"YOU HAVE HERPES. NOW WHAT?": STIGMA IN HEALTHCARE SYSTEMS AND DISCLOSURE RHETORICS

by

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Cultural beliefs about sexually transmitted infections, and herpes specifically, are rhetorically constructed and, crucially, the medical realities of such conditions do not often align with the socially constructed ones. This dissertation project explores how stigma and disclosure intersect with communication about sexual health between healthcare providers and their patients. Using a queer feminist methodology and a mixed methods approach, this research answers how healthcare providers are trained to communicate with patients about stigmatized conditions, how stigma impacts disclosure of sexually transmitted infection diagnoses, treatment information, and patient care, and what patients with sexually transmitted infections and technical communicators are doing and can do to intervene in the unjust rhetorical construction of sexually transmitted infections. Findings from semi-structured interviews with currently practicing healthcare providers suggest medical professionals lack access to robust communication training and often go without specific training on how to communicate with patients who have a stigmatized condition, which can have a negative effect on their interactions with patients. In response to this gap in communication and support, individuals with herpes have successfully created a community of both medical and experiential knowledge and support on the social media website tumblr, known as "herpblr." Ultimately, this dissertation theorizes

disclosure rhetorics as the process that informs how humans determine who, when, and how they disclose potentially stigmatizing information about themselves to others, and provides avenues for technical communicators to intervene on behalf of both healthcare providers and patients.

“YOU HAVE HERPES. NOW WHAT?”: STIGMA IN HEALTHCARE SYSTEMS AND DISCLOSURE RHETORICS

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by

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Chapter One: Rhetoric and Technical Communication and Stigma and Disclosure, Oh my!

> “There are certain things we know are impossible to get rid of—terrorism, herpes, and Guy Fieri.” – John Oliver, *Last Week Tonight*, Nov. 2015

Introduction

Prior to being diagnosed with herpes simplex virus II (HSVII), I had very little experience with sexually transmitted infections[1] (STIs) in general, and no one in my life had ever disclosed to me that they had had one. Sex and sexual health education was rarely discussed in either my family or school life beyond perfunctory guidance or scare tactics. I knew next to nothing about herpes from a medical standpoint and what I did know I had learned from popular culture, i.e. it is bad and you do not want it and it is acceptable to shame and/or mock people who do, and I certainly didn’t know about the existence of online groups like herpblr (the herpes community on the social media platform Tumblr, the site of inquiry in Chapter Four). In the months following my diagnosis, as I desperately sought the support and information I did not get from my doctor, the curious academic researcher in me began to consider what knowledge and cultural systems might have influenced my doctor’s diagnostic approach, and how other newly diagnosed patients experience their diagnoses and navigate their lives post-diagnosis.

In the West, cultural beliefs about herpes and other STIs are rhetorically constructed and, crucially, the medical realities of such conditions do not often align with the socially constructed ones. The disconnect between these two realities is therefore a rhetorical-technical problem. Further, healthcare providers occupy several roles in their practice: they are already highly

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[1] Although still used interchangeably, sexually transmitted infections differ from sexually transmitted diseases (STDs) in that, medically speaking, “infection” is broader than “disease” because it includes those conditions that often do not exhibit symptoms. For example, it’s common for individuals to exhibit no symptoms when infected with, say, human papillomavirus (HPV), just as it is uncommon for HPV to develop into the disease cervical cancer.

trained experts in their respective fields and specialties; they are learners required to add to their field-specific expertise at regular intervals in their practice in order to maintain licensure; and they are de facto technical communicators responsible for translating their knowledge to a lay audience of patients. Therefore, I believe, like Scott (2014) and Frost (2012), that such rhetorical constructions of risk can be damaging, and that rhetoricians and technical communicators are ideally positioned to intervene in these unjust rhetorical constructions. I aim to address how herpes and other stigmatized conditions are rhetorically constructed between healthcare providers and patients under their care in this project, which I ground in rhetoric and technical communication because of the potential for change offered by these fields especially. To do so, I use a queer/feminist approach to examine healthcare providers' training and experiences communicating with their patients, and patients' attempts to fill in gaps in their healthcare knowledge and experiences. This combined methodological approach enables me to situate stigma—a defining factor in cultural understandings of herpes and other STIs—as a concept to be troubled and subverted. Further this project works toward articulating rhetorics of disclosure that rhetoricians and technical communicators can use to help all parties create better provider-patient communication in potentially stigmatizing situations.

My primary research question for this project is "How do stigma and disclosure intersect with communication about sexual health, specifically sexually transmitted infections, between healthcare providers and their patients?" Under the umbrella of this question, and in order to better understand some of the nuances of health and medical rhetoric as it relates to stigma and STIs, I have drafted a series of related questions. These questions are:

- How are healthcare providers trained to disclose STI diagnoses and/or communicate with patients under their care about stigmatized conditions throughout their career?

- To what extent or in what ways does social stigma impact disclosure of STI diagnoses, treatment information, and patient care between healthcare professionals and patients under their care?
- How might rhetoricians/technical communicators positively intervene and/or mitigate negative social stigma in the communication/disclosure process of STIs between healthcare providers and patients under their care as well as between patients and their families, friends, sexual partners, etc.? What, if anything, are these groups already doing to make positive changes?

While each of these questions could be the subject of an entire dissertation, I find it important to consider them concurrently because they are intertwined, connected. Not only does my queer feminist orientation toward research allow me—indeed, compel me—to consider them in relationship to each other, so too does the field/discipline from which I write. Rhetoric itself has deep roots in cultures and contexts, and research from the field largely attends to the circumstances that inform a given research topic or site. Technical communication as a field, on the other hand, has only recently shifted away from predominantly uncritical research of technical communication practices in institutions and taken instead a cultural turn, as the editors of *Critical Power Tools* (2006) explore in their introduction. Because my research site lies at the intersection of cultural knowledge and institutional knowledge, the scope of my project must straddle these fields.

Rhetorical research can be, as Judy Z. Segal (2005) writes in her book *Health and the Rhetoric of Medicine*, either useful and/or applied (p. 4). Similar but not synonymous, Segal defines useful research as that which can help to understand certain persuasive strategies; by applied, she means research that can make said persuasive strategies more effective (p. 4).

Further, incorporating tenets of cultural analysis and awareness into the study and practice of technical communication has led to valuable critiques of assumptions and institutions previously untouched in the field. I intend for this research to be both useful and applicable to institutions, meaning it will interrogate the cultural and institutional rhetorical conditions leading up to and surrounding provider/patient communication about STIs. I will also suggest ways such communication can be improved upon based on my interpretation of the research I undertake for this project. While this means I will sacrifice some depth for breadth, I believe the sacrifice necessary in order to account for more variables and perspectives, to better understand how different discourses work (or do not work) together, and to be able to begin addressing the gaps in knowledge and communication. The mixed methods and queer feminist methodological approach I use to answer these questions is detailed in Chapter Two. In the remainder of this chapter, I bring together scholarship from rhetoric, technical communication, stigma, and health communication to argue that technical communicators are well equipped to intervene for the good of healthcare provider and patient alike. Along with a summary of each chapter, I also preview disclosure rhetorics, the process I theorize in Chapter Five that informs how humans determine who, when, and how they disclose potentially stigmatizing information about themselves to others.

Review of Literature

The foundations of our understanding of science and medicine in the West evolved from gendered ideologies, and it is therefore reasonable to assume that these ideologies can negatively impact how we approach discussions of sexual health, especially with populations already positioned at a disadvantage in the structures of health and medicine. In the context of this project, what the following rhetorical scholars reveal is the extent to which health and medical discourses reflect, and indeed reproduce, hegemonic structures already in our larger society, structures that we already know to be stigmatizing and therefore disenfranchising.

Rhetoric is often maligned for its hegemonic intellectual roots, which tend to be averse to change and progress and prefers instead the comfort of the way things have always been. As offshoots of the larger field of rhetoric, I see technical communication and the rhetoric of health and medicine as important sub-fields that have allowed scholars to take up the most useful bits of rhetoric proper and worked to negotiate and establish new boundaries for the field as a whole. Moreover, I see technical communication underpinning much of the rhetoric of health and medicine because folks who practice medicine are themselves technical communicators. Viewed in this way, it’s easy to see how the rhetoric of health and medicine dovetails with technical communication principles.

