Most of these tumors are benign (non-cancerous) and never spread beyond the ovary. Benign tumors can be treated by removing either the ovary or the part of the ovary that contains the tumor.	20-22
Ovarian tumors that are not benign are malignant (cancerous) or low malignant potential tumors. These types can spread (metastasize) to other parts of the body and can be fatal. Their treatment is discussed later in this document.	

Figure 7: Ovarian cancer definitional section excerpt continued

Like the cervical, vaginal, and endometrial cancer DGs discussed above, the ovaries are framed as purely reproductive in nature. Sentence 2 defines the ovaries as “reproductive glands found only in females (women),” thus situating the ovaries as “reproductive” and asserting a connection between reproduction and women. Sentence 3 uses language that assumes pregnancy and fetal development, noting that “the fertilized egg implants and develops into a fetus.” Sentence 4 assigns gender to the hormones produced in the ovaries with the assertion that “The ovaries are also the main source of the female hormones estrogen and progesterone.” Importantly, these strong associations between reproduction and femaleness exclude the potentiality for alternate functions. For example, by framing the ovaries as “reproductive glands” that produce “female hormones,” the text ignores the role in and impacts of estrogen and progesterone regarding bone and organ health, and sexual function.

Furthermore, by insisting on the “femaleness” of the ovarian glands and the hormones they produce, the DG excludes the role of the ovaries in the production of testosterone, which the

ovarian cancer guide introduces as a “male hormone” on page 6. Furthermore, as is discussed in chapter 4, the testicular and prostate cancer DGs define testosterone as the “male hormone” in their definitional sections on pages 2 and 3 respectively. The assignment of “maleness” to this hormone necessarily excludes the female body, and while the term “testosterone” appears in the ovarian cancer text 3 times, it is mentioned only in reference to malfunction, and is never described as being produced by the ovaries.

The exclusion of this information is significant, as the ovaries and adrenal gland are responsible for 50% of the total amount of testosterone present in women. While testosterone is found at much higher levels in men than in women, testosterone is essential to women’s health and biological function, as it plays a key role in bone health, muscle mass, strength, energy levels, and libido, including sexual desire and sexual pleasure.

Remarks

The definitional sections of the 4 female oriented cancer patient detailed guides examined here each establish the purpose, function, and health of the vagina, cervix, uterus, and ovaries within a frame of reproduction. By contextualizing these organs, glands, and their associated muscles and hormones as purely reproductive in nature, the text ignores the vital roles they play in the overall health and wellbeing of patients, including organ health and function, bone health, sexual function, and digestive health.

A key question in my research is: How does the definitional framework established at the beginning of the cervical, endometrial, ovarian, and vaginal cancer DGs inform other areas of content throughout the guides? In the section below, I will examine three key aspects of the DGs under discussion. These sections were chosen because of their prominence throughout the genre, which makes them ideal for cross-analysis. Sections regarding risk factors and prevention occur

in all 7 guides, while sections regarding the emotional and sexual impact of cancer treatments occur inconsistently across the DGs.

Effects on Information and Reinforcement of Definitions

In this section, several key sections of the informational body of the DGs are analyzed. Themes prevalent in the sections below are prevalent throughout all 7 DGs analyzed for this study, and will be discussed in further detail in chapter 5.

The layout and focus of the “risk factors” and “prevention” sections of the 4 female affiliated DGs are discussed first, followed by a close analysis of the human papilloma virus (HPV) sections of the cervical and vaginal cancer guides’ “risk factors” and “prevention” sections.

Risk Factors

The table below lists the risk factors included in the “Risk factors” section of the four female-affiliated cancer DGs under examination. The factors are listed in order, from left to right, and are color- and style-coded based on the level of patient culpability associated with each. While some risk factors are considered “lifestyle choices,” other factors are considered unavoidable. This distinction will be discussed in more detail below.

Table 2: Female associated table of risk factors

Risk Factors for Cervical Cancer					
Human papilloma virus infection	Smoking	Immunosuppression	<i>Chlamydia</i>	<i>Diet</i>	Oral Contraception (increased risk over time)
Intrauterine device use	Multiple full term pregnancies (≥ 3)	Young age at the first full-term pregnancy (<17 years old)	Poverty	Diethylstilbestrol (DES)	
Risk Factors for Vaginal Cancer					
Age	Diethylstilbestrol (DES)	Vaginal adenosis	Human papilloma virus	Cervical cancer	Smoking
<i>Alcohol</i>	Human immunodeficiency virus	Vaginal irritation			
Risk Factors for Endometrial Cancer					
Estrogen therapy	Birth control pills (decreased risk over time)	Total number of menstrual cycles	Pregnancy (“having many pregnancies protects against endometrial cancer”)		Obesity
Tamoxifen	Ovarian tumors	<i>Use of an intrauterine device</i>	Age	Diet and exercise	Diabetes
Family history	<i>Breast or ovarian cancer</i>	Prior pelvic radiation	Endometrial hyperplasia		
Risk Factors for Ovarian Cancer					
Age	Obesity	Reproductive history (risk decreases per pregnancy)	<i>Gynecological surgery</i>	<i>Fertility drugs</i>	<i>Androgens</i>
<i>Estrogen therapy and hormone therapy</i>	Family history of ovarian cancer, breast cancer, or colorectal cancer	Personal history of breast cancer	<i>Talcum powder</i>	Diet	<i>Analgesics</i>
					<i>Smoking and alcohol use</i>

Key: Black font denotes no indication of patient culpability. Red font denotes indication of patient culpability. Orange font denotes potential of patient culpability. Green font denotes preventative effects of factor. *Italicized font* denotes that a factor is inconclusive or not directly related to cancer risk. Blue font is used for items that are listed, but are not risk factors and have no positive or negative association with the disease.

The American Cancer Society considers factors such as smoking, birth control, reproduction, diet, and alcohol consumption lifestyle choices. Lifestyle choice factors invoke patient responsibility regarding the development of cancer. As illustrated by the table above, some such factors can be considered positive in one instance of cancer, and negative in another. For example, the choice to consume oral contraceptives increases the risk of cervical cancer, but decreases the risk of endometrial cancer. Similarly, pregnancy and childbirth are considered lifestyle choices, which prove to be positive or negative risk factors, depending on the variety of cancer a woman has. For example, in the case of cervical cancer, the DG notes that having 3 or more full-term pregnancies increases a woman's risk of developing cervical cancer. Additionally, having a full-term pregnancy at a "young age," which the cervical cancer DG describes as younger than 17, also increases cervical cancer risk. However, concerning both the endometrial and ovarian cancer, the associated ACS DGs explain that "having many pregnancies protects against endometrial cancer," and "the risk goes down with each full-term pregnancy," respectively. Neither the endometrial nor ovarian cancer DGs specifies an age that is considered too young for reproduction, however, both guides specify that a greater number of full-term pregnancies leads to a lower risk of each cancer type, with the endometrial cancer guide noting that the more menstrual cycles a woman has, the more likely she is to develop endometrial cancer. Thus, while the cervical cancer DG places a significant value on a woman "waiting to get pregnant until they [are] 25 years or older," the endometrial and ovarian cancer guides place value on high reproductive function, without concern for age.

In all four of the female associated cancer DGs, the "Risk factors" sections articulate a set of moral standards that fit easily within the definitional frame articulated by each DG. Some moral standards are similar across guides, such as the endometrial and ovarian cancer DGs,

which both focus on the uterine and ovarian contributions to women's reproductive processes. The "Risk factors" sections of both these guides reinforce the reproductive value of the uterus and ovaries by listing "risk" factors that are associated with reduced risk. Long-term use of birth control pills, use of intrauterine devices, and "many pregnancies" are listed as positive factors associated with a reduced risk of cancer development, indicating that planning and controlling "many pregnancies" improves women's overall health, linking reproduction with health and moral behavior.

On the other hand, with the exception of one positively associated factor listed in the cervical cancer DG, the cervical and vaginal cancer DGs list only risk factors associated with increased risk of cancer development, with "lifestyle" factors making up 73-82% (respectively excluding or including "Poverty") of the factors listed in the cervical cancer "Risk factors" section, and 50% of the factors listed in the vaginal cancer "Risk factors" section. While the ACS DGs refer to the uterus as an "organ" and the ovaries as "glands," both the cervix and vagina are denied any such functional labels. Rather, the cervix is repeatedly referred to as a "part" of something else, or described in terms of place, while the vagina is described as a "tube." As a place and a thing, the ACS DGs assign the cervix and vagina appropriate uses, namely as an exit for a fully formed fetus. As discussed earlier in this chapter, the vaginal cancer DG briefly mentions the function of the vagina in relation to "sexual intercourse," but immediately follows with "the birth of a baby" as an adjacent function, thus linking sexual intercourse and reproduction. Based on the definitions of the cervix and vagina offered in the DGs, the cervix and vagina are used correctly when a baby passes through them.

However, because they are defined as a place or thing with a specific, "correct" use, the cervix and vagina also have "incorrect" uses. The cervical and vaginal cancer ACS DGs largely

exclude sexual function from the definitions of the cervix and vagina, choosing to omit information regarding blood flow, nerve response, and mucus excretion during arousal. Through omission, the DGs outline the “incorrect” use of the female body – female sexual pleasure – which does not become apparent until the “Risk factors” and “Can _____ cancer be prevented?” sections of these DGs. Thus, the intense focus on reproductive function directs readers to associate female bodily function with reproduction, and reproduction with correct use. Subsequently, by omitting sexual function from the definition of the female body, the ACS DGs encourage readers to consider female sexuality as erroneous, immoral, and ultimately dangerous and unhealthy. The risk and prevention sections of the cervical and vaginal cancer guides both frame the sexually active female body as out of control and in need of discipline.

Examining the occurrence of the word “sex-” (including “sex,” “sexuality,” “sexual,” etc.) in the female associated cancer DGs offers some insight. The endometrial and ovarian cancer guides use the word “sex-“ 4 and 3 times respectively, with 3 symptomatic or side effect related uses and 1 reference in the endometrial cancer DG, and 1 symptom and 2 reference related uses in the ovarian cancer DG. On the other hand, the vaginal and cervical cancer DGs use the term sex- 31 and 43 times respectively. Concerning the vaginal cancer DG, “sex-“ is used 1 time as definitional, 6 times as related to symptoms or side effects, 5 times as a reference, and 19 times as a negative association with disease and sexual behavior. Similarly, of the 43 times sex- is mentioned in the cervical cancer guide, it is mentioned 9 times as related to symptoms or impact, 4 times as referential, and 30 times as negatively associated with disease and sexual behavior. While all four DGs implicate patients in the development of their own disease by highlighting the “misuse” of the uterus, ovaries, vagina, and cervix through lack of reproduction, based on the definitions offered by the DGs, only the vagina and cervix can be involved in use

for purposes other than reproduction. Thus, the vaginal and cervical cancer DGs' equally relentless association of the female body with reproduction, and association of sex with disease and bad behavior, establishes stringent moral codes that hold vaginal and cervical cancer patients highly accountable for the development of their own cancers.

While risk factors and prevention should be addressed in an effort to improve patient health outcomes and longevity, the manner in which these risk factors and preventative measures are discussed in the 4 female-associated cancer DGs serve to establish moral culpability. This attribute is striking, especially when similar sections are compared across genders in the guides analyzed for this project. The remainder of this section will focus on a particularly salient factor – human papilloma virus (HPV) – that surfaces in the risk factors and prevention sections in both the cervical and vaginal cancer guides. While these sections vary slightly between the cervical and vaginal cancer guides, the differences do not overtly impact the overall content or message. Because the message and moral guidelines are communicated especially clearly through the cervical cancer DG, I have chosen to analyze the HPV components of the cervical cancer DGs risk factor and prevention sections.

Risk Factors and HPV

The first subsection in the risk factors section of the cervical cancer DG is titled “Human papilloma virus infection.” The table below contains the text of that section in the main body of the table, with accompanying sentence numbers in the right hand column to help with easy reference between the text and associated analysis.

Human papilloma virus infection	P. 5
The most important risk factor for cervical cancer is infection by the human papilloma virus (HPV). HPV is a group of more than 100 related viruses, some of which cause a type of growth called a <i>papilloma</i> , which are more commonly known as <i>warts</i> . HPV infection can also cause some forms of cancer, including cancers of the penis, cervix, vulva, vagina, anus, and throat.	1-3
HPV can infect cells on the surface of the skin, and those lining the genitals, anus, mouth and throat, but not the blood or internal organs such as the heart of lungs.	4
HPV can be passed from one person to another during skin-to-skin contact. One way HPV is spread is through sex, including vaginal and anal intercourse and even oral sex.	5-6
Different types of HPVs cause warts on different parts of the body. Some cause common warts on the hands and feet; others tend to cause warts on the lips or tongue.	7-8
Certain types of HPV may cause warts on or around the female and male genital organs and in the anal area. These warts may barely be visible or they may be several inches across. These are known as <i>genital warts</i> or <i>condyloma acuminatum</i> . HPV 6 and HPV 11 are the 2 types of HPV that cause most cases of genital warts. They are called <i>low-risk types</i> of HPV because they are seldom linked to cancer.	9-13
Other types of HPV are called <i>high-risk types</i> because they are strongly linked to cancers, including cancer of the cervix, vulva, and vagina in women, penile cancer in men, and cancers of the anus, mouth, and throat in both men and women. The high-risk types include HPV 16, HPV 18, HPV 31, HPV 33, and HPV 45, as well as some others. Infection with a high-risk HPV may produce no visible signs until pre-cancerous changes or cancer develops.	P. 6 14-16
Doctors believe that a woman must be infected by HPV before she develops cervical cancer. Although this can mean infection with any of the high-risk types, about two-thirds of all cervical cancers are caused by HPV 16 and 18.	17-18
Infection with HPV is common, and in most people the body is able to clear the infection on its own. Sometimes, however, the infection does not go away and becomes chronic. Chronic infection, especially when it is caused by certain high-risk HPV types, can eventually cause certain cancers, such as cervical cancer.	19-21
The Pap test looks for changes in cervical cells caused by HPV infection [...] If the test finds a high-risk types of HPV, it can mean she will need a full evaluation with a colposcopy procedure.	22-26
Although there is currently no cure for HPV infection, there are ways to treat the warts and abnormal cell growth that HPV causes.	27
For more information on preventing HPV infection, see the section “Things to do to prevent cervical pre-cancers” in this document or ask for our document <i>Human Papilloma Virus (HPV), Cancer, and HPV Vaccines: Frequently Asked Questions</i> .	28

Figure 8: Female associated HPV section excerpt

The first line of this section states “the most important risk factor for cervical cancer is infection by the human papilloma virus (HPV).” In this sentence, the reader is asked to understand that HPV is a key aspect of the cervical cancer patient. The second and third sentences of the paragraph work to establish a broad and causal relationship between HPV and cancer. The second sentence states, “HPV is a group of more than 100 related viruses, some of which cause a type of growth called a *papilloma*, which are more commonly known as *warts*” [original emphasis]. Alone, the sentence is merely informative. However, preceded by the information that HPV is the “most important risk factor for cervical cancer infection,” and followed by the information that “HPV infection can also cause some forms of cancer, including cancers of the penis, cervix, vulva, vagina, anus, and throat,” the sentence serves to lay a foundation for the issue and preventability of HPV. By noting that HPV is a large group of related viruses, but not pointing out that HPV rarely causes cancer, or that papillomas/warts are not themselves cancerous, the reader is led to understand HPV as intrinsically harmful.

The fourth and fifth/sixth sentences constitute their own miniature paragraphs, and inform readers of the possibility of infection and how infection occurs. The fourth sentence informs readers that “HPV can infect cells on the surface of the skin, and those lining the genitals, anus, mouth and throat, but not the blood or internal organs such as the heart or lungs.” Thus, readers understand that while HPV can cause cervical or throat cancers, it cannot cause lung or liver cancers. The fifth and sixth sentences of the subsection informs readers that “HPV can be passed from one person to another during skin-to-skin contact. One way HPV is spread is through sex, including vaginal and anal intercourse and even oral sex.” This sentence creates a solid link between HPV infection and sexual activities.

Sentences 7-18 explain where HPV related warts may occur. Sentences 11 and 12 note that “HPV 6 and HPV 11 are the 2 types of HPV that cause the most cases of genital warts. They are called *low-risk types* of HPV because they are seldom linked to cancer.” Despite that these sentences are making reference to the fact that HPV related cancers are uncommon – especially considering the prevalence of HPV, which the text has not yet referenced at this point – the word “seldom” used in sentence 12 indicates that these strains are sometimes linked to cancer occurrence, which serves to reinforce the established notion that HPV is inherently threatening and dangerous.

In the following paragraph, sentences 14-16 explain that “high-risk types” of HPV are “strongly linked to cancers.” The text states that “high-risk types include HPV 16, HPV 18, HPV 31, HPV 33, and HPV 45, as well as some others.” With 5 types of HPV specifically named, and an unknown number of “others” left to the imagination, the text offers over 3x as many high-risk types that are “strongly linked to cancers,” compared to the two low-risk types mentioned in the text. While the text clearly states the fact that the two low-risk types it mentions cause most HPV infections, the DG acknowledges 3x as many high-risk types, drawing attention to and inflating the perceived prevalence of high-risk types of HPV and diminishing the statistically accurate prevalence of low-risk types of HPV.

In the two-sentence paragraph that follows, the text establishes a causal, rather than correlative, relationship between HPV and cervical cancer specifically, and builds on the focus on high-risk types of HPV from the previous paragraph. Sentences 17-18 state, “Doctors believe that a woman must be infected by HPV before she develops cervical cancer. Although this can mean infection with any of the high-risk types, about two-thirds of all cervical cancers are caused by HPV 16 and 18.” Sentence 17 begins with the statement “Doctors believe,” which draws

attention to the fallible, human element of science and medicine. In this instance, the human element “Doctors” maintains an anonymous and hierarchical authority over the knowledge presented through the text, so that “Doctors” is representative of all doctors. Potentially in opposition to doctors’ authority, the term “believe” introduces the potential for inaccuracy, as beliefs are not necessarily fact. Consider, for example, the differences between the answers to the question “What time is the flight?” The answer, “I believe it is at 2:00” indicates that the response is founded on the recollection of a general time, but that additional research is needed to be certain. On the other hand, the answer “It is at 2:00” indicates certainty. Thus, the phrase “Doctors believe” is indicative of an authoritative connection between HPV infection and cervical cancer that is presumably based on observation and research, but that allows for the possibility of not-yet-discovered causal elements unrelated to HPV. However, sentence 18 works to reinforce the authority of the previous sentence by linking factual elements to the aforementioned causal relationship between HPV and cervical cancer.

The next paragraph begins with sentence 19 acknowledging the prevalence of HPV infection: “Infection with HPV is common, and in most people the body is able to clear the infection on its own.” However, the text quickly returns to the danger of HPV with sentence 20 explaining, “Sometimes, however, the infection does not go away and becomes chronic. Chronic infection, especially when it is caused by certain high-risk HPV types, can eventually cause certain cancers, such as cervical cancer.”

Sentences 22-26 of the “Human papilloma virus infection” subsection discusses Pap and other tests that look for cellular and DNA indicators of HPV. In sentence 27, the text notes that “Although there is currently no cure for HPV infection, there are ways to treat the warts and abnormal cell growth that HPV causes,” alerting the reader to potential preventative measures

that can be taken to avoid cervical cancer development. Finally, sentence 28 directs readers to the DG section “Things to do to prevent cervical pre-cancers,” which I will examine next.