In the middle of her Introduction, Segal conveys a message from her mentor to help frame rhetoric as a frame of analysis in health and medical discourses: “you can start rhetorical investigation anywhere, and you can get everywhere from there” (p. 2). In the spirit of that message, rhetorical studies scholars have investigated society and culture, and the discourses that arise out of them, through critical examination of the power structures of society. Germane to the current project is the prevalence of masculinist bias from its ancient origins to how it appears in contemporary society.

Ruth Berman (1992) provides an accessible review of how bias worked its way into science discourses begins in the sixth century B.C. in her article “From Aristotle's Dualism to Materialist Dialectics: Feminist Transformation of Science and Society.” Her culturally contextual reading moves quickly through how the “great” thinkers throughout time, including Pythagoras, Plato, Aristotle, Bacon, and Descartes, could only understand their world and science through the lens of their time, location, and experience as white, well-funded males of the elevated or ruling social classes. She contends, along with many other scholars (Sauer 1994; Kleinman 1998; Wajcman 1991; Koerber 2000) that "science" as we know it can only be the "science *of* a given society" since scientific practices, and the discourses they produce, do not occur in a vacuum (p. 250). The privileging of white male perspectives, experiences, and knowledge over any others has been written into the foundations of society and, as such, created skewed ideologies and value systems which result in inequitable power structures.

Many in the field of rhetoric and technical communication, feminists in particular, have argued that these power structures inform our relationship to and place within society (Ahmed, 2006; Blair & Takayoshi, 1999; Hayles, 1999; Haraway, 2006; Hubbard, 2003; Tannen, 1996; Turkle, 2007). Our field has also explored how these structures affect our conception of self. Many queer studies scholars have added significantly to our understanding how such inequity plays out in (often intersectional) marginalized groups. For example, Nadine Hubbs (2014) asserts the musical preferences commonly associated with particular social classes often result in larger society incorrectly ascribing certain conservative and male dominated political identities onto said social classes in her book *Rednecks, Queers, and Country Music*. And Robert McRuer (2006) presents *Crip Theory* as a means to recognize the influence disability exerts in the cultural construction of "normal" bodies and sexualities.

The work done by these and other scholars essentially provide the very basis upon which this dissertation rests: cultural power structures are designed to include and exclude, to create in and out groups, and are therefore at the crux of the issues that result from stigma in healthcare (and other) contexts. Further, from a rhetorical perspective, the masculine biases present in the discourses of science and medicine manifest most clearly in the language, the words themselves, used in said discourse. As Pierre Bourdieu (1991) argues in *Language and Symbolic Power,* language is a medium of power which users adapt based on context which means all interactions retain aspects of social structures and work to reproduce them if used uncritically. For example, historian Ludmilla Jordanova (1999) contends in her chapter “Natural Facts: A Historical Perspective on Science and Sexuality” that the overtly sexualized language used by scholars during the Enlightenment brought about a concretizing of the fabricated nature/culture dichotomy in scientific discourse. This language often characterized nature as feminine and culture or science as masculine and, as such, nature could only be understood when examined, probed, unveiled by masculinist science (Jordanova, 1999, p. 158).

The Rhetoric of Health and Medicine

Falling under the broad umbrella of rhetoric, and an offshoot of the rhetoric of science, the rhetoric of health and medicine has been defined as “how specific symbolic patterns structure meaning and action in health and medical contexts and practices” (Keränen, 2012, p. 37, qtd in Melancon & Frost, 2015, p. 8). Rhetoricians, and even technical communication scholars, who study these patterns place an “emphasis on understanding the contextual situations of the discourse and understanding what those contexts (including language, place, people, and actions) mean for health and medicine” (Meloncon & Frost, 2015). One way rhetoricians have broadened our understanding of health and medicine is by turning a critical eye on the problematic assumptions embedded within our historical conception of these disciplines. Rooted in the seemingly unimpeachable ethics of the scientific method, health and medicine is often viewed as being the purely logical, impartial formation of facts delivered by its practitioners, who are, of course, beyond reproach (Derkatch 2016). Questioning those assumptions has revealed flaws in those foundational beliefs, particularly with regard to the effects of power and culture in the context of Western medicine.

Perhaps the most well-known scholar to illuminate these problematic foundations is social theorist Michel Foucault. In his book *The Birth of the Clinic: An Archaeology of Medical Perception* (1994), he argues that there were significant changes to medical discourses beginning in the late 18th century which effectively authorized the medical community to label citizens as normal or deviant based on their health status. Deviance from this new normal served as an impetus for medicalized, i.e. socially sanctioned, stigmatization. Since the “gaze” of the medical community is the “gaze that dominates,” Foucault argues individuals and communities lower on the socio-cultural rungs of power were denied the authority to label themselves and were instead labeled as deviants when they strayed from dominant patriarchal standards (p. 39).

Foucault’s work informs much of the scholarship relevant to the scope of this project, as what was labeled deviant by the medical community eventually became stigmatized by society at large. Jeffrey Bennett (2015), for instance, addresses and analyzes the complex rhetorical processes at work behind the initial banning of blood donations from men who have sex with men in the United States in his book *Banning Queer Blood: Rhetorics of Citizenship, Contagion, and Resistance*. The HIV/AIDS scare of that began in the 1980s begat the banning of such donations, but further digging by Bennett reveals connections between questionable science publications and government agencies that have kept the ban in place despite more credible sources refuting the need to keep it in place. His analysis touches on the rhetorical process by which men who sleep with men are seen as already contagious and whose blood is automatically considered a danger to the rest of the nation, thereby excluding them from full civic participation.

In the context of STIs broadly and herpes specifically, Robert E. L. Roberts (1997) furthers the work of Foucault in his survey of media representations of genital herpes and those who carry the virus through a close, contextually situated reading of 141 magazine articles published in the U.S. over the course of nearly three decades (1968-95) in his article "Power/Knowledge and Discredited Identities: Media Representations of Herpes." His observational data reveals that the majority of articles were written at a time when pharmaceutical companies were aggressively marketing anti-viral medications but before HIV/AIDS had made a significant impact on the larger culture. The data indicates that not only was genital herpes negatively characterized as a public health crisis as grave as plague and the logical consequence of a society more sexually liberated than it had been before, but that carriers of the virus were also discredited as physically ill and morally defective individuals who should be avoided at all costs (p. 275-76).

Technical Communication

Technical communication scholars have also made inroads toward understanding how the rhetoric of health and medicine plays out in healthcare contexts, mainly by way of special issues in the major journals in the field. For example, in her introduction to the special issue of the Journal of Business and Technical Communication published in 2005 titled “The Discourses of Medicine,” Ellen Barton writes “no other field focuses its research on genres and their interactions with professions…[or works] to uncover the constitutive relations between the details of language and the description of content and context in medicine” (p. 248). Amy Koerber and Brian Still wrote in their introduction to the 2008 special issue of Technical Communication Quarterly titled “Online Health Communication,” that they hoped to “not only to spark new conversation, but to provide a forum where these conversations could achieve the close focus necessary to develop even further and ensure that, as technical communication scholars, our contributions do not ultimately stay confined to the pages of our own specialized journals, but also might have a chance of being heard in the interdisciplinary realm" (p. 261-2). In their introduction to the 2015 special issue of Communication Design Quarterly, "Charting an Emerging Field: The Rhetorics of Health and Medicine and Its Importance in Communication Design," authors Lisa Meloncon and Erin A. Frost state their hope that the issue will "offer the opportunity for reflection on the breadth of the work being done in the rhetorics of health and medicine and how this emerging field is complementary to communication design" (p. 11). Elizabeth L. Angeli and Richard Johnson-Sheehan (2017) state that their purpose in putting together another health-specific special issue of *TCQ* from this year was to "explore the intersections and tensions between [the medical humanities and the rhetoric of health and medicine]...[and] to bring these fields side by side in a way that will open exciting new pathways for research, analysis, expression, and application in the field of technical communication" (p. 5)[2].

Other scholars in the field have made more substantial connections to TPC and health and medical discourses. For example, Beverly Sauer's (1994) discussion in "Sexual Dynamics of the Profession: Articulating the *Ecriture Masculine* of Science and Technology" of the sexualized jargon-based language in technical operator's manuals highlights the dangers of relying on sexual metaphors to instruct workers in the operation of machinery. T. Kenny Fountain's (year) *Rhetoric in the Flesh: Trained Vision, Technical Expertise, and the Gross Anatomy Lab* is an excellent example of this process. His dense ethnographic approach to understanding how medical students professionalize in the anatomy lab illuminates how discourses become

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[2] I see my work as contributing to the medical humanities and, while I pull from research that could be considered situated there, I do not consider it a discrete area that is necessary for my foundational work for this project.

embodied and put into action, which eventually results in expertise. Most pertinent to the current project on stigma and medical rhetoric is Fountain's assertion in Chapter 6 that the rhetoric used in anatomy lab discourses "facilitates a certain formation of clinical attachment," wherein the student comes to see their cadaver primarily as useful to their training rather than a former living person (p. 150). This rhetorical process that favors a detached discourse, especially at such an early stage in professionalization, could account to some degree for why some healthcare providers struggle to empathize with their patients, especially those with stigmatizing conditions.

Further, J. Blake Scott (2014) leverages Foucault's theorizing of discipline and a robust rhetorical/cultural studies approach to argue throughout his text *Risky Rhetoric: AIDS and the Cultural Practices of HIV Testing* that the rhetoric of HIV testing functions as a way to shape an individual's subjectivity in relation to hegemonic values and, further, that this rhetoric has negative material impacts on those whose subjectivity is shaped as risky as a result of a positive HIV test (p. 9). Scott looks at public health discourse and pedagogy, clinical experiences, public debates of laws requiring expectant mothers and their infants to undergo mandatory testing, and at-home HIV tests, the rhetorical processes of each he argues is used to discipline and exclude at risk bodies in ways that do more harm for the larger public than good. His final chapter articulates a response-based intervention strategy that he believes will be more useful than current practices because it emphasizes the need to contextualize risk and to involve all citizens in this process.

Technical communication, working within the scope of rhetoric and the rhetoric of health and medicine, is ideally situated to investigate systemic issues that negatively affect a given population because our field draws on an "extensive repertoire of methodological approaches [such as] developing our own combination of ethnographic studies of the workplace and textual analyses" (Barton, 2005). By virtue of our theoretical and experiential expertise, I believe technical communication scholars can intervene in many of the moments that lead up to an interaction between provider and patient about a stigmatized medical condition.

In the context of my project, however, the major issue in the respective bodies of research discussed above is that there is very little in these fields, barring Scott, that connects the human parties involved in, addresses the socio-cultural/institutional constructs that impact this sphere of communication, and provides feasible solutions based on evidence from both provider and patient. In the course of reviewing literature, it became clear that no one field has everything I need to ground this research. In that context, and because I intend this project to be both useful and applicable, I find reason to bring into conversation scholarship on stigma, healthcare communication, and disclosure.

Stigma

The Oxford English Dictionary cites the first use of stigma in the 16th century based on a literal mark of disgrace forcibly and visibly conferred onto one's body as a sign of deviation from certain cultural values, i.e. slaves, criminals, traitors: "impressing a painefull stigma, or caracter in Gods peculiar people" (OED). Separate from concepts like stereotypes, prejudice, or disgrace, the nature of stigma has been a topic of study for researchers in a number of fields. Although once thought to be a reflection of one's personality (Adorno, Frenkel-Brunswik, Levinson, & Sanford, 1950), sociologist Erving Goffman defines stigma in his text foundational work, *Stigma: Notes on the Management of Spoiled Identity*, as "an attribute that is deeply discrediting" by the standards of a given society (p. 3). Most scholars in sociology, psychology, and related disciplines now agree that stigma is culturally determined (Neuberg, Smith, & Asher, 2000) and assigned to an individual or group by another to negatively define and classify in order to protect the larger social group. As Goffman states:

> “By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma-theory, and ideology to explain his inferiority and account for the danger he represents...We tend to impute a wide range of imperfections on the basis of the original one... (p. 5).

In other words, stigma is a character attribute/part of one’s physical or social identity, visible or otherwise, that a given social group has deemed undesirable or deviant, so much so that said group feels it is acceptable to devalue and exclude from certain social interactions those who exhibit a particular stigmatizing attribute or condition. A stigmatized person is seen as a danger, not unlike the HIV/AIDS patient. For the purposes of this project, I use Jenell Johnson’s (2010) rhetorically based definition of stigma from her article “The Skeleton on the Couch: The Eagleton Affair, Rhetorical Disability, and the Stigma of Mental Illness”: “the active rhetorical propagation of community norms and values coupled with the demand for visibility” (p. 475). For the purposes of this project, the community norms and values being propagated are those concerning the prohibition of discussing sexual health and STIs while simultaneously ostracizing and shaming those “visible” (or not) individuals who do discuss sexual health or have an STI.

Stigma is vital to this study because of its relationship to shame, as well as to healthcare communication, disclosure, and health outcomes by extension. The damaging effects of stigma inform, and sometimes undercut, our ability or willingness to be vulnerable and connect with others; that is, the effects of stigma are both affective and physical. For example, Goffman also defines stigma as the shame someone experiences when they feel they do not or will not meet another’s cultural standard for morals, behavior, beliefs, physical attributes, etc. (p. 2,3). Feelings of shame often mean that individuals conceal, or choose not to disclose, that part of their identity to others, including healthcare professionals, out of a fear of rejection. For example, Jeffrey Q. McCune, Jr.'s (2014) analysis of African American men on the "down-low," i.e. having sex with men while maintaining a heterosexual public personal, in *Sexual Discretion* traces the complex ways society censors AA men's behavior while placing immense pressure on individuals to perform masculinity in public to avoid rejection.

Methodologically, stigma provides an avenue in which to delve into why and how healthcare providers and patients communicate the way they do about stigmatized conditions like STIs. Coupled together with an emphasis on preventing STI transmission (risk as opposed to crisis[3]), stigma surrounding STI discourses is both overblown and firmly rooted in our cultural psyche. The origins of STI stigma in the West is complex and inherently tied to religious/puritanical beliefs about the forbiddenness of sex. Terri D. Conley, Rosemary A. Jadack and Janet Shibley Hyde (1997) argue in their article "Moral Dilemmas, Moral Reasoning, and Genital Herpes" that "in many religions, including traditional Judaism and Christianity, sexual behaviors can determine whether a person is considered moral or immoral" (p. 256). Therefore, the authors contend, "People who have acquired STDs are often viewed as immoral because of the disease itself or what they did to acquire it" (p. 256). Such views are especially hard on women, as Ruth Hubbard's (1990) analysis of health discourses pertaining to sexuality reveal. In her book, *The Politics of Women's Biology*, Hubbard shows how Christian overtones paint sex as sinful, and women as either sacred mother or tainted whore (p. 130). And in her

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[3] For the purposes of this project, I focus on crisis communication as opposed to risk communication. I define risk communication as that which emphasizes avoidance and prevention, and crisis communication as that which is useful only during or after a "worst case scenario" event, such as being diagnosed with an incurable STI. One of critiques I explore in Chapter Four is that people try to redirect crisis STI communication back to risk STI communication.

book, *Dirty Words: The Rhetoric of Public Sex Education, 1870-1924*, Robin E Jensen (2010) states that "discourse about public sex education in the contemporary United States is driven by ambiguous language and produces programs that fail to foster sexually healthy individuals" to this day (p. 159).

Although we know that more knowledge about a certain stigma does not equal more acceptance, the way our society communicates information on traditionally taboo topics like sexuality and sexual and reproductive health does not help to reduce the stigma surrounding these topics. One issue regarding how stigmas are communicated that this project addresses is what's called anticipatory socialization. Similar to Fountain's discussion of how medical students professionalize in the gross anatomy lab, anticipatory socialization happens when an individual assimilates into a new social group. We all go through anticipatory socialization at various points in our life, and it is this process that healthcare students go through as they navigate the formal institutions of medical/nursing/pharmacy school, then preceptorship and training as interns and residents in clinical settings as they become a full-fledged healthcare provider. This socialization is in addition to the other cultural messages they have absorbed in the time before attending medical/nursing/pharmacy school, like those Roberts described regarding herpes in the media. One part of this research focuses on that assimilation, specifically how practicing healthcare providers learned and continue to learn how to communicate with patients under their care.

In her conclusion from "The Skeleton on the Couch," Johnson states that combating stigma requires a focus on the rhetorical environment, i.e. the values and practices that uphold and perpetuate stigma. Stigma can be studied, researched, and its effects mitigated or removed from a society altogether. Once something is defined as rhetorical, i.e. socio-culturally constructed, as stigma is, then it can then be intervened rhetorically. The aim of this project is to explore/interrogate potential avenues for such intervention, specifically health communication/education and disclosure.