Things to do to prevent pre-cancers: Avoid being exposed to HPV. “Things to do to prevent pre-cancers” is the second subsection of the “Can cervical cancer be prevented” section, and “Avoid being exposed to HPV” is the first of three tertiary sections within this subsection.

Things to do to prevent pre-cancers	Pg. 15
Avoid being exposed to HPV	
Since HPV is the main cause of cervical cancer and pre-cancer, avoiding exposure to HPV could help you prevent this disease. HPV is passed from one person to another during skin-to-skin contact with an infected area of the body. Although HPV can be spread during sex – including vaginal intercourse, anal intercourse, and oral sex – sex doesn’t have to occur for the infection to spread. All that is needed is skin-to-skin contact with an area of the body infected with HPV. This means that the virus can be spread through genital-to-genital contact (without intercourse). It is even possible for a genital infection to spread through hand-to-genital contact.	1-6
Also, infection with HPV seems to be able to be spread from one part of the body to another. This means that an infection may strrt in the cervix and then spread to the vagina and vulva.	Pg. 16 7-8
It can be very hard not to be exposed to HPV. It may be possible to prevent genital HPV infection by not allowing others to have contact with your anal or genital area, but even then there may be other ways to become infected that aren’t yet clear.	9-10
In women, HPV infections occur mainly in younger women and are less common in women older than 30. The reason for this is not clear. Certain types of sexual behavior increase a woman’s risk of getting genital HPV infection, such as having sex at an early age and having many sexual partners. Although women who have had many sexual partners are more likely to get infected with HPV, a woman who has had only one sexual partner can still get infected. This is more likely if she has a partner who has had many sex partners or if her partner is an uncircumcised male.	11-15
Waiting to have sex until you are older can help you avoid HPV. It also helps to limit your number of sexual partners and to avoid having sex with someone who has had many other sexual partners. Although the virus most often spreads between a man and a woman, HPV infection and cervical cancer are seen in women who have only had sex with other women.	16-18
HPV does not always cause warts or any other symptoms; even someone infected with HPV for years may have no symptoms. Someone can have the virus and pass it on without knowing it.	19-20

Figure 9: Female associated prevention section excerpt

The first tertiary section in the “Things to do to prevent pre-cancers” subsection is stated as a directive, instructing readers to “avoid being exposed to HPV.” The first line of the “Avoid being exposed to HPV” tertiary section notifies readers that, “Since HPV is the main cause of cervical cancer and pre-cancer, avoiding exposure to HPV could help you prevent this disease.”

The remainder of this paragraph focuses on *how* HPV infection is spread. The second sentence explains that HPV is passed through skin-to-skin contact, and the third sentence serves to reinforce the notion of “skin-to-skin” by explaining that while HPV can be spread through vaginal, anal, and oral sex, sex is not necessary for HPV for the spread of HPV. The DG again reinforces the fact that vaginal, anal, and oral sex are not the only means of HPV spread when the fourth sentence re-states, “All that is needed is skin-to-skin contact with an area of the body infected with HPV.” The fifth and sixth sentences continue, “This means that the virus can be spread through genital-to-genital contact (without intercourse). It is even possible for a genital infection to spread through hand-to-genital contact.”

The message that sentences 2-6 restates and reinforces throughout is that HPV is easily spread through all sexual activity, including “hand stuff.” Taken on their own, sentences 2-6 might be considered informative in nature. However, when contextualized by the heading and first sentence, the nature of the paragraph changes completely. The heading “Avoid being exposed to HPV” and the phrase in the second half of the first sentence, “avoiding exposure to HPV could help you prevent this disease” are particularly responsible for setting the tone of the section. Concerning the first paragraph specifically, the heading, written as a directive, instructs readers to not expose themselves to HPV. The use of second person in the first sentence, “you prevent this disease,” places the onus of prevention and, subsequently, infection, squarely on the reader. Thus, as sentences 2-6 explain to readers how HPV infection spreads – skin-to-skin

contact – the text is informing readers of how to “avoid being exposed to HPV” and how to “prevent this disease.” In other words, the text is informing the reader that, in order to prevent HPV infection – in order to engage in disease prevention – they must avoid skin-to-skin contact, including vaginal and anal intercourse, oral sex, non-penetrative genital-to-genital contact, and hand-to-genital contact. In short, the text is warning women that if they engage in sexual contact of any kind, they put themselves at risk of HPV infection, which, as the first sentence reminds, “is the main cause of cervical cancer and pre-cancer.” Essentially, if the reader, who has likely already been diagnosed with cervical cancer, touched another person in a sexual manner, she only has herself to blame.

Sentences 7-8 state, “Also, infection with HPV seems to be able to be spread from one part of the body to another. This means that an infection may start in the cervix and then spread to the vagina and vulva.” Acting as a sort of addendum to the first paragraph, this two-sentence paragraph notifies readers that they may also cause or have caused HPV infection and related cancers or pre-cancers of their vagina or vulva.

The third paragraph in the “Avoid being exposed to HPV” tertiary section acknowledges the prevalence of HPV, noting that “it can be very hard not to be exposed to HPV.” The text restates the notion of avoiding HPV in the first part of sentence 10 when it states “It **may** be possible to prevent genital HPV infection by not allowing others to have contact with your anal or genital area” [original emphasis]. However, sentence 10 goes on to note, “even then there may be other ways to become infected that aren’t yet clear.”

The fourth paragraph describes *who* becomes infected with HPV. Sentence 11 informs readers that “HPV infections occur mainly in younger women and are less common in women older than 30,” and the following sentence notes that “The reason for this is not clear.” However,

sentence 13 immediately follows with the assertion that “Certain types of sexual behavior increase a woman’s risk of getting genital HPV infection, such as having sex at an early age and having many sexual partners.” The behavioral-causal assertion of sentence 13 harkens back to the section heading and first paragraph of the section, noting that *behavior* – specifically *sexual behavior* – determines what kinds of women develop HPV and, consequently, cervical cancer. Referring back to the section heading and first paragraph, we understand that women who fail to “avoid being exposed to HPV” and do not work to “prevent this disease” also “have sex at an early age” or have “many sexual partners.” Because the first paragraph establishes that any skin-to-skin sexual contact is irresponsible and potentially life threatening, readers are led to understand that “sex at an early age” and “many sexual partners” are inherently irresponsible and immoral.

Sentence 14 takes this sexual irresponsibility a step further: “Although women who have had many sexual partners are more likely to get infected with HPV, a woman who has had only one sexual partner can still get infected.” This sentence, also referring back to the first paragraph, reaffirms the notion that any amount of sexual contact – even sexual contact that is conservative in numbers – potentially exposes women to HPV infection and cervical cancer. Sentence 15 ends the paragraph, noting, “This is more likely if she has a partner who has had many sex partners or if her partner is an uncircumcised male.”

The fifth paragraph offers some suggestions regarding how women should behave in order to avoid HPV infection. Sentence 16 informs readers “Waiting to have sex until you are older can help you avoid HPV.” Considering the entire context of this section, this sentence should be understood as instructive rather than informative. Beginning with the subsection heading, “Things to do to prevent pre-cancers,” to the tertiary section heading, “Avoid being

exposed to HPV,” through the first sentence, “...you prevent this disease,” and beyond, the use of commanding language and the second person “you” throughout positions “information” as instructions for how readers should or should not behave. Here, in sentence 16, the text uses the second person “you” twice, pointing the informative-command of the sentence directly at readers. As such, the text suggests that women should wait “until [they] are older” to have sex. This suggestion begs the question, older than what? The readers of this text are primarily women who have already been diagnosed with cervical cancers or pre-cancers. On page 4 of this DG, under the “What are the key statistics about cervical cancer?” section, the DG informs readers that “Cervical cancer tends to occur in midlife. Most cases are found in women younger than 50. It rarely develops in women younger than 20. [...] More than 20% of cases of cervical cancer are found in women over 65.” Considering these statistics, it appears that the DGs non-specific instruction to “wait until you are older to have sex” is directed primarily toward middle-aged women, with women over 65 and women in their 20’s-30’s as secondary targets.

Situated within the same context, and speaking to the same audience, sentence 17 offers some follow-up instructive-advice: “It also helps to limit your number of sexual partners and to avoid having sex with someone who has had many other sexual partners.” The first half of sentence 17, “It also helps to limit your number of sexual partners...” follows the instruction to “wait” with an instruction to “limit,” while the second half of the sentence, “...avoid having sex with someone who has had many other sexual partners,” insinuates not only that women should screen and choose potential sexual partners based on past sexual history, but also that women are responsible for curbing the spread of disease.

Taking this analysis a little deeper, paragraph 5 has more complicated implications. As mentioned above, the readers of the cervical cancer DG are primarily women who have already

been diagnosed with cervical cancers or pre-cancers. According to the Centers for Disease Control and Prevention (CDC), the median age of women diagnosed with cervical cancer is 48 years old (Centers for Disease Control and Prevention, 2013), with half of cases younger and half of cases older. Almost all cases occurred in women 20+ years of age, with the highest rates of incidence in women 30-50 years old. Thus, the primary audience of the cervical cancer DG is comprised of 30-50 year old women who have been diagnosed with cervical cancer or pre-cancers. As such, paragraph 5 functions as a mechanism to alert patients to their past behavioral “problems,” specifically in regard to the “certain types of sexual behavior” such as having sex, having more than one sexual partners, and having sex with someone who has had sex with many people (pg. 16). As such, this reminder of “bad” behavior serves as a shaming mechanism.

HPV and men. The “Avoid being exposed to HPV” tertiary section of this DG offers two subsections of its own: “HPV and men,” and “Condoms and HPV.”

HPV and men	
For men, the 2 main factors influencing the risk of genital HPV infection are circumcision and the number of sexual partners.	1
Men who are circumcised (have had the foreskin of the penis removed) have a lower chance of becoming and staying infected with HPV. Men who have not been circumcised are more likely to be infected with HPV and pass it on to their partners. The reasons for this are unclear. It may be that after circumcision, the skin on the glans (of the penis) goes through changes that make it more resistant to HPV infection. Another theory is that the surface of the foreskin (which is removed by circumcision) is more easily infected by HPV. Still, circumcision does not completely protect against HPV infection – men who are circumcised can still get HPV and pass it on to their partners.	2-6
The risk of being infected with HPV is also strongly linked to having many sexual partners (over a man’s lifetime).	7

Figure 10: Female associated prevention section excerpt HPV and men

Sentence 1 in the first of these two, “HPV and men,” tells readers that “For men, the 2 main factors influencing the risk of genital HPV infection are circumcision and the number of sexual partners.” Sentences 2-6 offer potential explanations for why uncircumcised men are

more likely to become and stay infected with HPV. Sentence 7, the final sentence of this subsection notes, “The risk of being infected with HPV is also strongly linked to having many sexual partners (over a man’s lifetime).”

It is prudent to note here that this subsection focuses almost exclusively on uncircumcised penises’ seeming vulnerability to HPV. Despite the text’s admission in sentence 3 that “the reasons for this are unclear,” sentences 4 and 5, beginning with the phrases “it may be” and “another theory is” respectively, spend the bulk of the subsection speculating over the physical characteristics of uncircumcised penises.

Finally, even though sentence 7 is short, there are several significant aspects that must be discussed. First, sentence 7 appears at the bottom of the section almost as an aside. Here, the text prioritizes the discussion of circumcision to a significant degree, minimizing the impact of sexual activity as a result. The ratio of attention to circumcision versus sex communicates to readers that circumcision – something done *to* men – is a significant predictor of HPV in men. Second, sentence 7 lacks a subject. While sentences 2-6 use the phrases, “Men who are circumcised” (s2), “Men who have **not** been circumcised” [original emphasis] (s3), and “men who are circumcised” (s6), the main body of sentence 7 does not offer a subject to be at risk of HPV infection due to many sexual partners. The notion that “The risk of being infected with HPV is also strongly linked to having many sexual partners” was continuously directed at readers throughout the “Avoid being exposed to HPV” section through the use of the second person “you.” While the second person “you” would not fit in sentence 7 of the section under examination, the subject “men” is absent from the main body of the sentence. In other words, instead of using wording such as “A man’s risk of being infected,” or “Men’s risk of being infected,” the sentence offers a

general statement about HPV infection and sexual partners. This is a distinct break from the preceding text.

The parenthetical note at the end of sentence 7 is also a distinct break from the preceding text. Sentence 7 ends with the comment, “(over a man’s lifetime).” It is unclear what

Condoms and HPV. This section is designed to inform readers about the role of condom use in HPV prevention.

<p>Condoms and HPV</p> <p>Condoms (“rubbers”) provide some protection against HPV. Men who use condoms are less likely to be infected with HPV and to pass it on to their female partners. One study found that when condoms are used correctly they can lower the HPV infection rate in women by about 70% if they are used every time sex occurs. One reason condoms cannot protect completely is that they don’t cover every possible HPV-infected area of the body, such as skin of the genital or anal area. Still, condoms provide some protection against HPV, and they also protect against HIV and some other sexually transmitted diseases. Condoms (when use by the male partner) also seem to help the HPV infection and cervical pre-cancers go away faster.</p>	<p>1-6</p>
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Figure 11: Female associated prevention section excerpt condoms and HPV

Sentences 1 and 2 of this section state, “Condoms (“rubbers”) provide some protection against HPV. Men who use condoms are less likely to be infected with HPV and to pass it on to their female partners.” Sentence 1 informs readers that condoms can protect against HPV, but the use of the word “some” alerts readers to the notion that condoms do not offer complete protection. Sentence 2 specifies “men” as the subject of condom use, placing the onus of condom use and HPV infection on men. Sentence 3 states, “One study found that when condoms are used correctly they can lower the HPV infection rate in women by about 70% if they are used every time sex occurs” (pg. 16). This information is offered with the anonymous institutional authority discussed in previous sections. The use of the phrase “one study” emphasizes the scientific aspect of the information, adding authoritative validity to the 70% statistic cited. Sentence 4 explains why condoms do not completely protect against HPV infection, and sentence 5 reasserts

that “condoms provide some protection against HPV,” as well as other sexually transmitted diseases. Sentence 6, the final sentence of this paragraph, also points out that “Condoms (when used by the male partner) also seem to help the HPV infection and cervical pre-cancers go away faster.” The addition of this information reinforces the notion that bodies usually clear HPV infections on their own, as well as the notion that chronic HPV infections are what cause cervical cancers and pre-cancers. Sentence 6 also reaffirms the importance of male partners’ use of condoms, and reinforces the notion that condom use is the responsibility of male partners.

Remarks. The HPV components in the cervical cancer DG risk factors and prevention sections begin to illustrate the power of the reproductive definition laid out at the beginning of the guide; outside of confines of that definition, the sexually active female body is framed as dangerous, diseased, and in need of discipline. Becoming especially evident in the prevention section, the text offers discipline in the form of suggestions or directions for behavioral modification. This authoritative and infantilizing language construction – first seen in the definitional section of the DG – is used throughout the prevention section, and includes titles that direct readers on what actions they should take: “Avoid being exposed to HPV,” “Don’t smoke,” and “Get vaccinated.”

The definitions established early in the DGs examined here narrowly determine specific functions for the uterus, ovaries, cervix, and vagina. The uterus (reproductive organ) and ovaries (reproductive glands) are framed as functioning optimally when “the baby” is being developed, and the vagina (thing/space) and cervix (place/piece) are framed as functioning optimally during “the birth of a baby” (Vaginal Cancer). While unused reproductive bodies garner negative consequences – namely cancer – the endometrial and ovarian cancer DGs emphasize the positive outcomes of controlled reproduction. However, unlike the uterus and ovaries, the cervix and

vagina can be implicated in instances of misuse, namely, sexual activity. Thus, the sexually active female body is framed as undisciplined and dirty, and the cancer patient as irresponsible. As a result, the cervical or vaginal cancer patient is strongly implicated in the development of her disease, which, using an authoritative tone and infantilizing language, the DG insinuates may have been avoided if the patient had simply behaved better.

The following section of this dissertation will examine the sections of the female affiliated DGs that discuss treatment side effects. Along with the definitional and risk factors sections discussed earlier in this chapter, the treatment side effects sections of all 7 guides offer clear examples of tone, structure, and language that work to illustrate the impact on and of the information provided in these guides.

Treatment Side Effects

This section examines excerpts from the cervical, vaginal, and endometrial cancer DGs. These sections will be discussed in chapter 5 in further detail, and will be cross-analyzed with similar sections from the ACS' penile, prostate, and testicular cancer DGs analyzed in the following chapter. First, sections from the vaginal, endometrial, and cervical cancer guides which include information on the effects of radiation therapy on the vagina will be examined. Next, three sections chosen from the cervical cancer DG, which are the only sections across the 4 female associated DGs that directly address sexual side effects of surgical treatments for gynecological cancer, and one section from the vaginal cancer DG will be examined.

The ovarian cancer DG is excluded from this analysis because there is no text to analyze. "Sex" or "sexuality" appears 4 times in the ovarian cancer DG: once on page 12 as, "[...] *sex cord tumor with annular tubules* (SCTAT)" [original italics]; once on page 18 under "Signs and symptoms of ovarian cancer" as a bullet point, "Pain during sex"; once on page 57 under

“Additional resources for ovarian cancer” as a listing for the ACS publication “Sexuality for the Woman With Cancer”; and once on page 58 under the same “Additional resources” heading as “articles on personal issues such as fertility, sexuality and quality of life.” Effects of pelvic radiation on the vagina are not discussed. These absences will be discussed in more detail in chapter 5.

Radiation therapy for cervical, vaginal, and endometrial cancer. The effects of radiation on the vagina are discussed in the cervical, vaginal, and endometrial cancer DGs. While these effects do not appear under headings that indicate sex-specific information, the text mentions vaginal intercourse. The three sections are similar, although they contain some significant differences. Because of these differences, all three sections are included below. Words, phrase, and sentences in each section have been altered to highlight similarities and differences between the texts.

Plain text indicates that the content is the same across all three guides, although the wording may vary. **Bolded text** indicates that words, phrases, or information in one text does not appear in the others. *Italicized text* indicates that information is similar between two texts, but is not included in another.

Radiation therapy: Vaginal cancer (excerpt 1). Under the “Radiation therapy for vaginal cancer” subheading, the “Side effects of radiation therapy” tertiary section discusses sexual side effects at its end. The last two paragraphs are included in the excerpt below.

Side effects of radiation therapy	Pg. 22
[...] Radiation can cause the normal tissue of the vagina to become irritated and sore. As it heals, scar tissue can form in the vagina. The scar tissue can make the vagina shorter or more narrow (this is called vaginal stenosis). When this happens, <i>sex (vaginal intercourse)</i> can become painful. Stretching the walls of the vagina a few times a week can help prevent this problem.	19-23 Pg. 23
One way to do this is to have vaginal intercourse at least 3 to 4 times a week. <i>Since this may be hard to do while getting cancer treatment</i> , another option is to use a vaginal dilator. A dilator is a plastic or rubber tube used to stretch out the vagina. It feels much like putting in a large tampon for a few minutes. Even if a woman is not interested in staying sexually active, keeping her vagina normal in size allows comfortable gynecologic exams. This is an important part of follow-up after treatment. Vaginal estrogens may also be used to relieve dryness and prevent painful intercourse and help maintain the size of the vagina. Still, vaginal dryness and pain with intercourse can be long-term side effects from radiation.	24-31
For more information on radiation therapy, see our document <i>Understanding Radiation Therapy: A guide for Patients and Families.</i>	32

Figure 12: Female associated side effects of radiation excerpt

Radiation therapy: Endometrial cancer (excerpt 2). The excerpt below is from the “Side effects of radiation therapy” tertiary section, found in the “Radiation therapy for endometrial cancer” subsection. The tertiary section is broken into two parts, “Short-term side effects” and “Long-term side effects.” Sentences 1-9 of the “Long-term side effects” part discuss the effects of radiation on the vagina. The remainder of the section discusses damage to surrounding organs and tissues, damage to the lymphatic system, bone weakening, and bladder problems. Only sentences 1-9 of “Long term side effects” are included below.