Health Communication

The field of health communication underwent a paradigm shift in literature that marked the turn away from old school paternalistic communication norms and towards what has been coined "patient-centered care" (PCC). Though PCC had been in the health communication ether for some time, there are two articles in particular, both published in a 1997 issue of the journal *Health Communication*, that seem to have prompted and laid the foundations for this shift: Keith Bennett and Harry Irwin's "Shifting the Emphasis to 'Patient as Central': Sea Change or Ripple in the Pond?" and Marsha L. Vanderford, Elaine B. Jenks, and Barbara F. Sharf's "Exploring Patients' Experiences as a Primary Source of Meaning."

In a patient-centered communicative healthcare model, as theorized by Bennett and Irwin, healthcare providers' consideration of "the diffuseness of power relations...allows patients to 'reclaim' their health care and challenge the traditional dyadic focus of much health communication" (p. 86). Further, patient-centered care also requires that healthcare providers question the "power and knowledge connection that contribute to the exclusion of the patient voice" (p. 89) in ways similar to rhetors who investigate the rhetoric of health and medicine. They also claim that "decision making and the creation of a co-equal role for patients is a primary way to redress imbalances within health care and its power structures and institutions" (p. 91). Vanderford, Jenks, and Sharf (1997) explain the idea that patient's narratives and experiences are necessary in the context of health communication. They propose that conceiving of patients as "active interpreters, managers, and creators of the meaning of their health and illness" means that healthcare providers will need to modify their assumptions about patient's experiences and their own views of stigma (p. 14). Two of the assumptions associated with the patient-centered care model of communication are that "patients' experiences matter" and that those experiences "must be understood in context," which includes understanding a patient's support networks (p. 14, 16).

Since the publication of those two articles, research in PCC has grown to include a more refined definition. Melissa Bekelja Wanzer, Melanie Booth-Butterfield, and Kelly Gruber (2004) define PCC as "the array of communicative behaviors that can enhance the quality of a relationship between the health care provider and patient, or the patient's family" in their article "Perceptions of Health Care Providers' Communication: Relationships Between Patient-Centered Communication and Satisfaction" (p. 364). Their study revealed "that improving 'friendliness' and reducing uncertainty for parents by using personal introductions, clear instructions and explanations, incorporations of warm immediate nonverbal cues, communicating empathy, and listening effectively were associated with enhanced satisfaction" (p. 377).

One reason for this shift is due to the fact that health communication scholars have known for some time that stigma negatively impacts health outcomes. Research indicates that people with stigmatized conditions like STIs are less likely to seek help or change behaviors that put them and others at risk, and more likely to suffer from mental health issues as a result of the stigma they experience (Lichtenstein, Hook, & Sharma 2005; Connor-Greene 1986; Mark, Gilbert, & Nanda 2009). In their article "Public Tolerance, Private Pain: Stigma and Sexually Transmitted Infections in the American Deep South," Lichtenstein, Hook III and Sharma (2005) concluded that "STI-related stigma is constructed in a local moral world and its influence on treatment, screening, and partner notification" impedes people from accessing health care and disclosing their status to partners (p. 54). And agencies dedicated to improving health for wide swaths of the population have reported stigma to be a primary impediment to seeking treatment and support for medical conditions (U.S. Department of Health and Human Services, 1999; World Health Organization, 2001). In fact, the inability and/or unwillingness—often because of material consequences—to disclose a stigmatized condition is a primary framework I use to examine the question of how rhetorical interactions between healthcare providers and their patients impact possible outcomes.

Disclosure Rhetorics

Psychologist Sidney Jourard (1971) acknowledges in *The Transparent Self* that "there is probably no experience more terrifying than disclosing oneself" (p. 31). However, he also theorizes that choosing not to disclose results in various maladies, both physical and psychological, and delves deeply into how disclosure can function not only from a patient's perspective, but also for healthcare providers. He delves into the "socialization factories," e.g. schools, families, and other institutions, that churn out citizens before turning to the benefits of disclosing, particularly concerning the relationship between healthcare providers and patients under their care. He argues that for healthcare providers to grow beyond the "technical expertise" of their field, they must undertake "a rehumanizing process" (p. 178) which includes learning how to recognize and cope with the anxieties that inhibit self-disclosure in themselves and patients under their care (p. 193). This re-humanizing is, of course, rhetorical.

If stigma is socially, i.e. rhetorically, constructed by a community/culture in order to perpetuate and/or preserve dominant social structures, then disclosure is the natural, obvious result or consequence of stigma. There would be no need to keep secret a potentially stigmatizing personal attribute unless the threat of rejection (stigmatization) loomed large and frightening. Psychologists have varying ideas regarding the hows of disclosure, from the need for privacy to the setting of boundaries, but the general agreement is that humans have a process by which they determine when, to whom, and how much to disclose of themselves to the people in their lives, from loved ones to doctors. The process I theorize for this project will be rhetorical in nature and will move rhetorical scholars of health and medicine and technical communicators toward a more sophisticated understanding of disclosure rhetorics with the goal of intervening in unjust patterns caused by stigma.

Chapter Previews

In this dissertation, I theorize disclosure rhetorics as a way of re-framing discussion of stigma within the fields of rhetoric, technical communication, and the rhetorics of health and medicine. This exploration is aimed at the research questions that appear earlier in this chapter; more specifically, it is aimed at better understanding how healthcare providers are trained to disclose (diagnose) stigmatized conditions, how stigma affects patient-provider communication, and how we—rhetoricians and technical communicators—might intervene in the interest of more socially just disclosure practices.

This chapter introduces the whole project, provides the primary research questions, and presents a review of literature that brings together disparate areas of study while firmly situating it within the field of rhetoric and technical communication. As you just read, I also argue in this chapter why technical communication scholars like myself are ideally suited to intervene in matters concerning technical/rhetorical issues, regardless of the field of study.

Chapter Two outlines the research questions and details both the methodology and methods that guide this research. This project is grounded in contemporary queer and feminist theories and methodologies, and I discuss the importance and value each of these theories afford the research project. Discussion of the different research sites and analytical methods are inextricably connected to methodology and thus are also included in this chapter.

Chapter Three presents relevant quotes and findings from the semi-structured interviews I conducted with currently practicing healthcare providers. The seed questions I use are meant to understand how these healthcare providers specifically are/were trained to communicate with patients in general as well as with patients who have stigmatized medical conditions. The interviews cover specifics regarding each providers' academic training in a formal university setting and in clinical settings along with a discussion of their continuing education as providers in a rapidly changing healthcare field. Nurses and nurse practitioners make up the majority of the participant pool, however I also interviewed a pharmacist and a medical doctor.

While Chapter Three is aimed at examining medical professionals' understanding of stigma, Chapter Four focuses on patients. This chapter is a review and content analysis of posts from the social media website Tumblr that have been tagged Herpblr, the portmanteau of Tumblr and herpes used by members of the Tumblr community who have been diagnosed with herpes. I am interested in cataloging what kinds of posts these users make, paying close attention to instances of users exhibiting technical communication skills in posts and comments regarding their diagnosis, disclosure practices, and other relevant topics.

Finally, Chapter Five outlines disclosure rhetorics and offers solutions, research sites, and potential analysis methods for future research.

Chapter Two: Methodology and Methods in Two Parts

> “This place, it smells like stripper’s perfume….we could get herpes just by sitting on this couch!” – Brian Bretter, played by Bill Hader, *Forgetting Sarah Marshall* (2008)

Introduction

As explained in Chapter One, the fields of rhetoric and technical communication have explored one of the connections between medicine and the humanities by turning a critical eye on the problematic assumptions embedded within medical discourse and practice. One issue has been the impact stigma has on communication practices between healthcare providers and their patients, an issue that has also been explored in the field of health communication. On the issue of sexual health, no one field or discipline has done enough to connect the human parties involved in, address the socio-cultural constructs that impact health communication, and provide feasible solutions based on evidence from both sides of the communicative coin. I believe rhetoricians and/or technical communicators can ably intervene in many of the moments that lead up to an interaction that may perpetuate STI stigma between provider and patient. My research aims to both bridge this gap in the field and eventually enact pedagogical and rhetorical change, to influence practice, for the benefit of all parties—and especially patients—rather than languish in a corner of an academic journal no medical provider will (think to) read. I operate from a queer feminist methodology to demonstrate that rhetoricians and technical communicators have a responsibility to address medical miscommunication issues and particularly those that arise from stigma related to sexual health.

Methodology

Western thought privileges logic, the scientific method, and the authority of institutions and many of the people who inhabit them, all of which align with/stem from patriarchal society. Berman (1992), for example, reveals how bias (which begets stigma) worked its way into science discourses beginning in the sixth century B.C. with Pythagoras, Plato, Aristotle, Bacon, and Descartes. She contends these “great” thinkers could only understand their world and science through the lens of their time, location, and experience as white, well-funded males of the elevated or ruling social classes (Berman, 1992, p. 250). Research methodologies in academic fields in the West have consequently privileged the same things, i.e. the perspectives and experiences—and attendant theoretical approaches—of white middle/upper class men. The introduction and subsequent use of feminist and queer research methodologies, upon which my research is grounded, challenges the assumptions inherent in this long-standing worldview and helps researchers, feminist/queer identifying or otherwise, avoid reproducing patriarchal ways of knowledge and knowledge production. An especially relevant example comes from Mara’s (2010) study of the “nonneutral terms and arguments” used to justify mandating female students be immunized with Gardasil, which protects against just four of the 200+ known human papilloma viruses, prior to admission into the sixth grade (p. 126).

From Chapter One, the work of Jensen (2010), Scott (2014), Fountain (2014), and Bennett (2015) in the fields of rhetoric and technical communication reveal ways in which powerful institutions like scientific and governing bodies can reinforce stigma and/or exclude stigmatized populations from access to fully realized civic participation. Additionally, in communications and sociology respectively, Johnson (2010) and Roberts’ (1997) scholarship examines the larger social forces at work that uphold and perpetuate stigma in public discourse and media representation. The work of the scholars above, and others from Chapter One, demonstrates how contemporary feminist and queer theories and research methodologies disrupt the status quo, subvert dominant ideologies by making apparent the realities of individuals who do not, in some or all ways, fit the hegemonic mold. Their work is especially relevant to this study and important to me because each has turned a critical eye on certain problematic assumptions embedded within our historical conception of health, medicine, stigma, and more. What their work collectively shows is that the power structures and hierarchies in place are detrimental to the health and welfare of bodies that exist outside standardized definitions of normal, i.e. cis-gendered, neurotypical, white, middle/upper class males, including those with STIs. Importantly, this snapshot of scholarship also represents where the field of rhetoric and technical communication often falls short in offering solutions to address the issues uncovered by the research of the field. The queer feminist methodologies and methods I use to investigate my research question allow for a nuanced and wholistic study, including a concrete path towards addressing this issue.

Contemporary feminist and queer methodologies are vital to conducting this study since illness by definition breaks from culturally standardized definitions of “normal” or “healthy,” and because any discussion of sex or sexual health is laden with the prevailing sociocultural baggage of the moment. That is, sexual behavior is often perceived to be connected to moral behavior, and so an individual’s decisions about sex become moral decisions and can therefore be used by others to determine the morality of said individual. Our cultural knowledge and how we as a society communicate about illnesses transmitted sexually exist at the intersection of multiple stigmatizing identity markers, like gender, race, and socioeconomic status, and as such require rhetorically sound technical communication methodologies that can ably address their systemic and multifaceted nature.

To begin, I turn to Karen Foss, Sonja Foss, and Cindy Griffin’s (2006) introduction to *Readings in Feminist Rhetorical Theory* for my definition of feminism: “the effort...to eliminate relationships of domination, oppression, and elitism and the creation instead of relationships of self-determination, affirmation, mutuality, equality, and respect" (p. 2-3). The authors state later in their introduction that feminist rhetorical practices are those that transform and/or disrupt traditional communication concepts like power, credibility, rationality, and even the very function of rhetoric (Foss, Foss, & Griffin, 2006, p. 5). One way scholars in rhetorical and technical communication do this work is to find and bring to light stories and perspectives from groups of people that are often left out of the official record of history, groups which are often made up of women and other minorities (Ehrenreich & English, 1973; Kramare, 2006; and McIntosh, 1989). Patricia Lather and Chris Smithies' (1997) express purpose in conducting and publishing their book *Troubling the Angels: Women Living with HIV/AIDS* is to provide information and support to women with HIV/AIDS, inspire other women to advocate on their own behalf, and to increase public awareness of the existence and particular needs of this population (p. xiv). These practices exist outside of academia, too, like the creation of groundbreaking work like *Our Bodies, Ourselves*, which was developed in response to the specific needs of women who wanted more information about their biology and bodies that the medical establishment had heretofore ignored (Wells, 2010). Further, since the nature of my research requires I look to other fields to address the larger cultural factors at play, sociologists theorize the power inherent in language and other sign systems themselves (Bourdieu, 1991), and investigate specific discourses rooted in the power structures of society (Foucault, 1978, 1994).

Methodologies that embody feminist rhetorical practices are those that have an awareness of and work towards undermining traditional communicative power dynamics and structures by emphasizing non-white male knowledge and experiences, making meaning collaboratively, and using narrative and personal experience as evidence, among many others (Kirsch and Royster, 2012; Sontag, 1001; Koerber, 2000; and Lay, 1991). Moreover, Sonja Foss and Cindy Griffin

(1995) state that invitational rhetoric “allows for the development of interpretations, perspectives, courses of action, and solutions to problems different from those allowed in traditional models of rhetoric” (p. 16). Cheris Kramarae (1989) argues along the same lines in her article, “Feminist Theories of Communication,” stating that many “feminists recognize that there is not a single human way of understanding” and so often “welcome a plurality of perspectives” (p. 40). Additionally, one of the earliest works to advocate for feminist research methodologies in technical communication was Mary Lay (1991) in her article "Feminist Theory and the Redefinition of Technical Communication." She argues that feminist theory and methods are necessary in the field because of its close ties to the masculine biased discourses of technology and science (Lay 1991). She argues that adding methods like ethnography, which parallel feminist concerns regarding the subjectivity of the researcher, pays special attention to the silences and gaps present in communities, and emphasizes the values and lived experiences of community members (Lay 1991).

As was the case in the review of literature in Chapter One, no one theory or methodology is sufficient to address the entirety of my research. Feminist methodologies and methods, though near and dear to my heart, still often embrace a dichotomous worldview and can be limiting in their ability to interpret complex systems and networks, much less provide solutions. In order to avoid the possibility of (re)producing research that relies on and perpetuates binary assumptions, I am also grounding this research in queer methodologies. Queer methodologies are “any form of research positioned within conceptual frameworks that highlight the instability of taken-for-granted meanings and resulting power relations” (Browne & Nash, 2010, p. 4). In other words, queer theories are well suited to accessing, critiquing, and proposing change in the kinds of formalized knowledge-making institutions like medical school and hospitals that constitute my research sites. Moreover, as discussed in Chapter One, to disclose is a renunciation of cultural norms and values, a queer act, and thus queer theories are required to conduct this research.

One example from the field of gender studies and queer theory is Jack Halberstam's (2011) *The Queer Art of Failure*. Halberstam queers the concept of failure in order to suggest that failing should not necessarily be avoided but rather deemed another valid way of knowing and being in the world (2011). He also claims that failure as an artform is "a way of refusing to acquiesce to dominant logics of power and discipline and […] a form of critique. As a practice, failure recognizes that alternatives are embedded already in the dominant and that power is never total or consistent" (Halberstam, 2011, p. 88). Sarah Ahmed's notions of orientation/positionality/space/location, intersections, and one's lived experiences from *Queer Phenomenology: Orientations, Objects, Others* is another example of how queer methodologies can work to disrupt standard perceptions of reality. Of particular interest to the scope of this dissertation is how Ahmed's work can help in making meaning of what it means to inhabit a body that is not oriented or in line with the invisible norm with regard to STIs and, consequently, how to create new lines and shift orientations. In sum, queer methodologies aid me as I both navigate a very personal research topic and work to find solutions that might be applied to this issue broadly.