Long-term side effects: Radiation therapy may cause changes to the lining of the vagina leading to vaginal dryness. This is more common after vaginal brachytherapy than after pelvic radiation therapy. In some cases scar tissue can form in the vagina. The scar tissue can make the vagina shorter or more narrow (called vaginal stenosis), which can make <i>sex (vaginal intercourse)</i> painful. A woman can help prevent this problem by stretching the walls of her vagina several times a week. This can be done by having sexual intercourse 3 to 4 times per week or by using a vaginal dilator (a plastic or rubber tube used to stretch out the vagina). Still, vaginal dryness and pain with intercourse can be long-term side effects from radiation. Some centers have physical therapists who specialize in pelvic floor therapy which can help to treat these vaginal symptoms and sometimes improve sexual function. You should ask your physician about this if you are bothered by these problems.	Pg. 28 1-9
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Figure 13: Female associated long term side effects of radiation excerpt

Radiation therapy: Cervical cancer (excerpt 3). The excerpt below is from the “Radiation therapy for cervical cancer” subheading. Sentences 1-24 offer some general information about radiation therapy and brachytherapy. Sentences 25-34 address effects of pelvic radiation on the vagina. Sentence 35-41 briefly mention bone weakening, lymphatic issues, and smoking, which will be addressed in chapter 5. The excerpt below includes only sentences 25-31 from the “Radiation therapy for cervical cancer subsection,” which address effects on the vagina with a focus on vaginal intercourse.

Radiation therapy for cervical cancer	Pg. 35
<p>[...]</p> <p>Pelvic radiation therapy may cause scar tissue to form in the vagina. The scar tissue can make the vagina more narrow (called vaginal stenosis) or even shorter, which makes vaginal intercourse painful. A woman can help prevent this problem by stretching the walls of her vagina several times a week. Although this can be done by engaging in sexual intercourse 3 to 4 times per week, most women find that hard to do during treatment. The other way to stretch out the walls of the vagina is by using a vaginal dilator (a plastic or rubber tube used to stretch out the vagina). A woman getting pelvic radiation does not have to start using the dilator during the weeks that radiation is being given, but she should start by 2 to 4 weeks after treatment ends. Because it can take a long time to see the effects of radiation, some experts recommend that the dilator be used indefinitely.</p>	25-31
<p>Vaginal dryness and painful intercourse can be long-term side effects from radiation. Vaginal (local) estrogens may help with vaginal dryness and changes to the vaginal lining, especially if radiation to the pelvis damaged the ovaries, causing early menopause. Radiation can also irritate the bladder and problems with urination may occur.</p>	32-34

Figure 14: Cervical cancer radiation excerpt

Discussion of excerpts. All three excerpts speak explicitly to vaginal intercourse, with excerpts 1 and 2 from the vaginal and endometrial cancer DGs defining “sex” as “vaginal intercourse,” explicitly excluding the possibilities of oral or anal sex. Through this focus on penetrative sex, all three texts problematize the health of the vagina in terms of the penis. Thus, the concern of the text is centered on the ability of the penis to penetrate the irradiated vagina.

In all three excerpts, readers learn that radiation therapy may cause scar tissue to develop in the vagina, potentially leading to a narrowed or shortened vagina. In excerpts 1 and 2 from the vaginal and endometrial cancer DGs, the texts note, “When this happens, sex (vaginal intercourse) can become painful” (excerpt 1) and “which can make sex (vaginal intercourse) painful” (excerpt 2). While pain may or may not occur according to these two texts, excerpt 3 from the cervical cancer DG is definitive regarding radiation related vaginal pain, stating, “which makes vaginal intercourse painful.”

The solution to the problems posed by the irradiated vagina is to stretch the vaginal walls. Each guide cites vaginal intercourse as one of two ways to accomplish this task, although the three texts address the topic slightly differently. In excerpt 1 from the vaginal cancer DG, the sentence 24 states “One way to do this is to have vaginal intercourse at least 3 to 4 times a week.” The phrase “at least” is used only in the vaginal cancer DG. This phrase insinuates that 3-4 times per week is the bare minimum that must be achieved, and that patients should exceed that frequency. The next line in excerpt 1 acknowledges the potential difficulty patients may have in achieving this frequency during treatment, and offers a vaginal dilator as an alternative to sexual intercourse. Excerpt 3 from the cervical cancer DG follows the same line of discussion: the text first states the circumstances (shortened or narrowed vagina), then the problem (difficult vaginal intercourse), then the solution (frequent vaginal intercourse). Excerpt 3 also cites 3-4 instances of vaginal intercourse per week as a solution, although it establishes 3-4 instances as satisfactory, not a minimum. Finally, like excerpt 1, excerpt 3 also notes that achieving that frequency of sexual frequency may be difficult during treatment. However, excerpt 3 states “most women find that hard to do during treatment.” In this instance, the phrase “most women” indicates certainty and offers concrete expectations for “most patients” regarding vaginal intercourse during

treatment. This certain, concrete tone reinforces the definitive nature of the text's knowledge established earlier in the cervical cancer DG, and restated in sentence 26, "which makes vaginal intercourse painful."

Next, the texts introduce the dilator, which all three describe as "a plastic or rubber tube used to stretch out the vagina." Once defined, however, the three texts all go in different directions regarding the discussion of the dilator. In excerpt 1, the vaginal cancer DG explains that using the dilator "feels much like putting in a large tampon for a few minutes." This is the only instance through the three texts that offers such an explanation. Next, the vaginal cancer DG adds an additional argument for why women should keep their vaginas stretched: "Even if a woman is not interested in staying sexually active, keeping her vagina normal in size allows comfortable gynecologic exams. This is an important part of follow-up after treatment." While the text is drastically diminishing the scope of the term "sexually active" by equating sexual activity with penetrative vaginal sex, of the three excerpts, only the vaginal cancer excerpt allows for the notion that patients may not be interested in vaginal intercourse. The statement "This is an important part of follow-up after treatment" lends weight to the notion of clinical importance, and also adds an element of patient responsibility. The following sentence (30) returns to intercourse, noting the potential of vaginal estrogens to help "relieve dryness and prevent painful intercourse and help maintain the size of the vagina." While the sentence structure makes it difficult to discern whether vaginal estrogens or intercourse help maintain the size of the vagina, the previous discussion indicates that it is the later. Finally, the excerpt notes "Still, vaginal dryness and pain with intercourse can be long-term side effects from radiation," alerting patients to the potential inevitability of damage they may face.

The endometrial cancer DG excerpt uses the same sentence discussed above, “Still, vaginal dryness and pain with intercourse can be long-term side effects from radiation,” which directly follows the introduction of the dilator. However, the text goes on to offer additional information regarding the issue, stating, “Some centers have physical therapists who specialize in pelvic floor therapy which can help to treat these vaginal symptoms and sometimes improve sexual function.” Like the vaginal cancer DG discussed above, this text severely narrows the definition of “sexual function” – which broadly refers to pleasure, desire, arousal, and orgasm (American Psychiatric Association, 2013, pp. 535-536) – to refer only to penetrative vaginal sex.

Excerpt 3 from the cervical cancer DG implements a dilator use timeline after introducing the device in the previous sentence. The text states, “A woman getting pelvic radiation does not have to start using the dilator during the weeks that radiation is being given, but she should start by 2 to 4 weeks after treatment ends.” This sentence is given as a mandate. In the first half of the sentence, the phrase “does not have to start [...] during the weeks that radiation is being given” indicates that “a woman” will indeed “have to start” at some point after “the weeks that radiation is being given.” Although the use of the word “should” in the second half of the sentence would normally be indicative of a suggestion, in this case, the phrase “should start by 2 to 4 weeks” simply offers a timeline for the mandate inherent in the sentence.

Surgery for cervical and vaginal cancers: Sexual impact. Surgical effects on female sexuality are discussed in the cervical and vaginal cancer DGs. The cervical cancer DG is the only guide across the 4 female affiliated guides that dedicates space specifically for the discussion of patients’ sexual selves. While there is no dedicated space specifically for the discussion of “sexual impact,” the vaginal cancer DG’s “Vaginal reconstruction” tertiary section provides some information regarding sexual intercourse.

First, three sections from the cervical cancer DG will be examined, “Sexual impact of hysterectomy,” “Sexual impact of radical hysterectomy,” and “Sexual impact of pelvic exenteration.” Next, one section from the vaginal cancer DG will be examined, “Vaginal reconstruction.”

There are three tertiary sections regarding sexual impact within the “Surgery for cervical cancers and pre-cancers” section. Each tertiary section occurs after the surgery it is related to. For example, the subsection “Hysterectomy” is followed by the tertiary section “Sexual impact of hysterectomy.” This is the first tertiary section analyzed in this section. Prior to discussing each tertiary section, the ACS’ explanation of the surgery related to each “Sexual impact” tertiary section will be briefly described.

Sexual impact of hysterectomy. The hysterectomy subsection of the “Surgery for cervical cancers and pre-cancers” section describes hysterectomy as the removal of the uterus and cervix, “but not the structures next to the uterus. The vagina and pelvic lymph nodes are not removed” (Cervical 31). The rest of the section offers general information regarding the procedure and recovery time, and informs the reader of resulting infertility. The “Sexual impact” tertiary section states: “Hysterectomy does not change a woman’s ability to feel sexual pleasure. A woman does not need a uterus or cervix to reach orgasm. The area around the clitoris and the lining of the vagina remain as sensitive as before” (Cervical, 32). While the DG notes that hysterectomy, depending on how it is done, requires between 1-5 days in the hospital and 2-6 weeks recovery, the DG does not allow for the possibility of any potential sexual impact. The definitive phrase “does not” in the first and second sentences excludes the possibility of sexual impact, while the length of the section – just 39 words – communicates to readers that the information is unimportant.

Sexual impact of radical hysterectomy. The ACS defines radical hysterectomy as the removal of the “uterus along with the tissues next to the uterus (the *parametria* and the *uterosacral ligaments*) and the upper part (about 1 inch) of the vagina next to the cervix [original emphasis]” (Cervical, 32). The ovaries and fallopian tubes are only removed when medically necessary. The surgery is conducted through an incision in the abdomen, where some pelvic lymph nodes are often removed. The remainder of the ACS subsection offers a general overview of the procedure, recovery time, potential complications, and associated cancer stages, while the following tertiary section addresses sexual impact.

The “Sexual impact of radical hysterectomy” tertiary section states:

“Radical hysterectomy does not change a woman’s ability to feel sexual pleasure.

Although the vagina is shortened, the area around the clitoris and the lining of the vagina remains as sensitive as before. A woman does not need a uterus or cervix to reach orgasm. When cancer has caused pain or bleeding with intercourse, the hysterectomy may actually improve a woman’s sex life by stopping these symptoms (Cervical, 33).

Similar to the “Sexual impact of hysterectomy” tertiary section discussed above, the “Sexual impact of radical hysterectomy” tertiary section discloses the potential for women who undergo this surgery to experience sexual impact. Despite the fact that this surgery results in a shortened vagina, the text seems to double down, arguing not only that patients’ sexual pleasure will remain intact, but that the operation may result in an improved sex life. While ending painful symptoms is certainly a positive result, the text here only leaves opportunity for improvement, actively excluding the potential for negative impacts.

Sexual impact of pelvic exenteration. The third and final subsection under the “Surgery for cervical cancers and pre-cancers” section addresses pelvic exenteration. The text explains

that this extensive operation includes removal of all organs and tissues removed in a radical hysterectomy with lymph node dissection. “In addition, the bladder, vagina, rectum, and part of the colon may also be removed, depending on where the cancer has spread” (Cervical, 33). The remainder of this subsection offers brief explanations of what might happen if the bladder, rectum and part of the colon, or vagina are removed. These explanatory paragraphs offer general information on the potential of new methods of waste elimination and the possibility of reconstruction, and consist of 87, 95, and 23 words respectively.

The sexual impact tertiary section, “Sexual impact of pelvic exenteration,” reads:

Recovery from total pelvic exenteration takes a long time. Most women don’t begin to feel like their normal selves again for 6 months after surgery. Some say it takes a year or two to adjust completely.

Nevertheless, these women can lead happy and productive lives. With practice and determination, they can also have sexual desire, pleasure, and orgasms. (Cervical, 34)

This 58 word tertiary section employs infantilizing and emotional language, and asserts a mind-over-matter point of view that dismisses the relevance of negative experiences as “not trying hard enough.” The first three sentences vaguely situate recovery as a long and mysterious process when women may not feel normal for six months to a year. Sentence 4 informs readers that “these women,” who do not feel normal, can lead happy and productive lives. The words “can” and “lead” are important, as “can” indicates both ability and choice, and “lead” is an active verb that assigns authority to the individual. Thus, the phrase “can lead” insinuates that the women in question will lead “happy and productive lives” if they choose to lead and choose to be happy and productive; however, women who choose not to lead and instead are led by their circumstance, may not be happy or productive. The word “happy” is emotional language, while

the notion of “production” seems to insinuate that, although a woman may no longer be able to serve as a reproductive vessel, she may still be able to produce and contribute in other ways.

The fifth and final sentence in this tertiary section decisively closes the discussion: “With practice and determination, they can also have sexual desire, pleasure, and orgasms.” In this sentence, the text asserts that sexual desire, pleasure, and orgasms are readily available to women who work hard enough to get them. This sentence places the onus of pleasure and desire exclusively on patients, while the language of “determination” reinforces societal notions that women’s sexuality is situated in their minds; fickle female attraction and the elusive female orgasm are located in women’s imaginations, and if they really want to – if they focus hard enough, and for long enough – they might be able to conjure desire and pleasure.

Vaginal reconstruction. Under the “Surgery for vaginal cancer subheading,” the “Vaginal reconstruction” tertiary section describes “vaginectomy” as a “surgery to remove the vagina.” A partial vaginectomy removes part of the vagina, while a total vaginectomy removes the entire vagina. “A radical vaginectomy is when the vagina is removed along with the supporting tissues around it.” The tertiary section “Vaginal reconstruction,” included below, addresses vaginectomy.

Vaginal reconstruction	Pg. 24
If all or most of the vagina must be removed, it is possible to reconstruct (rebuild) a vagina with tissue from another part of the body, which will allow a woman to have sexual intercourse. A new vagina can be surgically created out of skin, intestinal tissue, or myocutaneous (muscle and skin) grafts.	1-2
A reconstructed vagina produces little or no natural lubricant when a woman becomes sexually excited. A woman should prepare for intercourse by using a lubricating gel inside the vagina. If the vagina was rebuilt using muscle and skin from the leg, touching the new vagina may make a woman feel as though her thigh is being stroked. This is because the walls of the vagina are still attached to their original nerve supply. Over time, these feelings become less distracting and may even become sexually stimulating. (For more information about vaginal reconstruction, see our document, <i>Sexuality for the Woman With Cancer</i>).	3-8

Figure 15: Vaginal reconstruction excerpt

Sentence 1 of this tertiary section once problematizes the vagina in terms of the penis, noting that vaginal reconstruction “will allow a woman to have sexual intercourse.” In the following paragraph, sentences 3 and 4 explain that women should use lubricant to accommodate penetration. Sentences 5 and 6 explain that reconstructed vaginas “rebuilt using muscle and skin from the leg” may give a woman the sensation that her thigh is being stroked, “because the walls of the vagina are still attached to their original nerve supply.” While this may sound strange or intimidating, the text assures that “Over time, these feelings become less distracting and may even become sexually stimulating.” The use of the words “feelings” and “distracting” invoke the notion of women’s sexuality as mentally produced and dictated by emotion. Following this setup, the phrase “may even become sexually stimulating” evokes the notion that women’s sexuality does not come naturally, and that they must exert conscious effort to achieve sexuality and sexual satisfaction.

Final Remarks

The definitions offered for the vagina, cervix, endometrium, and ovaries in their respective cancer patient detailed guides (DG) focus on the reproductive function of these female tubes, passages, organs, and glands. The frame of reproduction is maintained throughout each DG, carrying into and working to shape subsequent sections, such as the risk factors and treatment sections. In addition, the relentless focus on the reproductive functions of women’s bodies limits the potential not only for cancer information and treatment to be effectively discussed and rendered, but also for future cancer research, and treatment and prevention development. The definitional frame laid out at the beginning of these texts has seemingly influenced both the type of information offered to patients, and the way the information is structured and limited.

Chapter 4 will examine the male associated cancer patient detailed guides, and will focus on similar sections using the same textual analysis approach used in this chapter. Chapter 5 will discuss similarities and differences between female and male oriented DGs, and explore potential implications.

CHAPTER 4: ANALYSIS

It's a Boy!:

Analyzing Men's Cancer Patient Detailed Guides

In this chapter, I analyze the penile, testicular, and prostate cancer patient detailed guides (DG) produced by the American Cancer Society (ACS). I first examine the definitional sections of each DG, and then move on to examine the risk factors and side effects sections. The analysis of these DGs is structured in the same way as the analysis from the chapter 3, and focuses on comparable sections. This process of examination will continue to demonstrate how definitional frames go on to influence how patients are instructed to understand their disease, their bodies, and the potential side effects they may face with different treatment options.

Defining the Male Body

I will begin by examining the definitional sections of the three male oriented DGs. The penile and prostate cancer guides each offer a dedicated "About" subsection that defines and describes the affected part of the body. While the testicular cancer guide does not contain a dedicated "About" subsection, the first section under the "What is testicular cancer?" heading is largely dedicated to defining and describing the structure and function of the testicles.

Penile Cancer

About the penis: The male sexual organ. Through cultural and medical norms alike, the average American is encouraged to consider men as sexual beings above all else. The American Cancer Society's penile cancer DG is no exception. As the male symbol, the penis is defined in terms that are active, assertive, and sexual by nature (e.g., Braun & Kitzinger, 2001; Martin,

1991; Metoyer & Rust, 2011). In the definitional subsection of the penile cancer DG, “reproduction” is never mentioned as a possible function of the penis, and instead frames the penis an instrument of sex.