Using these methodologies allows me to understand a slice of healthcare providers' education and patient experiences from a non-patriarchal, non-hegemonic perspective while in pursuit of a more nuanced, equitable, and robust understanding of stigma and disclosure rhetorics. These theories provide a framework that allows me to bring together the various strands of my research into a cohesive and productive whole that addresses the gaps in literature and practice. Feminist methodologies are crucial to this study because it is important to foreground the experiences, voices, and needs of all persons involved. Queer methodologies are equally crucial to subvert and critique the assumed authority of the medical community and address the lack thereof afforded to the embodied experiences of patients with stigmatized illnesses/STIs. Additionally, drawing from Rapp (1999), contemporary and queer methodologies affords me the opportunity to theorize the affordances of my own positionality and life experience in the context of this research.

Grounding this research in these theories also means that I can expand the scope of who is traditionally considered to be a “healthcare provider.” I define healthcare providers as doctors, nurses, and pharmacists, all of whom regularly interact with patients, in some cases far more than primary physicians themselves, and who can have a significant impact on the dismantling or perpetuation of the stigma a certain illness might have. People with stigmatized conditions are less likely to seek help or change behaviors that put them and others at risk, and more likely to suffer from mental health issues as a result of the stigma they experience. As rhetoricians, we have the skills necessary to bridge the gaps between healthcare provider and patients created by stigma, and I would argue that we have a responsibility to do this work.

I can imagine this work extending to address similar/related issues experienced by those with stigmatized identities. In the realm of healthcare, for example, my approach could be used to address the same issue with different populations, i.e. miscommunication in women’s healthcare, LGBTQ healthcare, healthcare for people of size that stem from stigma. Additionally, it could address issues surrounding disclosure and miscommunication in broadly stigmatized communities, such as communities of color, LGBTQ communities, differently abled communities, and many others.

Research Question

Rather than simply rearticulating my research questions from Chapter One, Table One below provides my primary research question and the sub-questions, which I have developed toward better understanding the nuances of health and medical communication. While the implications of my project extend across a number of fields – biomedicine, communication studies, feminist and queer studies, and more – these questions are aimed at aligning my project within the fields of rhetoric and technical communication because rhetoricians and technical communicators are uniquely positioned to fill some of the communicative gaps that provide the urgency for this dissertation. The specific research method I use to answer/address each sub-question is provided as well, and I map my reasons for matching each method to its associated question below.

How does stigma affect communication and disclosure practices about sexual health, specifically sexually transmitted infections (STIs), between healthcare providers and their patients?	
Sub-Question	**Research Method**
How are healthcare providers trained to disclose STI diagnoses and/or communicate with patients about stigmatized conditions in their academic institutions?	Semi-Structured Interviews with Seven Currently Practicing Healthcare Providers
To what extent and in what ways does stigma impact disclosure of STI diagnoses and treatment information between healthcare professionals and their patients?	
How might rhetoricians positively change the negative impacts of stigma in STI disclosure between healthcare providers and their patients? What, if anything, are these groups already doing to make positive changes?	Content Analysis of Herpblr Posts on Tumblr

Table 1: Primary and Sub Research Questions and Corresponding Research Method

Methods

To answer my research question, I utilize three sub-questions in order to triangulate my findings and increase the reliability of my conclusions. Because I utilize multiple questions which each require different measures, I engage a mixed methods approach to ensure satisfactory cogency for my study. First, I interview practicing healthcare providers and analyze transcripts for patterns and differences among and between provider experiences. I also conduct content analysis of the rhetorical and strategies used on Herpblr (the herpes community on the social media platform Tumblr, the site of inquiry in Chapter Four), paying specific attention to posts that discuss first-hand patient experiences with physicians as well as other rhetorical contexts involving disclosure. Investigating these two discourses using these distinct methods is necessary in order to adequately account for healthcare provider experiences and perspectives, patient experiences and perspectives, and the environments and wider cultures that shape them. These methods, essentially rhetorical criticism, via the attendant methodologies detailed above, allow me to make apparent and so critique the hierarchical systems that influence healthcare provider-patient communications surrounding illnesses transmitted sexually. Although analyzing this combination of discourses does not afford me the ability to make causal arguments, I am able to identify and make sense of points of congruence and disjuncture between and among the interviews with healthcare providers and Herpblr posts from Tumblr. In other words, these discourses allow me to trace the extent to which they seem to be connected to, or disconnected from, each other and argue for ways rhetoricians can positively intervene at points along this thread.

First, I conduct semi-structured interviews with seven healthcare providers who are currently practicing in order to understand how these individuals have been trained to communicate with patients about stigmatized illnesses/STIs, especially when disclosing a diagnosis or providing treatment information, in both academic and hospital settings. I ask each participant for relevant background information about themselves, such as their age, where/when they attended college, their position/title and how long they have been in said position, the geographic location in which they currently practice, etc. Then I use the following seed questions to conduct a semi-structured interview:

- How do you approach communication with patients who have a stigmatized illness/STI?
- How were you trained to communicate with patients about stigmatized health issues like STIs in traditional academic settings? Since you've graduated and began practicing in your profession?
- Now that you're practicing/technically no longer a student per se, what if anything do you wish you had been taught about how to communicate with patients who have a stigmatized illness/STI in traditional academic settings? In real life healthcare contexts, i.e. an internship, residency, etc.?
- What sorts of curriculum/other kinds of training do you think should be used now to train new/incoming healthcare providers to more effectively communicate with patients who have stigmatized illnesses/STIs?
- Can you describe a situation when you feel you did a good job/bad job communicating with a patient who has a stigmatized illness/STI? What was the experience like? What communicative strategies do you use that seem to be most effective for these patients?
- What else would you like to add about communicating with patients or anything else that we've covered?

My choice of semi-structured interviews aligns with the feminist methodology grounding this research. Feminist research methods are those that foster "openness…and the development of a potentially long-lasting relationship," striving for intimacy with research participants rather than scientific objectivity and detachment (as cited in Reinharz, p. 27). Semi-structured interviews allow for the research question to drive the interview, as opposed to a method like a questionnaire which would likely yield fewer personalized responses, for a discussion of reciprocity between interviewer and participant, and for the possibility of a mutually beneficial professional relationship. Further, Sonja Foss and Cindy Griffin (1995) articulate in their article "Beyond Persuasion: A Proposal for Invitational Rhetoric" for "the potential of the audience to contribute to the generation of ideas" (p. 16). In my interviews, I work closely with each participant to collaboratively make meaning of their experiences, to formulate a plan for following up with each participant should any part of this project become helpful or relevant for them, and to maintain their anonymity. I also give each participant the chance to expand upon their comments in the days following the interview and plan to share with them my analysis of their interview.

The interviews with healthcare providers give me access to firsthand accounts of the various methods used to train healthcare providers on issues of communication and/or stigma. My analysis of the interview transcripts works to determine rhetorical trends that indicate how these healthcare providers understand stigma and communicate with patients about conditions that one or both parties know are stigmatized. My analysis also addresses the academic or clinical context in which many of these experiences and practices occur. I extrapolate how these practices might impact patients with stigmatized illnesses/STIs. Based on my analysis in this chapter and throughout the project, I argue that how a healthcare provider discloses a diagnosis or treatment information (and behaves in general during those important moments) has a serious impact on how patients receive that diagnosis and information, how they learn to disclose to those around them (or not), and if/to what extent they might negatively internalize a diagnosis. Also, these providers might be negotiating how cultural stigmas are shaping patient receptivity, so perceptions of stigma are shaping their interactions just as their interactions are shaping patients' self-perceptions of stigma. I also make apparent the connections and/or disconnections among these providers' perspectives and experiences.

And second, I review and conduct content analysis in the tradition of feminist rhetorical and technical communication researchers (Thompson, 1999) on relevant posts from the social media website Tumblr that have been tagged as belonging to the Herpblr community, paying close attention to those posts regarding disclosure and communication. Herpblr posts are coded to determine rhetorical trends generally as well as rhetorical moves in the disclosure process specifically. Since these posts contain elements of technical documentation, I treat the authors of the posts I analyze as technical communicators with relevant experiential knowledge whose work may offer solutions to issues of disclosure specifically, and healthcare provider/patient communication broadly.