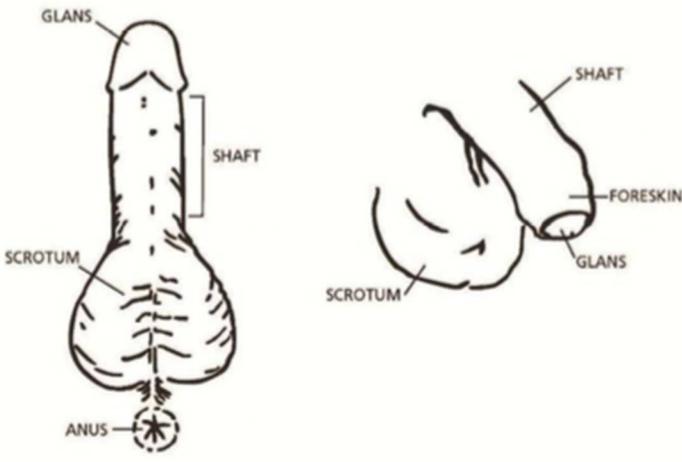
<p>What is penile cancer?</p>	<p>Pg. 2 1</p>
<p>To understand penile cancer, it helps to know about the normal structure and function of the penis.</p>	
<p>About the penis</p>	<p>1-2</p>
<p>The penis is the external male sexual organ, as well as part of the urinary system. It contains several types of tissue, including skin, nerves, smooth muscle, and blood vessels.</p>	<p>Pg. 3</p>
<div style="text-align: center;">  </div>	
<p>The main part of the penis is known as the <i>shaft</i>, and the head of the penis is called the <i>glans</i>. At birth, the glans is covered by a piece of skin called the <i>foreskin</i>, or prepuce. The foreskin is often removed in infant boys in an operation called a circumcision.</p>	<p>3-5</p>
<p>Inside the penis are 3 chambers that contain a soft, spongy network of blood vessels. Two of these cylinder-shaped chambers, known as the corpora cavernosa, lie on either side of the upper part of the penis. The third lies below them and is known as the <i>corpus spongiosum</i>. This chamber widens at its end to form the glans. The corpus spongiosum surrounds the <i>urethra</i>, a thin tube that starts at the bladder and runs through the penis. Urine and semen travel through the urethra and leave the body through an opening in the glans of the penis, called the <i>meatus</i>.</p>	<p>6-11</p>
	<p>Pg. 4</p>

Figure 16: Penile cancer definitional section excerpt

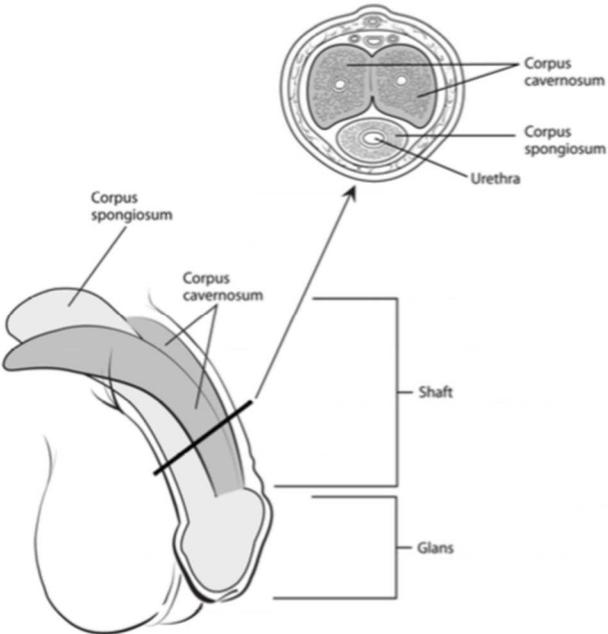
	
<p>When a man gets an erection, nerves signal to his body to store blood in the vessels inside the corpora cavernosa. As the blood fills the chambers, the spongy tissue expands, causing the penis to elongate and stiffen. After ejaculation, the blood flows back into the body, and the penis becomes soft again.</p>	12-14
<p>Semen is made up of fluid produced by the prostate gland, and the seminal vesicles (2 small sacs near the bladder and prostate), plus sperm cells that are made in the testicles. It is stored in the seminal vesicles. During ejaculation, semen passes into the urethra and out the meatus at the tip of the penis.</p>	15-17

Figure 16: Penile cancer definitional section excerpt continued

The first line of the “About the penis” section is: “To understand penile cancer, it helps to know about the **normal** structure and function of the penis” [emphasis added]. With this sentence, the reader is notified that: 1) there is a “normal” or standard “penis” 2) with a particular, “normal” format (structure) and 3) a particular, “normal” function. Finally, 4) the reader is not expected to be fully aware of the “normal structure and function of the penis”; thus, the DG takes on the responsibility of laying the foundation for “normal” and “penis,” telling the reader both what they *should* and *need* to know according to the DG’s socially derived standards of “normal.”

The second sentence in the introductory subsection states: “The penis is the external male sexual organ, as well as part of the urinary system.” Because the DG alerted the reader to “normal” structure and function, the reader now knows that the “normal” function of the penis is, first and foremost, sexual in nature. The reader is also introduced to the penis as an “organ,” which assigns autonomy, importance, and purpose, to the penis, such as that attributed to the heart, liver, or lungs. Considering the classification of the penis as the “male *sexual organ*” [emphasis added], the reader is further invited to consider the penis’ inherent function as sexual, and to think of the penis as autonomous and essential. It follows that because the primary function of the penis is sexual, then the “normal” structure of the penis is to engage in sex acts, and because heterosexual intercourse is considered “sex” (whereas other sex acts require modifiers, such as “oral sex”), then the “normal” function of the penis is to engage in penetrative sex, and the “normal” structure of the penis must facilitate an erection.

The implied notion of the penis as “normally” erect and engaging in penetrative sex is confirmed in the same section when the DG states:

When a man gets an erection, nerves signal to his body to store blood in the vessels inside the corpora cavernosa. As the blood fills the chambers, the spongy tissue expands, causing the penis to elongate and stiffen. After ejaculation, the blood flows back into the body, and the penis becomes soft again.

The word “when” used at the beginning of the passage implies that erection is inevitable and thus “normal” in both the structural and functional aspects of the penis. The phrase “after ejaculation” has the same implication of inevitability, with the resultant expectation that an erect penis should ejaculate, and that both erection and the resulting ejaculation are structurally and functionally necessary for a penis to be considered “normal.” Finally, the phrases “his body” and

“the body” reinforce the notion of the penis as an independent organ. The first sentence of the above passage indicates that erection causes nerves to signal to “his body.” This phrasing indicates not only that the erect penis is independent of and external to “his body,” but also that the erect penis causes communication between the independent penis and the man’s body. The last sentence of the above passage has a similar effect, wherein once the penis has completed its normal sexual function, it returns borrowed blood to “the body,” and the independent penis “becomes soft again.”

The final line of the “About the penis” subsection of the penile cancer DG states “During ejaculation, semen passes into the urethra and out the meatus at the tip of the penis.” This final sentence serves to solidify the “normal” function of the penis as sexual by attributing sexual functions to the various parts of the penis. Like erections, ejaculation is discussed as inevitable, and the urethra and meatus of the penis are mentioned as passageways for bodily fluids that occur as a result of sexual arousal and stimulation.

Thus, from the first sentence of the “About the penis” subsection, the reader is asked to consider the “normal” structure and function of the penis as primarily sexual. The sentence, “The penis is the external male sexual organ, as well as part of the urinary system,” situates the penis as an independent organ that is sexual in nature, with a secondary function of evacuating biological waste from the body. In this first sentence, the penis *is* the male sexual organ, but it is only *part* of the urinary system. This notion is reinforced throughout the subsection as the structure of the penis is explained in detail and then related almost exclusively to sexual function; while the penis may be “part of the urinary system,” this fact is only alluded to once after this initial defining statement, when the text states, “Urine and semen travel through the urethra and leave the body through an opening in the glans of the penis, called the *meatus*.”

However, the process of urination is never explained, unlike erection and ejaculation, which are explained in significant detail. In this way, this definitional section of the penile cancer DG works to firmly situate the penis as primarily sexual in function, and is described in such a way that the reader is led to understand that its structure is designed to facilitate sexual engagement.

About the penis: Normally circumcised. Another key aspect of the penile cancer DG introductory subsection again relates to how the ACS conceptualizes – and asks the reader to conceptualize – the “normal structure and function of the penis.” Here, when describing the “normal” structure of the penis, the ACS penile cancer DG depicts a penis that has undergone surgical alteration. This focus on the altered penis as “normal” is important for how the “Risk factors” section is organized, and how, as a result, more important risk factors are muted and patient culpability is alleviated.

Prostate Cancer

About the prostate: The first line of the prostate cancer “about” section states, “To understand prostate cancer, it helps to know something about the prostate and nearby structures in the body.” This line informs readers that the prostate and “nearby structures” are important to the discussion. Sentence 1 following the “About the prostate” subheading defines the prostate as a gland and situates it as distinct to males. Sentences 2-4 offer information regarding the location and variable size of the prostate, which the text explains in relation to a walnut.

Beginning the next paragraph, sentence 5 assigns the prostate the “job” of “mak[ing] some of the fluid that protects and nourishes sperm cells in semen, making the semen more liquid.” Thus, sentences 1 and 5 situate the prostate as a productive gland specific to men which functions to make “some” protective, nourishing fluid. Sentence 6 introduces the seminal vesicles. As a “nearby structure,” these glands have already been situated as important; the

<p>What is prostate cancer?</p>	<p>Pg. 2</p>
<p>To understand prostate cancer, it helps to know something about the prostate and nearby structures in the body.</p>	<p>1</p>
<p>About the prostate</p>	
<p>The prostate is a gland found only in males. It is located in front of the rectum and below the urinary bladder. The size of the prostate varies with age. In younger men, it is about the size of a walnut, but it can be much larger in older men.</p>	<p>1-4</p>
<p>The prostate's job is to make some of the fluid that protects and nourishes sperm cells in semen, making the semen more liquid. Just behind the prostate are glands called <i>seminal vesicles</i> that make most of the fluid for semen. The <i>urethra</i>, which is the tube that carries urine and semen out of the body through the penis, goes through the center of the prostate.</p>	<p>5-7</p>
<p>The prostate starts to develop before birth. It grows rapidly during puberty, fueled by male hormones (called <i>androgens</i>) in the body. The main androgen, <i>testosterone</i>, is made in the testicles. The enzyme <i>5-alpha reductase</i> converts testosterone into <i>dihydrotestosterone</i> (DHT). DHT is the main hormone that signals the prostate to grow.</p>	<p>Pg. 3 8-12</p>
<p>The prostate usually stays at about the same size or grows slowly in adults, as long as male hormones are present.</p>	<p>13</p>

Figure 17: Prostate cancer definitional section excerpt

combination of the topic of sentences 5 and 6 – the production of seminal fluid – and the illustration of the prostate and seminal vesicle just below these sentences make the prostate and seminal vesicles seem nearly indistinguishable. The explanation of the urethra in sentence 7

finishes the second paragraph. This sentence defines the urethra as a tube, and explains that it “goes through the center of the prostate.” Although the urethra is a tube, it is depicted as an active structure that “carries urine and semen.” Although urine is mentioned in this sentence and the close-up in the illustration shows the urethra connecting to the bladder, the focus on sperm and semen in the previous two sentences highlights the urethra’s semen transport function above its waste elimination function.

The third paragraph of this section turns back to prostate development. Sentence 8 begins the prostate development history by noting that prostate development begins in-utero. Sentence 9 describes the mechanism of growth: “It grows rapidly during puberty, fueled by male hormones (called *androgens*) in the body.” This sentence establishes the existence of androgens, and indicates that this subsection of hormones is exclusive to males. The following sentence states “The main androgen, *testosterone*, is made in the testicles.” First, sentence 10 establishes testosterone as the “main androgen,” and, by extension, as a hormone that is exclusive to men. Second, sentence 10 introduces the testicles, where testosterone is made. As a “nearby structure,” readers understand the testicles as important to the prostate. Sentences 11, 12, and 13 further solidify the importance of testosterone production to the prostate.

Testicular Cancer

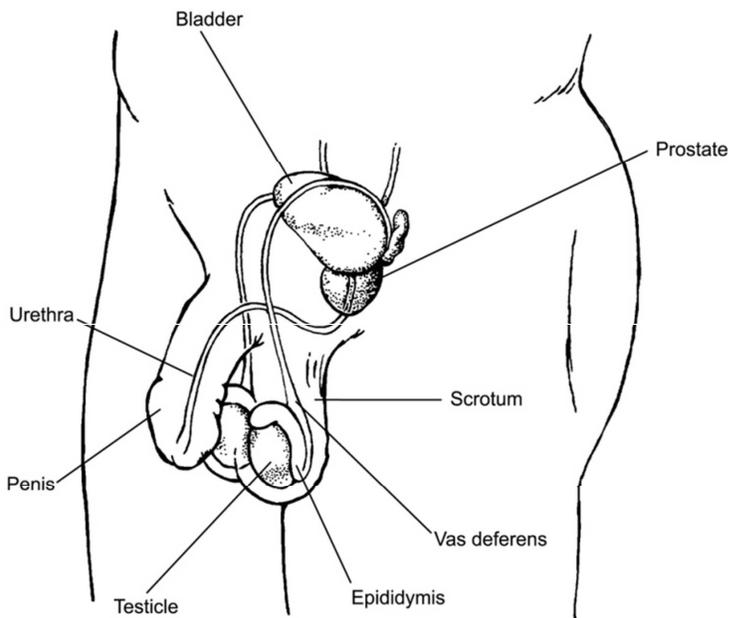
What is testicular cancer? The testicular cancer DG does not offer a dedicated “about ” section, and instead defines the testicles under the “What is testicular cancer” main heading. Sentence 1 of this section explains “testicular cancer typically develops in one or both testicles in young men.” Sentence 2 follows this information with the reassurance that testicular cancer is “a highly treatable and usually curable type of cancer.”

What is testicular cancer?

Testicular cancer typically develops in one or both testicles in young men. It is a highly treatable and usually curable type of cancer.

The testicles (also called the *testes*; a single testicle is called a *testis*) are part of the male reproductive system. These 2 organs are each normally somewhat smaller than a golf ball in adult males and are contained within a sac of skin called the scrotum. The scrotum hangs beneath the base of the penis.

The testicles make the male hormone testosterone. They also produce sperm. Sperm cells are carried from the testicle through the vas deferens to the seminal vesicles, where they are mixed with a fluid produced by the prostate gland. During ejaculation, sperm cells, seminal vesicle fluid, and prostatic fluid enter the urethra, the tube in the center of the penis through which both urine and semen leave the body.



The testicles are made up of several types of cells, and each may develop into one or more types of cancer. It is important to distinguish these types of cancers from one another because they differ in the ways they are treated and in their prognosis (outlook).

Figure 18: Testicular cancer definitional section excerpt continued

The second paragraph of this section begins to offer an explanation of what the testicles are. Sentence 3 notes that the testicles “are part of the male reproductive system.” Sentence 4

Pg. 2

1-2

3-5

6-9

Pg. 3

10-11

begins by defining the testicles as individual organs, and describes their individual size in reference to a golf ball. Sentence 4 goes to explain that these organs are “contained in a sac of skin called the scrotum,” while sentence 5 notes that “the scrotum hangs beneath the base of the penis.” Together, sentences 4 and 5 situate the testicles as organs that are independent from one another as well as from the rest of the body.

The third paragraph offers information on what the testicles do. Sentence 6 states “The testicles make the male hormone testosterone.” This sentence accomplishes two tasks. First, it situates the testicles as active. Second, it introduces the notion of male hormones, and indicates that testosterone is exclusive to male bodies. Sentence 7 reinforces the notion that testicles are active by situating them as producers. Sentence 8 describes the sperm as passively being “carried from the testicle through the vas deferens to the seminal vesicles, where they are mixed with a fluid produced by the prostate gland.” The vas deferens is not mentioned by the text beyond this sentence, although the illustration labels a tube-like structure that connects the testicles and prostate. Like the testicles, the prostate is also framed as an active producer.

The last sentence in the third paragraph, sentence 9, briefly explains the process of ejaculation. “During ejaculation, sperm cells, seminal vesicle fluid, and prostatic fluid enter the urethra, the tube in the center of the penis through which both urine and semen leave the body.” This sentence shows readers how the elements produced by the testicles, prostate, and seminal vesicles come together during the ejaculation event. Here, these products are described actively, as they “enter the urethra.” The urethra is described as a passage, a “tube in the center of the penis” through which both “urine and semen” actively “leave the body.” While both urine and semen are mentioned in this sentence, the focus on sperm, seminal fluid, prostatic fluid, and ejaculation in the rest of the paragraph highlight the urethra’s semen transport function over its

function as part of the urinary system. Sentences 10 and 11 begin to transition into the text's discussion of how cancer develops in the testicles.

While the testicles are defined as “part of the male reproductive system” in sentence 3, no further explanation of reproductive function is mentioned in the rest of the section. Even though the third paragraph (sentences 6-9) discusses sperm, semen, and ejaculation at length, the paragraph focuses on the *production* of semen and the *act* of ejaculation without linking either to the process of reproduction.

Effects on Information and Reinforcement of Definitions

In this section, key sections of the informational body of the DGs are analyzed. Themes prevalent in the sections below are prevalent throughout all 7 DGs analyzed for this study.

The layout and focus of the “risk factors” and “prevention” sections of the 3 male affiliated DGs are discussed first, followed by an analysis of the human papilloma virus (HPV) sections of the cervical and vaginal cancer guides’ “risk factors” and “prevention” sections.

Risk Factors

The table below lists the risk factors included in the “Risk factors” section of the three male-affiliated cancer DGs under examination. The factors are listed in order, from left to right, and are color- and style-coded based on the level of patient culpability associated with each.

While some risk factors are considered “lifestyle choices,” other factors are considered unavoidable. This distinction will be discussed in more detail below.

Table 3: Male associated table of risk factors

Risk Factors for Penile Cancer

Circumcision	Phimosis and smegma	Human papilloma virus infection	Smoking	UV light treatment of psoriasis	Age	AIDS
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Risk Factors for Prostate Cancer

Age	Race/ethnicity	Nationality	Family history	Genes	Diet
Obesity	Smoking	Inflammation of the prostate	Sexually transmitted infections	Vasectomy	

Risk Factors for Testicular Cancer

Undescended testicle	Family history	HIV infection	Carcinoma in situ	Cancer of the other testicle	Age
Body size	Unproven or controversial risk factors				

Key: Black font denotes no indication of patient culpability. Red font denotes indication of patient culpability. Orange font denotes potential of patient culpability. Green font denotes preventative effects of factor. *Italicized font* denotes that a factor is inconclusive or not directly related to cancer risk. Blue font is used for items that are listed, but are not risk factors and have no positive or negative association with the disease.

The most culpable of the male-associated patient detailed guides is the penile cancer DG. The penile cancer DG risk factors section describes “smoking” as definitively linked to increased risk of penile cancer. The DG also notes that “men with AIDS have a higher risk of penile cancer,” going on to point out that “This higher risk seems to be related to their lowered immune response, but lifestyle factors may also play a role.” The explicit link between AIDS and lifestyle “factors” (not “choices”) puts patients in a position of culpability. These two instances account for the only direct expression of patient culpability throughout the three guides. Two additional sections in the penile cancer DG lend themselves to potential patient culpability: Phimosis and smegma⁷, and HPV infection. However, the way these factors are framed work to excuse patient culpability. According to the definitional section of the penile cancer DG, the “normal” human penis is circumcised. Circumcision – or, more correctly, the lack of circumcision – is listed as the first risk factor of penile cancer. Phimosis and smegma are both conditions specific to uncircumcised penises, and although the guide notes that the conditions can usually be avoided by retracting the foreskin when washing the penis, the phimosis and smegma subsection follows the circumcision subsection, which notes that circumcision is a procedure usually performed on infants. Thus, phimosis and smegma are conditions that develop as a result of the parental decision to not circumcise a child.

Similarly, while human papilloma virus infection (HPV) could be considered in terms of lifestyle choices, the text situates HPV as an unavoidable condition common to the male experience. Thus, the inevitability of HPV excuses individual behavior that might otherwise be seen as irresponsible. This aspect is discussed in detail below.

⁷ Phimosis is a condition where the foreskin is too tight to pull back over the meatus. Smegma is an odorous white or yellow substance comprised of naturally occurring oily secretions and dead skin cells. It develops under the foreskin of the penis if it is not washed, and can also develop in the folds of skin around the clitoris.

The final risk factor that potentially frames patients as culpable in their disease is the “HIV infection” subsection in the testicular cancer DG. Here, HIV is not linked to lifestyle as it is in the penile cancer DG. Rather, the text hedges, stating, “Some evidence has shown that men infected with the human immunodeficiency virus (HIV), particularly those with AIDS, are at increased risk.” However, HIV/AIDS is imbued with social stigma that includes an assumption of personal irresponsibility, and I have therefore listed this factor as potentially invoking patient culpability. Notably, of the 11 risk factors listed in the prostate cancer DG, only 4 are known risk factors; the remaining 7 items listed are described as either inconclusive, uncertain, or as not being risk factors at all.

Apparently, it is difficult to engage in behavior that may put one at a higher risk of developing male-related cancers. And, just as it is difficult for men to identify what they did that resulted in their development of cancer, it is even more difficult for men to identify what they could have done to help prevent cancer from developing – there are no factors listed in the male-affiliated DGs that indicate that any lifestyle choices or behaviors have preventative or protective effects

Risk Factors and HPV

The third subsection in the penile cancer DG section “What are the risk factors for penile cancer?” is “Human papilloma virus infection.” The location of this subsection is interesting considering that, as the DG states, “HPV is found in about half of all penile cancers.” Despite the seeming significance of HPV in penile cancer occurrence, HPV is listed 3rd in the risk factors section, after “Circumcision” and “Phimosis and smegma.” This order of information will be discussed in further detail later in this chapter.

Even though the HPV subsection is present in the penile cancer DG section titled, “What are the risk factors for penile cancer?” the subsection “Human papilloma virus infection” does

Human papilloma virus infection	Pg. 8
<p>Human papilloma virus (HPV) is a group of more than 100 related viruses. They are called papilloma viruses because some of them cause a type of growth called a <i>papilloma</i>. Papillomas are not cancers and are more commonly called warts. Different HPV types cause different types of warts in various parts of the body. Some types cause common warts on the hands and feet. Other types tend to cause warts on the lips or tongue.</p>	1-6
<p>Certain HPV types can infect the outer female and male genital organs and the anal area, causing raised, bumpy warts. These warts may barely be visible or they may be several inches across. The medical term for genital warts is <i>condyloma acuminatum</i>. Two types of HPV, HPV 6 and HPV 11, cause most cases of genital warts. These 2 types are seldom linked to cancer, and so are called <i>low-risk</i> types of HPV. However, other HPV types have been linked with cancers and are known as <i>high-risk</i> types of HPV. These includes HPV 16, HPV 18, HPV 31, as well as others. Infection with a high-risk HPV may produce no visible signs until pre-cancerous changes or cancer develops.</p>	7-14 Pg. 9
<p>HPV infection is found in about half of all penile cancers. Researchers believe that infection with HPV is an important risk factor for penile cancer. HPV infection is also linked to many other cancers, including cancers of the cervix, vagina, and vulva in women and cancers of the anus in men and women. It is also a factor in some throat cancers (in men and women).</p>	15-18
<p>HPV is passed from one person to another during skin-to-skin contact with an infected area of the body. HPV can be spread during sex – including vaginal intercourse, anal intercourse, and oral sex – but sex doesn’t have to occur for the infection to spread. All that is needed is skin-to-skin contact with an area of the body infected with HPV. Infection with HPV seems to be able to be spread from one part of the body to another, for example, infection may start in the penis and then spread to the anus. The only way to completely prevent anal and genital HPV infection may be to never allow another person to have contact with those areas of the body.</p>	19-23
<p>HPV infection is common. One study found that about half of men 18 and older have a genital HPV infection at any point in time. In most people, the body is able to clear the infection on its own. In some, however, the infection does not go away and becomes chronic. Chronic infection, especially with high-risk HPV types, can eventually cause certain cancers, including penile cancer.</p>	24-28

Figure 19: Male associated HPV section excerpt

not immediately discuss the link between HPV and penile cancer. In fact, HPV is not linked to cancer at all until the end of the subsection’s 2nd paragraph, in the 12th sentence, when the guide notes, “However, other HPV types have been linked with cancers and are known as *high-risk*

types of HPV.” The HPV subsection uses the 11 sentences preceding this sentence to stress the mundane nature of HPV, the fact that “papillomas are not cancers,” and that the most common strains of HPV “are seldom linked to cancer.” However, even in the 12th sentence of this subsection, the text does not establish a direct link between HPV and penile cancer, referring broadly to “cancers.” It is not until the 15th sentence of the subsection that the reader learns that “HPV infection is found in about half of all penile cancers,” and, in the 16th sentence, that “Researchers believe that infection with HPV is an important risk factor for penile cancer.”

However, while the connection between penile cancer and HPV is brought to light here, the way the 15th and 16th sentences are worded indicates a hesitance on the part of the authors to establish a causal relationship between HPV and penile cancer. Sentence 15 indicates correlation rather than causation: “HPV infection is found in about half of all penile cancers.” For example, if we replaced “HPV infection” with “earthworms” and “penile cancers” with “soil,” we would not mean to imply that soil caused earthworms. Similarly, the way the sentence is written in the penile cancer DG does not indicate that HPV infection causes penile cancer. The hesitant tone in the 15th sentence is reinforced by the hedging that occurs in the 16th sentence with the use of the phrase “researchers believe.” The guide states, “Researchers believe that infection with HPV is an important risk factor for penile cancer.” As discussed earlier in the methods chapter, the authorship of the ACS DGs remains at an institutional level, as opposed to assigning individual authorial representation. By keeping the notion of individual human authors away from the DGs, the ACS also keeps the notion of human bias away from the DGs, resulting in a text that is imbued with the kind of authority ascribed to dictionaries and encyclopedias. The sentence currently in question, however, uses the phrase “researchers believe,” which highlights human participation and points to the human biases that underlie human beliefs. Consider, for example,

the differences between the phrase “researchers believe” and phrases such as “research suggests,” “studies indicate,” or “researchers have found.” The first two alternate phrases remove people from the equation and replace the notion of “beliefs” with the notion of “evidence.” The third alternate phrase, “researchers have found,” differs from the phrase used in the penile cancer DG, “researchers believe,” insofar as the alternate phrase directly indicates that research was conducted and evidence was produced.

Further complicating the link between HPV and penile cancer, immediately following the 15th and 16th sentences, the guide points out that “HPV infection is also linked to many other cancers, including cancers of the cervix, vagina, and vulva in women and cancers of the anus in men and women. It is also a factor in some throat cancers (in men and women).” Thus, while the two paragraphs (14 sentences) preceding the direct link between penile cancer and HPV infection work to normalize and sanitize HPV infection as a common and mundane occurrence, the two sentences that follow this link serve to demonstrate that the link between HPV infection and cancer is widespread across several types of cancer, including cancers of the throat.

The over all effect of the “About penile cancer” subsection through the 3rd paragraph has thus far been to: 1) paint HPV infection as common and generally non-threatening; 2) distance general HPV infection from penile cancer; 3) highlight a correlative rather than causal relationship between HPV infection and penile cancer; and 4) to show that HPV infection is linked to other cancers. These individual effects work together to frame HPV infection as a generally non-treatening, and patients as victims of an unavoidable fluke in the normal male experience.

The remaining two paragraphs in the HPV infection subsection of the Risk factors section uses the foundation established by the language in the preceding paragraphs to reinforce the

penis as the male sexual organ and to reify the notion that HPV infection is so common as to be unavoidable.

The second to last paragraph is mostly dedicated to explaining how HPV infection is spread from one person to another. The text notes that “HPV can be spread during sex – including vaginal intercourse, anal intercourse, and oral sex – but sex doesn’t have to occur for the infection to spread. All that is needed is skin-to-skin contact with an area of the body infected with HPV.” In this way, the DG defines sex as a penetrative act wherein the penis – the “male sexual organ” – is inserted into another person’s body, while simultaneously removing HPV infection responsibility from the penis by referring back to the ease with which infection can and does occur. The use of the phrase “All that is needed” accomplishes the task of trivializing the role of sex in the face of the overwhelming notion that any human contact can lead to HPV infection.

The final sentence of this paragraph serves to solidify the pervasiveness of HPV infection and frames the notion of avoiding infection as absurd. “The only way to completely prevent anal and genital HPV infection may be to never allow another person to have contact with those areas of the body.” The words “only,” “completely,” and “never” are absolutisms that imply impossibility. “Only” and “completely” serve to highlight the commonness of HPV to such a significant degree that individual responsibility regarding the disease is eclipsed. The term “never” stands in stark opposition to the notion of the penis as “the male sexual organ,” and of man as sexual by nature. That this inherently sexual being would “never allow another person to have contact with those areas of the body” is an unnatural and absurd concept. As a result, this sentence asserts that the penis’ engagement in penetrative sexual activity is as natural and routine

as breathing, and that HPV is simply one of the pollutants that men may inhale as they go about their daily lives.

The first two sentences of the final paragraph state, “HPV infection is common. One study found that about half of men 18 and older have a genital HPV infection at any point in time.” The first of these sentences, “HPV infection is common,” clearly and definitively states what was previously alluded to, substantiating the earlier indications of commonness and social reach throughout the section. The second sentence of this final paragraph, “One study found that about half of men 18 and older have a genital HPV infection at any point in time,” is significant and requires close attention.

First, it is significant that, in this instance, the DG uses the phrase “one study found.” As previously discussed in this dissertation and in this section, the removal of human action and, subsequently, human bias and fallibility offers an additional layer of authority to what is being said in the text. Earlier in the “Human papilloma virus infection” subsection, the text stated that “researchers believe that infection with HPV is an important risk factor for penile cancer.” In that sentence, the human element was highlighted by the assignment of information to “researchers,” and the minimization of information to “beliefs.” Standing in stark opposition, the sentence currently under examination firmly situates the information being conveyed as scientifically proven, the phrase “one study found” simultaneously asserts scientific rigor and informational confidence. The scientifically derived fact that one out of two men has a genital HPV infection is followed by the phrase “at any given time.” Thus, in addition to once again reinforcing the notion that genital HPV infection is so common as to be unavoidable, this phrase invites the reader to think about genital HPV infection as a recurring fact of life, something that is passed around by and between people who have genital contact. As such, this sentence reifies the notion

that the penis is “the male sexual organ,” thus defining it as sexually active and social, and inviting the reader to understand that HPV infection is, without question, a normal part of being an adult male.

Can Penile Cancer be Prevented?: Definitely, but Probably Not

This section begins by asserting, “The large variations in penile cancer rates throughout the world strongly suggest that penile cancer is a preventable disease” (pg. 10). This sentence contextualizes its claim within unstated global statistics, asserting that these statistics “strongly suggest” penile cancer is preventable. The following sentence states, “The best way to reduce the risk of penile cancer is to avoid known risk factors whenever possible (see the section called ‘What are the risk factors for penile cancer?’).” The main part of this sentence tells readers that they can and should take responsibility of their health and avoid known risk factors. The use of the phrase “whenever possible” alleviates pressure from patients who may have risk factors that are difficult or impossible to account for, such as age or genetics. The parenthetical note added to the sentence directs readers to the “What are the risk factors for penile cancer?” section of the penile cancer DG. As discussed earlier, this section places heavy emphasis on circumcision, and downplays the role of and personal responsibility for HPV infection. Thus, while the second sentence of this section alleviates undue pressure on patients with unavoidable risk factors (e.g., age), it also references back to a section that diminishes personal responsibility and weakens the assertion of preventativeness made in the previous sentence. The remainder of the opening paragraphs of this section focus mostly on the history and preventative effect of circumcision, although one last mention of HPV prevention is made in sentence 7: “Men who wish to lower their risk of penile cancer can do so by avoiding HPV infection and not smoking.” Sentence 8 encourages uncircumcised men to practice good genital hygiene.

Genital hygiene. The first subsection, “Genital hygiene,” once again emphasizes the role of circumcision in HPV prevention. This subsection is aimed at uncircumcised men, and explains how to practice good hygiene through foreskin retraction. This subsection also informs readers of what can be done if the foreskin is difficult to retract.

Avoiding HPV infection. The HPV subsection under the “Risk factors” section establishes HPV infection as practically unavoidable. This notion is carried over in the first sentence of the “Avoiding HPV infection” subsection. The sentence states, “All men should do what they can to avoid human papilloma virus (HPV).” The phrase “do what they can” speaks back to the previously established inevitability of HPV as part of the male experience, thus exculpating patients from potential individual responsibility. The following sentence informs the reader that attempting to reduce HPV infection will both reduce penile cancer risk in individual male readers as well as reduce cervical cancer risk in potential female partners. This sentence begins to indicate a level of responsibility for selves and toward others.

Sentence 3 begins a new paragraph. It reads, “The 2 main factors influencing the risk of genital HPV infection in men are circumcision and the number of sexual partners.” This sentence establishes the natural penis (uncircumcised) as the foremost risk factor regarding the contraction of HPV. The remainder of the paragraph, sentences 4-9, focus on the natural penis as central to HPV contraction and spread. Sentence 4 states that men who have been circumcised have a reduced risk of contracting HPV. Sentence 5 makes the same statement through reversal, stating that men who have not been circumcised are at a higher risk of HPV infection. Sentence 6 states, “The reasons for this are unclear,” establishing uncertainty. Sentences 7 & 8 use this uncertainty to introduce hypothetical possibilities regarding the assertion that natural penises are at higher

Avoiding HPV infection	Pg. 11
<p>All men should do what they can to avoid infection with the human papilloma virus (HPV). In addition to decreasing penile cancer risk, this could have an even bigger impact on the risk of cervical cancer in female partners.</p>	1-2
<p>The 2 main factors influencing the risk of genital HPV infection in men are circumcision and the number of sexual partners. Men who are circumcised (have had the foreskin of the penis removed) have a lower chance of becoming and staying infected with HPV. Men who have not been circumcised are more likely to be infected with HPV and pass it on to their partners. The reasons for this are unclear. It may be that after circumcision the skin on the glans (of the penis) goes through changes that make it more resistant to HPV infection. Another theory is that the surface of the foreskin (which is removed by circumcision) is more easily infected by HPV. Still, circumcision does not completely protect against HPV infection – men who are circumcised can still get HPV and pass it on to their partners. The risk of being infected with HPV is also strongly linked to having many sexual partners (over a man’s lifetime).</p>	3-10
<p>Condoms (“rubbers”) provide some protection against HPV, but they do not completely prevent infection. Men who regularly use condoms are less likely to be infected with HPV and pass it on to their female partners. Condoms cannot protect completely because they don’t cover every possible HPV infected area of the body, such as the skin on the genital or anal area. Still, condoms do provide some protection against HPV, and they also protect against HIV and some other sexually transmitted diseases.</p>	11-14
<p>Infection with HPV can be present for years without any symptoms; so the absence of visible warts cannot be used to tell if someone has HPV. Even when someone doesn’t have warts (or any other symptom), he (or she) can still be infected with HPV and pass the virus to somebody else.</p>	15-16
<p>Vaccines have been developed to help prevent infection with some types of HPV. Gardasil protects against HPV types 6 and 11, which can cause genital warts, and HPV types 16 and 18, which cause some types of cancer. Another, Cervarix, protects against HPV types 16 and 18. Both Gardasil and Cervarix are approved for use in females, but only Gardasil is approved for use in males.</p>	17-20
<p>Gardasil’s approval in males is based on studies that show that it can help prevent genital warts and anal cancers in men. In 2011, the Advisory Committee on Immunization Practices (ACIP) published its recommendations for the use of Gardasil in males. The committee recommends that the vaccine be given routinely to males aged 11 or 12 years. ACIP also recommended that the vaccine be given to males aged 13 through 21 years who have not been vaccinated previously or who have not completed the 3-dose series. Men aged 22 through 26 years may also be vaccinated.</p>	21-25
<p>These vaccines work best if given before the person starts having sex (and is exposed to HPV). Giving the vaccine at a young age helps ensure that the person receiving the vaccine has not yet been exposed to HPV and so will likely benefit.</p>	26-27
<p>The hope is that HPV vaccines may eventually help reduce the risk of all cancers linked to HPV, including penile cancers.</p>	28

Figure 20: Male associated prevention section excerpt

risk of contracting HPV. Using phrases such as “it may be,” and “another theory is,” these sentences simultaneously introduce uncertainty and alleviate patient culpability by placing the onus of infection on the state of the skin on the penis. Sentence 9 states, “Still, circumcision does not completely protect against HPV infection – men who are circumcised can still get HPV and pass it on to their partners.” Once again, the text refers to the inevitability of contracting and spreading HPV, regardless of the skin on the penis. The final sentence of this paragraph notes, “The risk of being infected with HPV is also strongly linked to having many sexual partners (over a man’s lifetime).”

The following paragraph, sentences 11-14, focuses on the role of condoms in HPV prevention. The first sentence, sentence 11, states “Condoms (“rubbers”) provide some protection against HPV, but they do not completely prevent infection.” This sentence acknowledges condoms as an HPV preventative while simultaneously negating the usefulness of condoms in preventing HPV. Words and phrases such as “some,” “but,” and “not completely” point to deficiencies, ignoring positive attributes. While sentence 12 affirms that “Men who regularly use condoms are less likely to be infected with HPV and pass it on to their female partners,” the negation of the effectiveness of condoms from sentence 11 is continued in this sentence by the phrase “less likely.” The negation intensifies in sentence 13: “Condoms **cannot** protect **completely** because they **don’t** cover **every possible** HPV infected area of the body, such as the skin on the genital or anal area” [emphasis added]. The final sentence of this paragraph states, “Still, condoms do provide some protection against HPV, and they also protect against HIV and some other sexually transmitted diseases.” Beginning the sentence, the word “still” is indicative of an aside or potentially inconsequential result. Similarly, the word “do” preceding the word “provide” indicates a marginal increase or small result. Immediately

following, the phrase “some protection” carries forward the negation established in the preceding sentences, while the word “also” in the second half of the sentence carries the inconsequential tone forward from the first half. Finally, the word “some” in the second half of the sentence reinforces the impotency of condoms in preventing disease. In sum, sentence 14 is a nonchalant shrug at the end of an indirect and unclear argument.

Considered as a whole, sentences 11-14 reinforce the notion established in the “Risk factors” section, and carried through in the subsection under examination, that HPV is an inevitable part of the normal male experience. These 4 sentences primarily focus on the ineffectiveness of condoms, denying both the potential of patient culpability and the potential of men’s agency in preventing sexually transmitted disease.

Sentences 15-16 tell readers that HPV infection can exist and be transmitted without the presence of outward physical symptoms. Sentences 17-28 discuss HPV vaccines, noting in sentences 26 and 17 that “These vaccines work best if given before the person starts having sex [...] Giving the vaccine at a young age helps ensure that the person receiving the vaccine has not yet been exposed to HPV and so will likely benefit.” Similar to the explanation of circumcision, HPV vaccines are most effective in preventing disease when administered at an age when the individual had little to no agency in their health decisions. Once again, a potential preventative strategy is thwarted by age or ineffectiveness.

Throughout the risk factors and prevention sections, the natural penis is held in focus as the primary risk factor for contracting HPV. This notion is enforced and reiterated throughout the through structural organization. The order that subheadings are introduced in each section, and the order that content within each subheading is addressed, prioritizes information for readers, indicating “this is most important, and should be read first.” By listing and discussing

circumcision before HPV in the risk factors section, and discussing the risks of the natural penis prior to discussing the risks of sexual activity in the prevention section, the text points to patients' circumstance rather than patients' actions as culpable in HPV contraction and spread.

Treatment Side Effects

This section examines three excerpts regarding sexual side effects from the penile, testicular, and prostate cancer guides. While references to sex, sexuality, and sexual function persist throughout the 3 male oriented guides, the sections chosen for this analysis are dedicated to the discussion of effects on patients' sexual selves.