These Herpblr posts give me access to how patients with herpes discuss their experiences with the virus and how this largely anonymous online community works to subvert in important ways the authority traditionally ascribed to healthcare providers and, arguably, the medical community as a whole. They also allow me to understand how these patients experience their diagnoses as well as how they navigate the disclosure process with both healthcare providers and later, the important people in their lives, i.e. friends, family, sexual partners, etc. My analysis of text posts, asks, gifs, and shared resources works to make apparent the dis/alignment between the probable goals of healthcare communication training and practices applied by healthcare providers and patient experiences. In the spirit of Hertough (2018), part of my analysis includes discussion of "the evolving nature of online spaces," e.g. Tumblr's unique pseudo-anonymous microblogging platform offers affordances to users that other social media and even other medical websites cannot (p. 500). Further, as a research site, my analysis considers Herpblr's status as a counter public. In other words, it is a space where individuals of stigmatized groups convene and circulate discourses that run counter to the standard sociocultural narrative, yet another reason why a feminist/queer methodology is necessary to ground this research. In this case, with patients who have herpes, these discourses work to assist patients who are newly diagnosed with herpes manage the stigma and their lives post-diagnosis.

Cultural and Personal Considerations

Implicit bias is a real concern since I have herpes, had a bad experience with how the doctor disclosed my initial diagnosis, and wound up on Tumblr's Herpblr community to bridge the gap in knowledge about and how to live with this virus day to day. I address my implicit bias by remaining conscious of the possibility my personal experience may cloud or skew my perspective and interpretation of my data. I also place trust in my committee to point out and/or steer me away from such bias. However, I see this limitation also as a potential strength. Feminist Standpoint Theory posits that a researcher's position in society affords them more insight into some aspects of the world (Collins, 1989; Harding, 1995; Ellingson, 2000; Hausman, 2003; Johnson & Quinlan, 2017). In the context of this project, identifying as a feminist and as a female with herpes is more advantage than disadvantage. I believe my position as both researcher and herpes-haver affords me greater understanding and sensitivity of the participants whose perspectives and stories I analyze and discuss. Further, such a position decentralizes the authority inherent in the title of "researcher," something both queer and feminist in nature.

Additionally, much about how medical students are trained to communicate does not happen within traditional settings. Medical, nursing, and pharmacology students are expected to occupy a number of apprenticeship-type positions, i.e. internships, preceptorships, shadowing, etc., as a healthcare provider in training before being granted full licensure. It follows then that my data about how medical/nursing/pharmacy students are trained to and currently practicing healthcare providers actually communicate with their patients may be or will likely be incomplete. However, these methods should allow me to speak to the presence or absence of standardized education in this realm and determine what has been codified as being valued as part of the healthcare provider’s education. Further, I strive to avoid essentializing interview participants’ experiences.

Ultimately, I realize my analysis will not be generalizable to all or even many healthcare providers and/or patients. I view this project as a foray into initial understandings of what kind of communication education healthcare providers get, how some have learned to apply that education, and how some patients experience such communication. My goal here is not to make a broad argument about all of communication specific medical education, how all doctors diagnose, or how all patients experience their diagnoses. Rather, analysis of these specific discourses and sites allows me to make a point that medical education intends or ought to do certain positive things for healthcare providers and patients, and not all of it does. As a rhetorician and technical communicator, as a queer feminist, as a human with herpes, I feel called do to this work because I am certain we can do better for healthcare providers and patients.

Chapter Three: Communication Training for Healthcare Providers

> "At least it's not herpes. Or do you have that as well?" – Fat Amy, played by Rebel Wilson, *Pitch Perfect* (2012)

Introduction

I argue in Chapter One of this dissertation that technical communicators are well positioned to address the gap in communication between healthcare providers and their patients, especially with regard to disclosing STI diagnoses. Because sexual activity and sexual health are taboo topics in the West, people diagnosed with an STI often experience stigmatization, and many struggle to find the emotional or psychological support that is often missing from their interaction with their healthcare provider. In Chapter Two, I detail the queer feminist foundations of my research methodology and argue that these methodologies are necessary to understand the power systems at work in each of my research sites. I also outline my research questions and explain my rhetorical analytical approach for each site.

In this chapter, Chapter Three, I present, analyze, and discuss responses to interviews conducted with seven currently practicing healthcare providers about how they have been trained to communicate with patients in the course of their career[4]. As you can imagine, given the number of interview participants and the duration of some of our conversations, I ended up collecting data from participants that was outside of the scope of this research. This chapter then presents the data most relevant to the current project, knowing that the additional data collected may be useful as my investigation of this topic continues. My goal in talking with these

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[4] The interview chapter was perhaps the most challenging to write, and it was in the process of transcribing the interviews and writing the chapter that I began to sense there was more going on at the level of healthcare provider or healthcare system than what my focus in the diss would allow me to explore. So, I made the decision to include in this chapter only the data that most clearly aligned with the disclosure/stigma focus. The additional interview data will be the basis of future research that extends this chapter.

participants is twofold, with the first being to understand the process they have undertaken to professionalize on this particular area of their field. And secondly, I aim to get a sense of how these interview participants approach and/or think about communicating with patients who have a stigmatized condition in their practice. Of particular interest to this research are the moments when providers can perpetuate stigma during their interactions with patients or to potentially undo some of the negative psychological trauma associated with stigmatized diagnoses and conditions. Finally, the conclusion of this chapter sets the stage to begin thinking about and planning how to improve the foundational and ongoing curriculum healthcare providers receive on how best to communicate with patients who have stigmatized conditions and the ways in which technical communicators such as myself can supplement this work.

I recruited interview participants through social networks, both offline and on. Therefore, I share a mutual friend or family member with most participants, although I did not know any participants prior to contacting and interviewing them. The same six questions, articulated in Chapter Two and provided in the Appendix along with the interview transcriptions, were asked of each participant in a semi-structured, video phone call. Each question was designed to encourage firsthand accounts of the various instructional methods participants experienced during their medical training on how to communicate with patients broadly speaking, how stigma might impact the communication from their perspective as the healthcare provider, and communication lessons learned over the years of their practice. Asking these specific questions is important for this research because, as we know from Chapter One, there is a communication gap between healthcare providers and their patients when it comes to disclosing diagnoses of stigmatized conditions that often results in negative health outcomes for patients. Given the ethos inherent to careers in healthcare, understanding the ways providers are trained to communicate is vitally important when it comes to the goals of this research, i.e. closing the aforementioned communication gap, reversing the negative health outcomes stigmatized patients experience, and halting the perpetuation of stigma that clouds societal understandings of the reality of having a stigmatized condition, especially those which are usually transmitted through sexual contact.

I collected general demographic information prior to the interview, including details of participants' education, region of practice, age, and preferred gender pronouns. This information was the most pertinent to the current project and was within the scope of my time and resources for now. Interview participants were educated and provide healthcare to patients in various institutions and parts of the country: the Pacific Northwest, the East coast, the Midwest, and several locations across the South, with one educated in part internationally. Five of the seven participants are in their thirties with the remaining two in their twenties, and six self-identified as female. Although information on race was not collected, all participants appeared to be white or white passing. Additionally, participants were asked to choose a pseudonym, which I use throughout this and the remaining chapters of this dissertation. Three participants are nurse practitioners: Joslyn, a Certified Family Nurse Practitioner; Participant Two (P2), an Adult Geriatric Nurse Practitioner; and Emily, a Certified Family Nurse Practitioner. Nurse practitioners are nurses who, upon pursuing an advanced medical degree, are responsible for diagnosing, treating, and managing acute and chronic illnesses across a variety of specialties and in diverse clinical settings. Sari is a Registered Obstetrics Nurse who is certified in Maternal and Newborn Nursing, Collin is a pharmacist, Kathryn is a Doctor of Medicine practicing family medicine, and Stefanie is a Pediatrician. Participant Two and Sari work in a hospital setting, Collin works in a retail pharmacy setting, Kathryn is the director of a community health facility, and the other participants work in clinics.

I provided each participant with a description of my chosen semi-structured interview style and consent paperwork, and a synopsis of the project with instructions to consider stigma as it applies to their practice. I explained that although my project is concerned with STI stigma, there are other stigmatized conditions that may be more relevant to their experience, e.g. infertility, drug use, obesity, etc. Participants will have the option to see a copy of this chapter to ensure their contributions have been used according to their intentions and wishes. Interviews were conducted between January 13th and March 16th, 2019, and range in duration from just over a half hour to an hour and forty-seven minutes. Given the scope of some of the interviews, what follows is more a representation of the patterns and trends most relevant to this project that came out of our conversations and less a step-by-step accounting of responses to each question from each interview. The quotes provided in this chapter and elsewhere in the project are presented as stated with minor editing on my part to address continuity issues in conversational speech.