Penile Cancer Treatment Effects

As previously discussed, the 7 DGs examined follow the same general outline. In the penile cancer DG, the section "How is _____ cancer treated?" begins on page 21. In the penile cancer guide's "How is penile cancer treated?" the text notes :

Surgery is the most common treatment for all stages of penile cancer. If the cancer is detected early, the tumor can often be treated without having to remove part of the penis. If the cancer is detected at a more advanced stage, part or all of the penis might have to be removed with the tumor. (p. 22)

Similar to all 7 guides examined here, this section goes on to discuss various treatment options, including surgery, radiation therapy, chemotherapy, immune therapy, clinical trials, and complementary and alternative therapies, respectively (pgs. 22-32). Following the explanation of treatments, the DG organizes treatment options by stage, laying out viable treatment options as relative to cancer advancement (pgs. 32-34). Page 35 offers readers a list of questions to ask their doctors. Page 36 begins the section, "What happens after treatment for penile cancer?" Common to all 7 DGs, this section addresses follow-up care, emotional effects of cancer treatment, seeing

new doctors after cancer treatment is over, and lifestyle changes. Unlike the other 6 guides, however, the penile cancer DG includes a section that specifically addresses emotional health (pg. 40), as well as a section that addresses both physical and emotional aspects of treatment (pgs. 37-38). This subsection, titled “Physical and emotional aspects of penile cancer treatment,” is analyzed below.

Physical and emotional aspects of penile cancer treatment	Pg. 37
<p>For any man, dealing with cancer of the penis is a frightening prospect. Partially or completely removing the penis is often the most effective way to cure penile cancer, but for many men this cure seems worse than the disease.</p>	1-2
<p>It is natural for a man facing treatment for penile cancer to suffer mental distress, depression, and feelings of grief or despair. The better you can anticipate and prepare for these feelings in advance, the better your quality of life will be following treatment. You may want to ask your health care team for a referral to a counselor, who can help you sort through your feelings and adjust to your new body.</p>	3-5
<p>Effects on urination</p>	
<p>Most men are still continent after surgery – that is, they can still control the start and stop of urine flow. In certain cases, a partial penectomy leaves enough of the penis to allow relatively normal urination. Many men who have undergone a total penectomy must sit to urinate.</p>	6-8
<p>Effects on sexuality</p>	
<p>If cancer of the penis is diagnosed early, treatments other than penectomy can often be used. Conservative techniques (such as topical chemotherapy, Mohs surgery, and laser surgery) may have little effect on sexual pleasure and intercourse once you have fully recovered.</p>	9-10
<p>Removing all or part of the penis can have a devastating effect on a man’s self-image and ability to have sexual intercourse. You and your sexual partner may wish to consider counseling to help understand the impact of treatment for penile cancer and to explore other approaches to sexual satisfaction.</p>	11-12
<p>Satisfying intercourse is possible for many, but not all men after partial penectomy. The remaining shaft of the penis still becomes erect with arousal. It usually gains enough length to achieve penetration. Although the most sensitive area of the penis (the glans, or “head”) is gone, a man can still reach orgasm and ejaculate normally. His partner should also still be able to enjoy intercourse and often reach orgasm.</p>	13-17
<p>Normal intercourse is not possible after total penectomy. Some men give up sex after the surgery. Since cancer of the penis is most common in elderly men, some are already unable</p>	

Figure 21: Penile cancer physical and emotional effects section excerpt

to have intercourse because of other health problems. If a man is willing to put some effort into his sex life, however, pleasure is possible after total penectomy. He can learn to reach orgasm when sensitive areas such as the scrotum, skin behind the scrotum, and the area surrounding the surgical scars are caressed. Having a sexual fantasy or looking at erotic pictures or stories can also increase excitement.	18-23
A man can help his partner reach orgasm by caressing the genitals, by oral sex, or by stimulation with a sexual aid such as a vibrator. The activity some couples enjoy after total penectomy can give hope to those coping with fewer changes in their sex lives.	23-24
After total penectomy, surgical reconstruction of the penis may be possible in come cases. If you are interested in this, ask your doctor if this might be an option for you.	25-26

Figure 21: Penile cancer physical and emotional effects section excerpt continued

Sentence 1 of this subsection states, “For any man, dealing with cancer of the penis is a frightening prospect.” The phrase “for any man” works to destigmatize the notion of fear that is introduced in this sentence. The specification of “cancer of the penis” singles out penile cancer as special or different from cancers associated with other parts of the body, and, followed by the phrase “is a frightening process,” as especially frightening. That this sentence is unique among this sample indicates that the ACS believes that penile cancer is a uniquely frightening cancer. Sentence 2 asserts, “Partially or completely removing the penis is often the most effective way to cure penile cancer, but for many men this cure seems worse than the disease.” Here, readers are reminded that the partial or complete removal of penile cancer is “often the most effective” cure for penile cancer. The word “but” signals an opposing sentiment, view, or information; followed by the phrase “for many men,” the reader understands that the sentiment, view, or information that follows is common and acceptable. The view that opposes “the most effective way to cure penile cancer” is that the “cure seems worse than the disease. As such, the penis is here equated with life, or a reason to live, and the partial or complete removal of the penis is equated with something that is worse than dying of penile cancer.

Beginning the next paragraph, sentence 3 states, “It is natural for a man facing treatment for penile cancer to suffer mental distress, depression, and feelings of grief or despair.” The

phrase “it is natural” situates the content that will follow as “normal,” while “a man facing treatment for” universalizes the normality to all readers. Across the 7 texts examined, the term “suffer” appears only once – in this sentence. Using the term “suffer” here to describe the state of the patient accomplishes two tasks. First, “suffer” reifies the notion that penile cancer is a uniquely frightening and especially damning form of cancer, the eradication of which is often considered worse than allowing the disease to develop, spread, and eventually kill. Second, “suffer” serves to once again situate the patient as a bystander in his own life, who has unfortunate events happen to him by way of his mere existence. The text notes, “The better you can anticipate and prepare for these feelings in advance, the better your quality of life will be following treatment,” and ends with the suggestion that patients seek help from a counselor “who can help you sort through your feelings and adjust to your new body.” In these sentences, the text offers patients the opportunity to partially control their quality of life after treatment. This offer or suggestion of control is only partial, however, because the assumption imbedded in the text is that treatment is unequivocally devastating, potentially degrading a man’s quality of life so severely that cancer death may be preferable. Thus, the phrase “the better your quality of life will be following treatment” indicates that patients can affect the degree to which quality of life is degraded, but can not achieve autonomy from the effects of treatment.

Effects on urination. Sentences 6-8 in this 3 sentence tertiary section assure patients that “most men are still continent after surgery.” Sentence 7 notes that in “certain cases,” “relatively normal urination” is still possible. Sentence 8 states, “Many men who have undergone a total penectomy must sit to urinate.” This sentence offers “not sitting” as a definition to the notion of “relatively normal urination” from sentence 7, situating “sit[ting] to urinate” as abnormal.

Effects on sexuality. In the first paragraph of this tertiary section, sentences 9 and 10 note that if penile cancer is caught early, “treatments other than penectomy can often be used,” which “may have little effect on sexual pleasure and intercourse.” However, as was noted earlier in the text, surgical intervention – partial or complete removal of the penis – is the most common treatment for penile cancer, which is what the remainder of the section addresses.

Beginning the next paragraph, sentence 11 states, “Removing all or part of the penis can have a devastating effect on a man’s self-image and ability to have sexual intercourse.” Here again, we find a term used only in the penile cancer DG. Using the partial word “devastat,” a search found only one instance of the term “devastate,” in the form of “devastating” as used in the penile cancer DG, across all 7 cancer DGs. Use of the term “devastating” once again invokes the notion that penile cancer is uniquely frightening, difficult to cope with, and harmful to patients. By applying “devastating effects” to both “self-image” and “sexual intercourse” in the same breath, the text links “a man’s self-image” with his “ability to have sexual intercourse.” In framing this section, the text established that partial or complete removal of the penis 1) is a harsher, more drastic treatment than other cancer treatments, and 2) is considered “worse than the disease” by some. Within this frame, readers are led to understand that the penis – defined as the “male sexual organ” on page 2 of the guide – and its ability to physically penetrate others, is the essence of male identity. Sentence 12 offers the possibility of control by once again suggesting seeking help through counseling. Here, the focus shifts from penile identity and penetration to sexual satisfaction after the penis has been reduced or removed. The text suggests that patients and their partners seek counseling to “help understand the impact of treatment for penile cancer and to explore other approaches to sexual satisfaction.”

The following paragraph focuses on penetrative sex after partial penectomy, noting in sentence 13 that “Satisfying intercourse is possible for many, but not all men after partial penectomy.” The remainder of the paragraph discusses the potential of erections, penetrative sex, ejaculation, and the patient’s partner’s ability to “often reach orgasm” during intercourse.

The next paragraph, sentences 18-23, addresses sexual satisfaction after total penectomy. Sentence 18 explains, “Normal intercourse is not possible after total penectomy,” and is followed by the assertion that “Some men give up sex after the surgery.” The meaning of “normal intercourse” is unclear. Although “sexual intercourse” generally assumes heterosexual, penetrative vaginal sex, the term broadly refers to sexual contact including penetration. While the text refers to “female partners” when discussing HPV avoidance on page 11, the term “vagina” or “vaginal” occurs only twice throughout the text. Both instances are located on page 10 under the “Human papilloma virus infection” subheading. The term “vaginal intercourse” appears as part of a list on page 10: “HPV can be spread during sex – including vaginal intercourse, anal intercourse, and oral sex [...]” Because the definition of “sexual intercourse” broadly refers to sexual contact that includes penetration, it is possible that the text is referring to the generally assumed meaning of the term, situating penile-vaginal penetration as “normal” intercourse. If this is the case, then the “abnormal” intercourse the text alludes to may include digital or oral penetration, or penetration using a sexual device such as a vibrator or dildo.

Despite the cloudiness of what “normal intercourse” is, one thing is clear: men who have undergone total penectomy are incapable of engaging in “normal intercourse,” and thus must resort to “abnormal” measures. Perhaps this is why “Some men give up sex after the surgery.” Together, sentences 18 and 19 advance the notion that if a penis cannot penetrate the orifice of another human, then sexual contact with others may not be worth it. The phrase “some men”

offers readers the potential to opt out if they choose to adopt this view. However, the phrase also insinuates that “most men” do not choose to give up sex after surgery.

Sentence 20 notes, “Since cancer of the penis is most common in elderly men, some are already unable to have intercourse because of other health problems.” This sentence achieves two things. First, the first half of the sentence situates penile cancer as an issue mostly for “elderly men,” although on page 10 in the risk factors section, the text informs readers that “About 4 out of 5 cases of the disease are diagnosed in men over age 55,” so it is unclear what the text defines as “elderly.” More importantly, however, the second half of sentence 20 asserts that “some are already unable to have intercourse because of other health problems.” While this author will not attribute intent, the placement and organization of this sentence implies that if a penis cannot function “normally” as the “male sexual organ,” then the penis is already obsolete, and may not be missed. Here, sentence 20 serves almost as a shrug regarding both the inability of patients of total penectomy to achieve “normal” sexual intercourse, and patients’ resulting choice to completely give up sex.

In the same paragraph, sentence 21 shifts the conversation from giving up sex to working toward building a new sex life. Sentence 21 states, “If a man is willing to put some effort into his sex life, however, pleasure is possible after total penectomy.” Sentences 22 and 23 follow with suggestions regarding how patients can experience sexual pleasure after treatment, including caressing, fantasizing, and “looking at erotic pictures or stories.” Expanding even further on how patients can engage in sexual activity after total penectomy, the following two-sentence paragraph begins, “A man can help his partner reach orgasm by caressing the genitals, by oral sex, or by stimulation with a sexual aid such as a vibrator.” Sentence 24 states, “The activity some couples enjoy after total penectomy can give hope to those coping with fewer changes in

their sex lives.” While this seems to end the discussion on a bright note, the invocation of “hope” – a term widely used in relation to cancer cure and avoidance of cancer death – reinforces the notion established in sentence 2 that reducing or removing the penis is, perhaps, “worse than the disease.”

Testicular Cancer Treatment Effects

The tertiary section “Possible effects on sexual function and fertility” is located under the “Surgery for testicular cancer” subheading, and is preceded by two other tertiary sections: “Radical inguinal orchiectomy,” and “Retroperitoneal lymph node dissection.” Radical inguinal orchiectomy is the removal of the testicle or testicles that contain cancer. The surgery is completed through the groin, and the spermatic cord is cut. The text notes, “All stages of testicular cancer are typically treated with this type of surgery.” Retroperitoneal lymph node dissection is performed based on the type and stage of the cancer, and “can be a major operation,” often requiring a large incision to get to these lymph nodes, located behind the abdomen. The tertiary section “Possible effects on sexual function and fertility” addresses effects from both radical inguinal orchiectomy and retroperitoneal lymph node dissection.

The first paragraph in this tertiary section, sentences 1-5, offers an explanation for the effects of retroperitoneal lymph node dissection on ejaculation, and informs readers that “a man can still have erections and sexual intercourse,” although it may be “harder to father children.” This paragraph offers information and reassurance regarding patient sexuality.

Sentences 6-9 are also informative, alerting patients to two issues they will face if both testicles are removed: infertility and insufficient testosterone. This paragraph also offers information regarding testosterone supplements.

Possible effects on sexual function and fertility	Pg. 24
<p>Surgery to remove retroperitoneal lymph nodes may damage nearby nerves that control ejaculation. If these nerves are damaged, when a male ejaculates, the semen is not propelled forward through the urethra to exit the body but rather goes backwards into the bladder. This is known as <i>retrograde ejaculation</i>. This type of surgery does not cause impotence – a man can still have erections and sexual intercourse – but retrograde ejaculation can make it harder to father children. To save the normal ejaculation function, surgeons have developed a type of retroperitoneal lymph node surgery called <i>nerve-sparing</i> surgery that has a very high rate of success in experienced hands.</p>	1-5
<p>If both testicles are removed, sperm cells cannot be produced and a man becomes infertile. Also, without testicles, a man cannot make enough testosterone. He will need to take supplements, either in the form of a gel, a patch, or a shot. Pills are generally not reliable sources of testosterone.</p>	6-9
<p>Testicular cancer often affects men at an age when they may be trying to have children. Those men may wish to discuss nerve-sparing surgery with their doctors, as well as sperm banking (freezing and storing sperm cells obtained before treatment). Men with testicular cancer often have lower than normal sperm counts, which may make it difficult to collect a good sperm sample.</p>	10-12
<p>Men with testicular cancer are usually young and may be concerned that their appearance has changed. They may be single and dating and worry about a partner’s reaction, or they may be athletic and feel embarrassed by the missing testicle when in locker rooms. Since the operation also removes the cord above the testicle, that side of the scrotum can look and feel empty to them.</p>	13-15
<p>To restore a more natural look, a man can have a testicular prosthesis surgically implanted in his scrotum. The prosthesis approved for use in the United States is filled with saline (salt water), and it comes in different sizes to match the remaining testicle. When in place, it can look like a normal testicle. There can be a scar after the operation, but it is often partly hidden by public hair. Some men want to have a prosthesis and others do not. You should discuss your wishes with your surgeon before considering this surgery. It may also help to talk with someone who has a testicular prosthesis, to see what their experience has been like.</p>	16-22
<p>Losing a testicle usually has no effect on a man’s ability to get an erection and have sex. Men who have had both testicles removed are also still able to have sex as long as they are getting enough testosterone.</p>	23-24

Figure 22: Testicular cancer possible effects on sexual function and fertility section excerpt

Sentences 10-12 offer information regarding reproduction. The text notes, “Testicular cancer often affects men at an age when they are trying to have children,” and offers some general information on surgical and banking options to help improve their chances of conceiving children.

Most of the remainder of the section, sentences 13-22, focuses largely on genital appearance after surgery. Sentence 22 begins by noting, “Men with testicular cancer are usually young and may be concerned that their appearance has changed.” The following sentence states, “They may be single and dating and worry about a partner’s reaction, or they may be athletic and feel embarrassed by the missing testicle when in locker rooms.” The first half of this sentence assumes that young single men who are dating will end up naked with partners. The second half of the sentence again assumes nakedness, specifically that young athletic men will be naked with other men, who may judge the patient’s testicles. As a whole, sentence 14 problematizes the missing testicle in relation to the gaze of others on the patient’s body. The last sentence in this paragraph, sentence 15, takes the patient’s own gaze on his body into account, noting “Since the operation also removes the cord above the testicle, that side of the scrotum can look and feel empty to them.”

The following paragraph, sentences 16-22, discuss the possibility of a prosthetic testicle implant. The content of this paragraph is mostly informative, although the last two sentences, sentences 21 and 22, offer suggestions for decision making. The text notes, “You should discuss your wishes with your surgeon before considering this surgery,” and suggests in sentence 22, “It may also help to talk with someone who has a testicular prosthesis, to see what their experience has been like.”

The two final sentences in this section, sentences 23 and 24, offer reassurance. Sentence 23 states, “Losing a testicle usually has no effect on a man’s ability to get an erection and have sex.” While the term “usually” allows for some chance to the contrary, the text’s casual manner of addressing that possibility conveys improbability and unimportance. Importantly, the text uses the phrase, “get an erection and have sex,” which pairs “erection” and “sex,” centering the act of

sex on the penis and penetration, and potentially disclosing alternative possibilities. The last sentence of the section states, “Men who have had both testicles removed are also still able to have sex as long as they are getting enough testosterone.” Thus, while patients may be concerned about their appearance after surgery, testicles are not necessary for patients to “have sex.”

Prostate Cancer Treatment Effects

Under the prostate cancer DG subheading “Possible risks and side effects of radical prostatectomy (including LRP),” the text lists several tertiary headings. First, the text summarizes some surgical risks, which briefly summarizes some of the common, uncommon, major, and rare risks associated with anesthesia, lymph node removal, and general surgery. Next, the tertiary heading “Side effects” lists “Urinary incontinence,” “Impotence (erectile dysfunction),” “Changes in orgasm,” “Loss of fertility,” “Lymphadema,” “Change in penis length,” and “Inguinal hernia” respectively. The “Urinary incontinence” and “Impotence” heading comprise the majority of the “Side effects” subsection. The “Urinary incontinence” section begins in the middle of page 36 of the text and ends in the middle of page 38. Beginning in the middle of page 38 and stopping at the end of page 39, the “Impotence” section comprises a smaller portion of this section.

<p>Impotence (erectile dysfunction): This means you cannot get an erection sufficient for sexual penetration. The nerves that allow men to get erections may be damaged or removed by radical prostatectomy. Other treatments (besides surgery) may also damage these nerves or the blood vessels that supply blood to the penis to cause an erection.</p>	<p>Pg. 38 1-3</p>
<p>Your ability to have an erection after surgery depends on your age, your ability to get an erection before the operation, and whether the nerves were cut. Everyone can expect some decrease in the ability to have an erection, but the younger you are, the more likely it is that you will keep this ability.</p>	<p>4-5</p>
<p>A wide range of impotency rates have been reported in the medical literature, from as low as about 1 in 4 men under age 60 to as high as about 3 in 4 men over age 70. Doctors who perform many nerve-sparing radical prostatectomies tend to report lower impotence rates than doctors who do the surgery less often.</p>	<p>6-7</p>
<p>Each man’s situation is different, so the best way to get an idea of your chances for</p>	

Figure 23: Prostate cancer treatment effects section excerpt

recovering erections is to ask your doctor about his or her success rates and what the outcome is likely to be in your particular case.	8
If your ability to have erections does return after surgery, it often occurs slowly. In fact, it can take up to 2 years. During the first several months, you will probably not be able to have a spontaneous erection, so you may need medicines or other treatments.	Pg. 39 9-11
If potency remains after surgery, the sensation of orgasm should continue to be pleasurable, but there is no ejaculation of semen – the orgasm is “dry.” This is because during the prostatectomy, the glands that made most of the fluid for semen (the seminal vesicles and prostate) were removed, and the pathways used by sperm (the vas deferens) were cut.	12-13
Most doctors feel that regaining potency is helped along by attempting to get an erection as soon as possible once the body had had a chance to heal (usually several weeks after the operation). Some doctors call this <i>penile rehabilitation</i> . Medicines (see below) may be helpful at this time. Be sure to talk to your doctor about your situation.	14-17
Several options may help you if you have erectile dysfunction:	18
<i>Phosphodiesterase inhibitors</i> such as sildenafil (Viagra), vardenafil (Levitra), and tadalafil (Cialis) are pills that can promote erections. These drugs will not work if both nerves that control erections have been damaged or removed. The most common side effects are headache, flushing (skin becomes red and feels warm), upset stomach, light sensitivity, and runny or stuffy nose. Rarely, these drugs can cause vision problems, possibly even blindness. Nitrates, which are drugs used to treat heart disease, can interact with these drugs to cause very low blood pressure, which can be dangerous. Some other drugs may also cause problems, so be sure your doctor knows which medicines you are taking.	19-24
<i>Alprostadil</i> is a man-made version of the prostaglandin E1, a substance naturally made in the body that can produce erections. It can be injected almost painlessly into the base of the penis 5 to 10 minutes before intercourse or placed into the tip of the penis as a suppository. You can even increase the dosage to prolong the erection. You may have side effects, such as pain, dizziness, and prolonged erection, but they are usually minimal.	25-28
<i>Vacuum devices</i> are another option that may create an erection. These mechanical pumps are placed around the entire penis before intercourse to produce an erection.	29-30
<i>Penile implants</i> might restore your ability to have erections if other methods do not help. An operation is needed to put them in place. There are several types of penile implants, including those using silicone rods or inflatable devices.	31-33
For more detailed information on coping with erection problems and other sexuality issues, see our document, <i>Sexuality for the Man with Cancer</i>	34

Figure 23: Prostate cancer treatment effects section excerpt continued

The first sentence of this text states, “This means you cannot get an erection sufficient for sexual penetration.” Similar to the penile cancer DG, the sexual threat of prostate cancer is

centered on the inability of a man to penetrate the orifice of another person. However, unlike the penile cancer guide, the prostate cancer DG does not assert that prostate cancer treatment, which may result in insufficient erections and an inability to achieve sexual penetration, is worse than the disease. As a whole, the tone of the section is highly informative, offering readers a broad range of information about erectile dysfunction that can help patients understand what impotence is, why it occurs, and how they might remedy the issue. This section also offers some tips regarding questions patients should ask doctors regarding erections, and what patients can expect if they can still achieve erections after surgery. At the end of the section, the text offers four potential solutions or therapies that may help overcome erectile dysfunction: Medication such as Viagra, Levitra, and Cialis; injections to help improve erection success as well as to prolong erections; vacuum devices to help stimulate erections; and penile implants if other methods do work. While the information presented in this section is thorough, the text assumes that the erect penis is the center of sexual activity, and fails to suggest alternative sexual activities with others.

Throughout all three texts, sexual activity and enjoyment is assumed to be dependent on the penis. The alteration or absence of the penis invokes a dismal narrative with a bleak outlook. However, it is only in this absence that the ACS male affiliated DGs offer alternative versions of sexual activity that are not dominated by an erect penis capable of penetrative sex.

In the following chapter, the definitions and concurrent narratives within chapters 3 and 4 will be compared and discussed. I will first discuss how female and male bodies are defined, and then discuss how these definitions affect the way the texts address topics within the texts. I will also discuss how abiding by these socially invoked narratives threatens the integrity of the information offered in the American Cancer Society's detailed guides, how incorrect or missing information might impact patients' lives, and how such issues might be addressed.

CHAPTER 5: RESULTS AND DISCUSSION

“It is a balancing act and it is a dream”

From frosting filled cupcakes, to confetti, to large boxes filled with balloons, expectant parents are continuously devising increasingly creative and elaborate methods of unveiling the answer to the single most important question regarding their in-utero addition: “What is it?” Using ultrasound technology, expectant parents can find out the sex of their fetuses at just 18-20 weeks of development, although many expectant parents prefer to maintain mystery and choose to find out upon delivery. Regardless of when, where, and under what circumstances the great reveal occurs, the single factor of determination for “what is it?” is answered first and foremost by getting a look at the burgeoning human’s genitals.

The importance of the question “What is it?” hinges on social implications of sex (anatomy) and the associated gender (social performance) that have a long history of division, inequality, and oppression. While present day gender inequality in the United States is considerably less severe than in decades past, the genitalia of an unborn or newborn baby still dictate specific social expectations regarding morality, work, education, social engagement, social and domestic responsibilities, income, love, and reproduction that the developing person will be socialized into.

That these notions of sex and gender are entrenched in social, civic, and institutional life is frustrating, but unsurprising, and medical institutions are no exception – gender based biases have long been incorporated into scientific and medical theory and practice (Braun & Kitzinger, 2001b; Fausto-Sterling, 2000; Fournier & Russell, 1992; Kapsalis, 1997; Lane & Lawler, 1997;

Laquerur, 1990; Martin, 1987; Martin, 1991; Metoyer & Rust, 2011; Wooley, 1994; Wray, Markovic, & Manderson, 2007). Gendered theory and practice in science and medicine not only adversely affects patients, but also thwarts medical knowledge and advancements, and prevents medical professionals and institutions from doing the most good (Braun & Kitzinger, 2001b; Fausto-Sterling, 2000; Martin, 1991; Metoyer & Rust, 2011; Wooley, 1994; Wray, Markovic, & Manderson, 2007). The implications concerning the cancer patient literature examined in this dissertation are broad, impacting patients, doctors, medical effectiveness, and the American Cancer Society (ACS).

The Guides: Framing, Misinformation, and Implications

The definitions of women's and men's body parts provided by the American Cancer Society frame the way the purpose, function, and subsequent value of each body part is to be understood throughout each text. In the 4 female affiliated detailed guides (DG), the female body is equated with reproduction, with the name, purpose, function and structure of the vagina, cervix, ovaries, and uterus tied solely and explicitly to reproduction. The texts do this by either defining the body part as reproductive (e.g., "Ovaries are reproductive glands"), or by giving the body parts alternate definitions that specifically reference reproduction and childbirth (e.g. vagina/birth canal, uterus/womb). When discussing the uterus, the reproductive epicenter of the female body, the text goes so far as to use the phrase "the baby" ("Endometrial cancer detailed guide," 2013, p. 3) when discussing the function of the myometrium, a layer of muscle in the uterus. This phrase indicates that there can, should, and will be a baby, which will maximize the functionality of the uterus.

Within the definition sections of the 3 male affiliated DGs, reproduction is mentioned only once, in the testicular cancer DG. In fact, references to human reproduction appear only

three times across the male affiliated DGs: twice in the testicular cancer DG as “part of the male reproductive system” (p. 2) and “assisted reproduction methods” (p. 43); and once in the prostate cancer DG as “Urologists: surgeons who specialize in treating diseases of the urinary system and male reproductive system (including the prostate)” (p. 32). Despite the texts’ explanations of semen, ejaculation, and heterosexual sexual intercourse, none of the male affiliated DGs discuss the process of reproduction or men’s part in it. Rather, these texts focus on the male body and its associated parts as sexual by nature, going so far as to define the penis as the “male sexual organ.”

In addition to strict definitions of female and male bodies, the diagrams presented alongside these definitions send a message to readers regarding the importance of the body part under discussion. As hyper real depictions of the body – depictions that are somehow more real than actual photographs or real time views of the body – medical diagrams give viewers a perspective of the human body that they might never have otherwise (Kapsalis, 1997). Furthermore, medical diagrams communicate about what is known, or what ought to be known, about body parts, practice, and procedure. Relative to one another, stark contrasts develop between the DGs. The simple line drawings offered in the vaginal, cervical, and ovarian cancer guides indicates unimportance, and it seems that there is little to know about women’s simple bodies. However, in addition to a simple line drawing, the endometrial cancer DG includes a diagram that offers detailed, cross sectional views of the uterus, the body part most easily aligned with reproduction. Similarly, the testicular, penile, and prostate DGs offer detailed drawings, with the penile and prostate DGs offering cross sectional views. Broadly speaking, the definitional sections portray women’s bodies as simplistic and reproductive, and men’s bodies as complex and sexual.

As most anyone would point out, neither of these strict classifications – women as reproductive and men as sexual – offer accurate depictions of the people who actually have these body parts. This is a fact, and most readers would likely not identify as strictly reproductive or sexual – these are but two of the many aspects that make up individual identities. However, these definitions do affect not only how readers are asked to understand themselves and how the subsequent information is read but also what information is actually offered by the ACS. While it may be argued that “normal,” non-Ph.D. candidate patients who do not share the propensity for analytic reading that this author does will not notice all of these rhetorical elements that I have brought up, that is exactly part of the point: most patients won’t read these texts critically, they will read them as the factual, definitional, and objective texts they portray themselves as, like so many dictionary and scientific definitions before them (Braun & Kitzinger, 2001b; Fournier & Russell, 1992; Gershuny, 1977; Landau, 1985; Martin, 1991; Martin, 1994; Metoyer & Rust, 2011; Potter, 1996). As such, the multiple levels of authority imbued in these texts’ scientific, medical, and objective persona make patients much more likely to adopt the perspectives of and step into the subject positions provided by the DGs, and are thus at risk of developing lopsided and incorrect conclusions about themselves.

The reproductive and sexual subject positions presented by the DGs are available throughout the texts, which means that even if patients read the texts in a non-linear fashion, and even if they never read the definitional sections, the text will still affect how readers understand themselves and how information is interpreted. In fact, the most interesting aspect of the definitional sections in the American Cancer Society’s cancer detailed guides may be that they are telling of the ACS’s attitudes, perceptions, and approach towards female and male bodies and patients.

Read this as this subject, in this way. Going back to Bateson (1972), “The picture frame tells the viewer that he is not to use the same sort of thinking in interpreting the picture that he might use in interpreting the wallpaper outside the frame” (p. 187). These ACS texts are not only asking readers to interpret the information within the frame of “_____ cancer patient detailed guides” in a specific way, they are also encouraging readers to think of themselves as occupying specific subject positions (Charland, 1987). Considering the subject position “cancer patient” as inside the frame, and life prior to cancer diagnosis as “the wallpaper outside the frame,” then the ACS DGs are both acting as a guide through the life of cancer, and “[providing] individuals with narratives to inhabit as subjects and motives to experience” (Charland, 1987, p. 143). In other words, these definitional sections ask readers to understand themselves as either reproductive or sexual by nature – *by definition* – and to understand their bodies as such. As a result, patients must subsequently approach their disease and potential treatments as either reproductive or sexual subjects.

Risk factors and prevention. Because the information offered is aligned with reproduction or sexuality, patients are continuously asked to consider the information within the text through the lens of a reproductive or sexual subject. This becomes apparent when considering the “Risk factors” sections of the DGs. Referring back to the risk factors charts in chapters 3 and 4, it is notable that women are asked to consider their reproduction as risk factors, while men are not.

Across the 4 female associated DGs, all list multiple reproductive choice categories as risk factors, *or* as factors that could reduce risk. Like risk factors that have a negative impact, risk factors that have preventative or protective effects indicates that, if the patient had made different (perhaps better) choices, she would not have developed cancer in the first place.

However, the positive or negative effects of these reproductively linked lifestyle choices are in conflict; regardless of women's reproductive choices, they are always at risk for one of the gynecological cancers. For example, the cervical cancer DG lists oral contraceptives as having an increasingly negative effect over time, while the endometrial cancer DG lists birth control pills as having an increasingly protective effect over time. Even removing the chemical factors tied to the control of birth (e.g. fertility drugs, IUD), the conundrum still exists. The texts list age of first pregnancy and number of pregnancies – either too many or too few – as factors which affect risk. Regardless of whether a woman chooses to have 0, 1, or 3+ children, she is always choosing to either put herself at risk *or* not take steps to protect herself from risk – 3 or more pregnancies put a woman at risk for cervical cancer, but, for endometrial and ovarian cancers, the risk of developing cancer declines per pregnancy, with the endometrial cancer DG stating, “having many pregnancies protects against endometrial cancer” (p. 8). Women are culpable.

Across the 3 male associated DG risk factors sections, only the prostate cancer DG lists anything potentially related to reproduction: vasectomy. However, not only does the DG note that vasectomy is in no way related to prostate cancer, but vasectomy can be seen as the opposite of reproduction, as it is often used to permanently or temporarily preclude the possibility of pregnancy. Thus, its inclusion alludes to the notion of more freedom for the sexual subject. The prostate cancer DG also lists “sexually transmitted infections” (STI) in the risk factors section, and also notes that STIs have nothing to do with prostate cancer. Once again, the inclusion of this “risk factor” both alludes to freedom for the sexual subject and acts to reassure patients that they were not responsible for the development of their cancer. Even in the case of HPV and penile cancer, as my analysis in chapter 4 shows, the sexual subject develops HPV as a circumstance of their natural human condition, the text pointing to the skin of the penis and

ineffective protection from condoms as reasons leading to the penile cancer patient's plight.

There are no risk factors or contradictions listed in the male affiliated DGs that are equivalent to those listed in the female associated DGs. Equivalent risk factors for a sexual subject might include lifestyle choices such as age of first sexual act, age of first intercourse, number of partners, frequency of condom use, and frequency of ejaculation. Men are reassured.

Importantly, parallel risk factors for the reproductive and sexual subject are treated differently. This is glaringly apparent in the cervical and penile cancer DG discussions of the HPV risk factor. When first introducing the HPV risk factor, the reproductive subject is immediately told that HPV has a direct link to cancer risk, and the text spends a substantial amount of space broadening and intensifying the link between HPV and cervical cancer, almost going so far as to establish a causal link (p. 6). On the other hand, the sexual subject is first reassured for 14 sentences that HPV is a common and mundane disease that does not usually lead to cancer before he is told that HPV is "found" in half of penile cancers (p. 9). The text then continues reassuring the sexual subject, telling him that HPV is practically impossible to avoid, and restating the fact that "HPV infection is common," following up with a study to prove it: "One study found that about half of men 18 and older have a genital HPV infection at any point in time" (p. 9).

The same incongruences are found in parallel sections that address avoiding HPV. Beginning with the section titles, "Avoid being exposed to HPV" in the cervical cancer DG and "Avoiding HPV infection" in the penile cancer DG, the reproductive subject is ordered to not be exposed to HPV, while the sexual subject is offered information on how he might avoid infection. This permeates into the body of the section: The reproductive subject is told that she can avoid cervical cancer by avoiding HPV, and is then told that all forms of sex – even hand

stuff – can cause her to become infected; the sexual subject is told to “do what [he] can to avoid infection,” and is then reminded that if his parents did not circumcise him, the skin of his penis is more susceptible to becoming infected. The reproductive subject is told that it “can be very hard” to avoid HPV infection, but that it may be possible, and that in order to reduce her chances of being infected with HPV, she should wait until she is older to have sex, limit her number of sexual partners, and avoid having sex with someone who has had many sexual partners; the sexual subject is told that condoms aren’t a reliable way to prevent HPV infection, because they don’t cover everything. The reproductive subject gets two additional subsections regarding HPV avoidance: the first tells her that uncircumcised men are more likely to infect her (p. 16); the second tells her that condoms are a highly effective prevention method which, a study found, significantly reduce the rate of infection among women (p. 16). This study was not included in the penile cancer DG, even though men must wear the condoms. The inclusion of this study in the cervical cancer guide makes women responsible for condom use, in addition to the number of sexual partners and number of partners her partners have had.

Side effects. The differences between how female and male affiliated DGs approach side effects is striking, particularly in reference to how treatments affect the genital regions. As my analysis demonstrates, reproductive subjects are offered scant information regarding the short and long term effects of treatments on their bodies, and even less information regarding how to cope with the changes. The little information that is offered addresses how patients can reduce pain when their vaginas are penetrated. This focus problematizes patients’ genital health in terms of the penis, and, excepting the cervical cancer DG’s statement that after complete pelvic exenteration “With practice and determination, [women] can also have sexual desire, pleasure, and orgasms,” (p. 34), excludes discussions regarding patients’ sexual wellbeing. For any other

information regarding her genitals and sexual self, the reproductive subject is told to consult other sources. That the female affiliated DGs pay little attention to these issues, telling women they should seek information elsewhere if they are “bothered by these problems” (“Endometrial cancer detailed guide,” p. 28), or simply offering a reference to literature that addresses women’s sexuality in a section that offers “additional” information, communicates to women that these issues – issues of change, pain, and identity as related to the female sexual body – are unimportant. Here again, the culpable reproductive subject is responsible; in this case, she is responsible for developing ideas and seeking information regarding how to cope with the changes taking place in her body.

On the other hand, sexual subjects receive considerable information regarding the short and long term side effects of treatments on their bodies, and are offered detailed information. The DG’s focus is mostly on the penetrative ability of the erect penis, and the prostate cancer DG spends a significant amount of space explaining the causes of impotence and offering several solutions to the problem. However, this focus becomes troubled in the event of penile cancer, where the most common treatment is partial or complete removal of the penis. In this instance, the treatment is addressed as a tragedy that, the ACS DG asserts, many patients believe is “worse than the disease” (“Penile cancer detailed guide,” p. 37). Using notions of “hope” that are usually reserved for the terminally ill, or those facing decisions that have life or death consequences (e.g., in the movie *50/50*, Adam underwent a surgery in which there was a 50/50 survival/mortality rate), the penile cancer DG gently guides readers through non-penile penetrative options for sexual intimacy. Here, the DG concerns itself not only with patients’ sexual exploration and satisfaction, but also patients’ ability to satisfy their partners. In this way, the DG addresses patients’ quality of life regarding their sexual identities overall – both as

individuals leading satisfactory sexual lives, and as partners who are able to contribute to their partners sexual satisfaction. Once again, the sexual subject is a reassured victim.

The Implications of Gendered Narratives: Misinformation and Health Outcomes

The gendered narratives at play across the 7 guides leave all patients at risk of receiving no or partial information at best, and incorrect information at worst. The implications are far reaching. At a broad level, the female/male dichotomy constructed in the ACS patient literature has the effect of limiting and excluding information that may be considered “sexual” from literature written for female subjects, and, conversely, limiting and excluding information that may be considered “reproductive” from literature written for male subjects. This manifests throughout all 7 guides mostly in terms of exclusion – information regarding sex and sexuality is excluded from the female affiliated DGs, while information regarding reproduction is excluded from the male affiliated DGs.

In an interview about his novels, writer Henry Green observed, “the more you leave out, the more you highlight what you leave in,” (1958); and, much like maps (Bateson, 1972) or tales (Gaiman, 2001), what is in the American Cancer Society’s cancer patient DGs is highlighted all the more prominently by what is excluded from them. But the difference between medical literature, and maps and tales is that while map users don’t expect a representation of all topographical details, and while tale readers understand that their view into characters’ lives is limited by the narrator, medical texts are given an authoritative weight denied to other genres. As previously discussed, the combination of the American Cancer Society’s authoritative presence in cancer and medicine combined with the authority bestowed upon the medical information genre as a whole gives these texts a considerable level of authority, and are likely to be read as objective fact rather than fallible, subjective representation. Therefore, the information that *is*

offered by the ACS DGs is more likely to be read as *the* information that is/should be important to patients, and the information that *is not* offered DGs is more likely to be considered extraneous. Thus, when considering cancer patient literature, the notion that what is left in his highlighted by what is left out becomes an important point of consideration. There are two such examples that I wish to discuss here: hormones and sexuality.

Hormones. Both the female and male affiliated DGs emphasize the notion that there are “female hormones” and “male hormones”: estrogen and progesterone are “female hormones” and testosterone is a “male hormone.” This notion of female and male “sex hormones” is not new or surprising, although it is misleading. Both women and men need so called “female” and “male” sex hormones for organ health. Of this apparent inconsistency, Fausto-Sterling (2000) asks:

Why, then, have hormones always been strongly associated with the idea of sex, when, in fact, ‘sex hormones’ apparently affect organs throughout the entire body and are not specific to either gender? The brain, lungs, bones, blood vessels, intestine, and liver (to give a partial list) all use estrogen to maintain proper growth and development” (p. 147).

However, despite the fact that women’s and men’s bodies produce all three hormones, and that a balance of hormones is needed to maintain female and male organ health (e.g., Ali et al., 2012; Cawthon et al., 2016; Jankowska et al., 2009; Klein-Nulend, van Oers, Bakker, & Bacabac, 2015), all 7 texts examined here chose to draw a clear distinction between “female” and “male” hormones. They also chose not to discuss any function that hormones play outside of the reproductive or sexual narratives constructed in the texts, so that estrogen and progesterone are represented as being useful only insofar as reproduction and the menstrual cycle is concerned, and that testosterone is represented as especially important for male sex drive (esp. in

“Testicular cancer detailed guide”). Furthermore, these hormones are represented as being produced either exclusively by the ovaries or prostate, or as being produced by malignant tumors, at which point the presence of the “wrong” hormone in the “wrong” body is discussed as unnatural and dangerous (“Ovarian cancer detailed guide,” 2013, pp. 6, 22, & 49; “Testicular cancer detailed guide,” 2012, pp. 6 & 12)⁸. The texts do not explain that hormones are produced throughout the body by endocrine system, including the ovaries/testes, pancreas, adrenal gland, thyroid, and pituitary gland, nor that they are essential for overall health and wellbeing. As a result of excluding this information, or any reference to this information, patients are denied valuable information that involves their over all health. This could negatively impact the ability for patients to make informed decisions regarding treatment options, and leave patients feeling surprised and confused by side effects related to hormonal disruptions that they may not have been able to anticipate.

Sexuality. Sexuality is a significant factor in many people’s lives. Cancer treatments can adversely affect people’s sexual selves, including treatments such as surgeries that lead to nerve damage, incontinence, or disfigurement; radiation treatments that cause burns and both temporary and permanent changes to the skin; and drugs such as chemotherapy that affect whole body systems and lead to physical, chemical, and emotional changes. These issues are addressed differently in the female and male affiliated cancer DGs, which leads to different implications for women and men.

Sexuality and women. As demonstrated through my analysis and as discussed earlier in this chapter, female affiliated cancer DGs offer little information, guidance, or coping methods for women with gynecological cancers. Even in reference to one of the most extreme surgeries –

⁸ Estrogen is also discussed as a hormone treatment option in the “Prostate cancer detailed guide” on pages 49, 50, & 67.

pelvic exenteration – the cervical cancer DG offers only five sentences under the “Sexual impact of pelvic exenteration” tertiary section. Within these five sentences, the text essentially tells the patient, “It’s normal to not feel normal. If you really want to, you can feel normal again, you just have to try.” Similarly, in the vaginal, cervical, and endometrial cancer DGs, the text notes that radiation can cause damage to the vagina, and that this can be treated with intercourse and dilators; and in the vaginal cancer guide, the text situates the loss of the vagina as an interruption of penile penetration, discussing patients’ vaginas and sexual health in terms of the penis, and offering solutions that only remedy penetrative access – one of which is sexual intercourse. Unlike the penile cancer, which offers suggestions for alternative sexual engagement with partners for both partial and full penectomy, patients who undergo vaginal shortening or removal are offered no such alternatives.

Despite the DGs’ insistence that removing the cervix, uterus, and vagina will not affect sexual pleasure and orgasm, and that removing the cervix and uterus may actually improve sexual pleasure, recent research finds differently (Jannini et al, 2012; Komisaruk, Frangos, & Whipple, 2011; Komisaruk et al., 2011). Rather than the entirety of women’s sexuality existing in the clitoris, as the DGs indicate, women actually experience a wide range of sexual pleasure including stimulation of the vagina, cervix, uterus, and clitoris. Jannini et al (2012) note:

It is also important not to put women into a model of only one or two ways to experience sensual and sexual pleasure, satisfaction, and orgasm. Women need to be encouraged to feel good about the variety of ways they experience sexual pleasure, without setting up specific goals (such as finding the G-spot, experiencing female ejaculation, or experiencing a VAO [vaginally activated orgasm]). (Jannini et al., 963).

However, the silences that occur around topics of women's sexuality, and the silencing that occurs within the guides themselves, works to reinforce social stigmas surrounding women's bodies (Braun & Kitzinger, 2001a; Wray, Markovic, & Manderson, 2007). Within the medical setting, social stigmas can disrupt health communication, resulting in patient confusion, isolation, and detrimental patient experiences. Discussing gynecological brachytherapy, a radiation technique used in some gynecological cancers in which a device is inserted into the vagina, Wray, Markovic, & Manderson (2007) explain that patients consistently experienced a communicative breakdown regarding the procedure, noting "Women felt that the explanations given to them were concise yet full of ambiguity and uncertainty, because neither the location of the radioactive implants nor the duration of implantation was explained to them" (p. 2266). This study demonstrates how the stigma surrounding women's sexual bodies troubles communication, in this case to the point that patients did not know the size, shape, or composition of devices (pp. 2266-2267), did not know that the device would be sewn into the vagina (pp. 2266-2267), and did not know that the treatment would be painful (p. 2267). Furthermore, because of the social stigma surrounding women's sexual bodies, women who endure gynecological cancer surgeries and treatments cannot openly discuss their experiences with social others, leading to a sense of isolation in patients (Wray, Markovic, & Manderson, 2007).

Sexuality and men. If leaving women's sexuality out of the female affiliated DGs highlights the importance of the penetrative heterosexual penis, then what is left out the male affiliated DGs that highlights sexuality? Essentially, what is left out of the penile, testicular, and penile cancer that so strongly highlights male sexuality is – well – anything else that makes men whole beings. The problem with how the DGs address male sexuality isn't that the topic lacks attention; on the contrary, male sexuality is discussed at length, and is referenced throughout the

guides, whether directly through discussions of sex, or indirectly through references to ejaculation, “male sex hormones,” etc.

And that is where the problem lies. The DGs so thoroughly align men with sexuality, and sexuality with the penis, that there is not room for men to be something else. This becomes especially problematic when cancer treatments threaten men’s sexual selves, perhaps most clearly articulated in the penile cancer guide. Here, the prospect of partial or complete removal of the penis is discussed as something thought by “many men” (p. 37) to be worse than cancer, insinuating that “many men” would rather experience cancer death than have their penises partially or completely removed. In this narrative, men facing partial or complete penectomy are “frightened,” “suffer[ing],” and “devastat[ed]” (p. 37), highly emotional words that do not appear in the other 6 DGs.

This sentiment is rooted in social, scientific, and medical constructions of difference between men and women, historically used to justify and maintain hierarchical social structures and the subjugation of women (Kapsalis, 1997; Laquerur, 1990; Martin, 1987; Martin, 1991; Rogers, 1966; Wooley, 1994). Laquerur, 1990). Early biological and medical assumptions about men and women were based on the premise that men “had penises because they were more nearly perfect,” (Wooley, 1994, p. 24), framing women in terms of absence, as “imperfect men” (Wooley, 1994, 25). Harkening back to Genesis (2:18, 22, NIV), “the basic paradigm was this: ‘Man is to woman as God is to man. Men are higher on the Great Chain of Being than women’” (Wooley, 1994, pp. 24-25).

Present day depictions of masculinity are still based on notions of power, strength, and sexuality, and “the penis and testes are signifiers of masculinity, with penile size representing status and power” (Bullen et al., 2010, p. 994). Indeed, the importance of the penis remains a

strongly held conviction. A recent article from *The New York Times* reported on an upcoming penis transplant on a wounded veteran. The article explains the utility of penis transplants for veterans. Quotes throughout the article echo the sentiments expressed in the ACS penile cancer DG:

“I think one would agree it is as devastating as anything that our wounded warriors suffer, for a young man to come home in his early 20s with the pelvic area completely destroyed” (Grady, 2015, quoting Dr. W.P. Andrew Lee, chairman of plastic and reconstructive surgery at Johns Hopkins).

“Our young male patients would rather lose both legs and an arm than have a urogenital injury” (Grady, 2015, quoting Scott E. Skiles, social work supervisor at the Veterans Affairs Palo Alto Health Care System).

“I don’t care who you are – military, civilian, anything – you have an injury like this, it’s more than just a physical injury” (Grady, 2015, quoting Sgt. First Class Aaron Causey).

“To be missing the penis and parts of the scrotum is devastating. That part of the body is so strongly associated with your sense of self and identity as a male. These guys have given everything they have” (Grady, 2015, quoting Dr. Richard J. Redett, director of pediatric plastic and reconstructive surgery at Johns Hopkins).

These excerpts align with the narrative constructed in the ACS’s penile cancer DG, with doctors quoted above using the terms “devastate” and “suffer” in common with the penile cancer DG. When such socially constructed notions of the penis show up in the language of prestigious medical institutions *and* individual medical practitioners, patients lose. Men who require amputation of all or part of the penis are likely to suffer under the additional weight of learning that science and medicine agree – yes, losing your penis is the worst possible thing, because,

apparently, it is “everything [you] have” (Grady, 2015, quoting Dr. Redett). While the penile cancer DG offers reassurance to patients using the language of hope, the constructed narrative of the guide indicates that it is against all odds.

Implications for The American Cancer Society

This study has found that the American Cancer Society’s female and male affiliated cancer patient detailed guides frame cancer patient subjectivity based on social stereotypes and assumptions about women and men. The narratives that develop within this context are narrow and one-dimensional. Thus, biological and medical information must be skewed or excluded in order for the guides to maintain their narratives. As a result, patients are offered biased and partial information regarding their bodies, treatments, and side effects, leading to potentially detrimental patient experiences, including isolation, shame, embarrassment, silencing, and unexpected health outcomes.

These findings align with research that has shown that “scientists do not simply read nature to find truths to apply in the social world. Instead, they use truths taken from our social relationships to structure, read, and interpret the natural” (Fausto-Sterling, 2000, p. 116). However, these findings are contrary to the American Cancer Society’s history and persona of benevolence, and threaten negative experiences and outcomes for patients who may rely on their literature as part of their information acquisition and decision-making processes.

The American Cancer Society’s patient detailed guides are updated on a regular basis. The most recent updates to these guides made two important changes that reflect the ACS’s intent to ensure that the information they provide is accurate, up to date, and unbiased. These changes were in line with two key factors discussed in my analysis and in this chapter. The most significant changes occurred in the cervical and penile cancer DGs.

Cervical. In their most recent revision, the ACS completely removed the “Avoid HPV exposure” section from the text. Instead, under the subsection “Things to do to prevent pre-cancers,” the document now offers a bullet point list that includes “Avoiding exposure to HPV,” “Getting an HPV vaccine,” and “Not smoking.” This revision eliminates the directive language (compare to “Avoid HPV exposure” and “Don’t smoke”), and also removes the directives that were in the body of the “Avoid HPV exposure” that told women to wait until they were older to have sex, limit their number of sexual partners, and to avoid having sex with someone who has had many partners. Furthermore, the elimination of this section removed language that made uncircumcised men seem dangerous. Most importantly, removing this section eliminated some of the culpability and shaming implied by the text.

The most recent revision also updated the “Smoking” risk factor in the risk factor section. Whereas the guide examined for this study informed readers of the harm caused by smoking, the most recent revision uses new language that implicates the patient in both her own and other people’s health. The new language reads, “When someone smokes, they and those around them are exposed to many cancer-causing chemicals that affect organs other than the lungs” (“Cervical Cancer Detailed Guide,” 2016, p. 5). While this information is true, this language was not updated in any of the other 6 DGs, and similar language is not present in the more extensive “Tobacco smoke” risk factors subsection of the non-small cell lung cancer DG (“Non-small cell lung cancer detailed guide,” 2016, p. 5), a section that addresses the impacts of smoking as well as the risk of patients’ exposure to second hand smoke.

Penile. Three significant changes were made. First, in revising the risk factors section, the first three risk factors were reordered from “Circumcision,” “Phimosis and Smegma,” and “Human papilloma virus infection,” to list the HPV risk factor first and rename the circumcision

heading. Thus, the new order is, “Human papilloma virus (HPV) infection,” “Not being circumcised,” and “Phimosis and smegma.” This reordering helps to emphasize the significance of HPV in penile cancer occurrence.

Second, a revision was made in the “Can penile cancer be prevented?” section. The introduction to this section more clearly addresses the improbability of circumcision preventing penile cancer in the U.S. The text states, “based on the low risk of this cancer in the U.S., it would take over 900 circumcisions to prevent 1 case of penile cancer in this country” (“Penile cancer detailed guide,” 2016, p. 8).

Finally, the “Effects on sexuality” tertiary section was moved up to a new subsection, “Long-term side effects of penile cancer treatment” (pp. 35-36), although it is still located under the “What happens after treatment for penile cancer?” By making this change, the “Effects on sexuality” section is no longer preceded by the problematic notion that partial or complete penectomy is worse than cancer death. However, that language is still present on page 39 of the most recent revision under the subsection, “How might having penile cancer affect your emotional health?” While separating the discussion of the long-term side effects of penectomy from the notion that “for many men [penectomy] seems worse than the disease” (“Penile cancer detailed guide,” 2016, p. 39) is a step in the right direction, the language remains problematic.

Recommendations for future revisions. Based on my analysis and research for this project, I recommend one key revision: Do away with gendered narratives. The analysis for this project showed that inconsistencies, partial information, and language issues were largely due to adherence to social and medical biases and assumptions regarding men and women. Rewriting sections of the DGs in order to eliminate these biases and assumptions would help to create a more comprehensive, dynamic, and useful tool for cancer patients.

While this recommendation does ask for gendered narratives to be removed, it does not ask for sex or gender to be ignored. For example, including information about sexuality in men's DGs that centers around their genitals, and including reproduction information in women's DGs that centers around their genitals and organs is important; however, assuming that men are especially sexual by nature, whereas, seemingly in opposition, women are especially reproductive by nature, excludes the fact that men are also reproductive, and women also sexual. Below are three specific recommendations that will help eliminate gendered informational issues prevalent in these DGs.

Recommendation 1: Ovaries, testicles, and the endocrine system. The definitions of the ovaries and testicles in the definitional section of the ovarian and testicular cancer DGs should be changed to reflect their overall function in the body. Defining the ovaries and testicles as “part of the endocrine system” as well as part of the female/male reproductive systems will allow the ACS to offer fuller, more comprehensive explanations regarding the functions of the ovaries and testicles. Such a change would help patients understand their bodies, conditions, and treatments more completely.

Recommendation 2: Focus on the people, not the penis. As previously discussed, all detailed guides focus on penile penetration when discussing sex. While including the penis in discussions of sex can be very useful for patients, information targeted at women should focus on women's bodies and women's health. Furthermore, the strict focus on the penetrative ability of the penis in the prostate and penile cancer DGs may increase feelings of anxiety, guilt, and despair in patients who cannot achieve erections or who have had part or all of their penis removed. Changing this focus will also allow the ACS to remove the problematic notion that penectomy may be worse than cancer.

The guiding information regarding alternative sexual activities offered in the penile cancer DG should be offered to all patients who undergo cancer treatments that may affect their sexual bodies, such as surgery or pelvic irradiation. Including such information for such patients will help to offer a more holistic view and approach to patient sexuality and coping with cancer related changes.

Recommendation 3: Reproduction and cancer risk. While it may be helpful for patients to have a full understanding about known risk factors, perhaps to be able to place blame somewhere, any reproductive choices that a woman makes is damning in at least one of the gynecological cancer DGs. While it may not be prudent to remove all risk factors related to reproduction, the ACS should take into account that each of those reproductively linked risk factors serves to tell women that they either did something wrong, or that they could/should have done something better. The ACS could consider eliminating only the risk factors related to the number of children a woman has had, as this is not something she can change in any way, or perhaps consider making it clear to patients that the children they have are not “lifestyle factors,” and explaining that a woman’s choice to utilize birth control is not what caused the cancer; rather, the chemicals in the birth control led to changes in her body which led to cancer.

By implementing strategies that help to eliminate gender bias in the ACS DGs, the ACS will continue its tradition of paving the way forward in cancer research, prevention, and information.

Limitations and Future Research

This project has several limitations. First, this project was highly selective. Only 7 American Cancer Society DGs were examined, and only certain sections of those DGs were

analyzed. Second, this study focused on representations of gender, excluding important discussions regarding representations of race, socioeconomic status, and age.

Third, the ACS DGs examined were updated during this project. This means that the most updated DGs available were not scrutinized.

The selections for this project were made with the goal of discovering what, if any, differences exist between the information offered to female vs. male cancer patients. Thus, texts written specifically for male or female audiences were chosen. Furthermore, the analysis sought to examine the intricacies of the texts, and was conducted as a close reading. The time spent on each line analyzed precluded a large sample.

In addition to limitations based on data selection, this study also selected to examine the texts through the lens of gender, ultimately ignoring other factors at play in the DGs, such as race, age, and socioeconomic status. These are all important factors that, like gender, have specific implications for patients. These areas require further research.

Finally, as should be expected, the American Cancer Society updates their information regularly, which includes documents published for patient use. Because of this, analysis was performed on texts that are no longer up to date, and this study did not offer a close reading of the newest versions of these texts. However, the ACS's continuous revisions offer researchers a chance to witness the evolution of ACS's approach to patient literature. This could provide an interesting long-term research opportunity in the areas of race, age, gender, and/or socioeconomic status.

I am interested in building upon this research to analyze other cancer patient literature in the future, including the ACS's breast cancer DG and additional breast cancer literature. In order to more efficiently examine such literature, I will implement the use of data analysis software to

help isolate themes and more efficiently detect specific occurrences of word use. Using such software would also allow for the scope of the study to be expanded.

Conclusions

Cancer patients need access to reliable sources of information, and, often, “patients want as much information as possible” (Jenkins, Fallowfield, & Saul, 2001). Such information helps patients understand their diseases, make informed decisions, and cope with side effects and changes resulting from cancer treatments. While medical institutions must make choices regarding what information is most important for patients to see, understand, and refer back to, they must also strive to offer a comprehensive, well-informed, and diligently informative guides designed to help patients through their cancer journeys. Returning once again to Bateson (1972):

In the next twenty years there will be other ways of saying it and, because the discoveries are new, I can only give you my personal version. The old versions are surely wrong, but which of the revised pictures will survive, we do not know. (p. 456)

While Bateson is referring to notions of the mind, the general principle applies here, too. New paradigms will allow for new ways of perceiving and, in turn, treating; and just as analysis, scrutiny, and a certainty that there must be a better, different, more correct way to do things has led to revisions in theories of physics, the continuous scrutiny of how things are done, and subsequent discussions regarding how they might be done better, will lead to increasingly better patient experiences and outcomes in the future.

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