Though limited in number, I believe these participants' experiences in academic and clinical settings are largely representative of the experiences many healthcare providers have in the course of their careers largely because of the consistency in responses despite each participant having been educated and practicing in different regions of the country. Still, responses from seven interview participants cannot truly encompass the vastness of provider experience, especially given the demographics of this participant pool as outlined above. I discuss how the homogeneity in the race, gender, and likely class, of the interview participants limits to some extent the applicability of the solutions I provide in Chapter Five.

Themes from the Interviews

Several trends emerged in my analysis of the interview transcripts. First, methods of instruction used to teach healthcare providers to talk to patients about illnesses, stigmatized or otherwise, appear to be inadequate in both traditional academic settings like medical/nursing/pharmacy school, and clinical ones where newly graduated students can observe and interact with patients. Second, participants described approaching communication with patients as a purely informative practice, again regardless of whether the patient's condition is stigmatized or not. Several participants revealed that an information driven approach sometimes led to a less effective communication experience for their patients. And third, participants indicated that working against perpetuating stigma and/or not stigmatizing patients is possible and already happening for some providers by pursuing additional training and cultivating opportunities for self-reflection in their own practice.

Methods of Instruction: Classroom, Clinical, and Continuing Education

Broadly speaking, participants' experiences with patient communication instruction suggest that such training is largely oriented towards the logistics of practicing medicine. In the context of traditional classroom settings, like medical, nursing, or pharmacy school for example, most participants told me their program's instruction on communicating with patients was treated as a means to an end rather than the primary focus. In other words, communication training for these participants consisted primarily acquiring enough information about a patient to make a diagnosis, with little classroom, clinical, or continuing instructions on how to engage patients in difficult conversations about their health. Many described the focus of their particular program to be predominantly on things like anatomy, biochemistry, and physics, for instance. The only communication training Joslyn could recall from nursing school was when she was taught how to take a patient's history. In pharmacy school, Collin told me that his instructors "never really talked about...how to deal with counseling in general" and instead instructors "focused on being really deep...telling patients how to store the medication and telling them all the potential side effects.” Stefanie and Sari shared similar experiences from their time in medical and nursing school respectively, with Stefanie stating “I don’t remember sitting down and doing a lot of communication stuff” and Sari claiming “there was not a whole lot of teaching given over to this topic.” Participant Two noted that her undergraduate degree in nursing was “not...about...the best way to communicate or how [to] handle these difficult situations.” However, at the graduate level, Participant Two had a drastically different experience with communication instruction, stating that her program was especially “sensitive to stigmatized diseases and gender and sexuality,” than did Emily, who told me her program’s assumption was that she already knew and/or was competent at communicating with patients because of her prior experience as a nurse.

Further, participant descriptions of what little instruction was offered concerning patient communication did not seem to be authentic for the clinical experiences participants would have once outside of the classroom setting. One common strategy all participants mentioned was roleplay provider-patient communication, either with other students and/or “Standardized Patients,” who are usually local volunteers who are given a script for a particular medical condition and trained to act out symptoms and responses to students’ patient assessment questions. The problem with this instructional strategy that participants noted was the lack of authenticity in these interactions. For example, Joslyn conceded that while roleplaying with classmates “can be quite helpful, there’s still a lot that can kind of happen” in clinical settings with real patients. Emily’s concern with roleplaying is that “it’s not always taken as seriously as it should be” by other students since they were all familiar with each other. Another concern that Collin voiced had to do with the issue of roleplaying within a homogeneous student population, stating “I went to school in Iowa. We had mostly white and Indian students, a few black students, and Asian students” and lamented not having “more opportunities to role-play with people that are going to ask odd questions.”

Some programs have mannequin patients, which are controlled by instructors and can be filled with a variety of fluids to simulate a slightly more realistic and acute patient interaction. Even with this newer technology, participants still emphasized how inauthentic those simulations could be when compared to interacting with a real patient. Emily told me that “it’s difficult to talk to a mannequin...It’s kind of an undue stress, trying to make it seem like it's a natural conversation with the mannequin.” Moreover, communication wasn’t the primary focus for instructors when using such simulations, as articulated by Stefanie: instruction via simulation focused “on the medical aspect of it. Like how could we have run this code better? What questions did you ask of Mom? What didn't you ask? What would have been pertinent to what's going on?.” These observations align with research from health communication scholars Shannon L. Arntfield, Kristen Slesar, Jennifer Dickson, and Rita Charon. Their research on skill development in medical students indicate that simulations are presented to students sans context and with simplistic, one-sided learning goals, which may result in a skewed measurement of skill acquisition (2013). Further, simulation-based education historically lacks opportunities for students to reflect the emotions they and/or their patient may feel or on other considerations they would need to make in an authentic clinical setting, especially potentially sensitive ones like a patient’s cultural background (Arntfield et al., 2018; Campbell, 2018).

Communication training outside of traditional academic settings occurs in clinical or hospital settings wherein a supervising physician, practitioner, or pharmacist, sometimes called a preceptor, practice patient care in a given specialty with one or several students shadowing and observing their interactions with patients for a set amount of time. This years-long portion of healthcare training that happens once providers complete medical/nursing/pharmacy school is called a residency, and the shadowing of preceptors as they provide patient care is called clinical rotations, or rotations. Students usually participate in clinical rotations for a number of specialties during the course of their residency. Communication instruction for participants during residency seemed to consist almost entirely of observing preceptors and replicating their communication strategies.

Descriptions of clinical rotations that most participants provided indicate that rotations seemed to lack opportunities to demonstrate their knowledge or improve upon practices authentically and/or with communication as the primary instructional focus. Joslyn said of her residency experience that she was "taught essentially by watching in a lot of ways, especially about the communication aspect of communicating with patients." Of all the participants, Emily described perhaps the most successful clinical rotation experience: "I'd watch [the preceptor] do a few patient exams and whatnot. And then…[the preceptor] would [observe as I] conduct the interview with the patient and the exam and tell them what I thought was going on" with the preceptor ultimately signing off on her medical assessment, with seemingly no attention paid to the communication aspect beyond whether Emily asked the appropriate questions to diagnose.

Overall, participants told me that their time during these clinical rotations was a positive experience, which suggests perhaps some internal process when choosing preceptors and ensuring these individuals have certain qualities and qualifications when it comes to successful patient interaction. When I pushed further and asked how a participant would have handled a rotation with a provider who was not as effective at communication, Participant Two revealed that she would proactively "seek out the providers that I had seen in practice doing a good job and...go in for these discussions [and] observe. And when I felt confident to try to go and do it myself, I would have someone come with me and give me feedback or jump in if...the conversation was going in a wrong direction."

Finally, it is a standard requirement given the ever-changing nature of healthcare for providers to take so many hours of continuing education courses to maintain their licensure. According to participants, some licensing bodies require a certain number of hours of certain kinds of continuing education, such as pharmacology. However, it seems that providers have a certain number of "elective" hours, wherein they can choose what courses in topics of personal interest to them. For Joslyn, patient communication "is built into [continuing education topics], but...I don't know that there's much out there about just communicating." In her workplace, Sari said that "as far as like...formal employee training...communication is addressed maybe on the level of customer service, basic human interaction. There is a [annual] required" module every employee needs to complete. Collin shared a similar experience with the use of modules in continuing education, stating "A lot of the continuing education that I do is not live continuing education. It's continuing education done through articles and answering quizzes at the end. There are webinars and things I have seen that talk about LGBTQ issues."

Based on participants' experience and perceptions, institutions responsible for the foundational education of many healthcare providers do not consider patient communication instruction to be a priority. The experiences participants spoke of at the undergraduate level indicate a disconnect between hands-on but inauthentic classroom instruction via roleplay, simulations, or electronic modules, and authentic but largely observation only clinical instruction during residency or clinical rotations. Moreover, the variance at the graduate or medical level suggests that how well (or not) a healthcare provider is taught to communicate in an academic setting may very well boil down to their access to the robust kinds of programs, or drive, Participant Two had access to.

Moreover, these experiences seem to fly in the face of “patient-centered care” (PCC), which has been a standard approach in healthcare communication since the 1990s. As outlined in Chapter One, Keith Bennett and Harry Irwin’s 1997 article “Shifting the Emphasis to ‘Patient as Central’: Sea Change or Ripple in the Pond?” and Marsha L. Vanderford, Elaine B. Jenks, and Barbara F. Sharf’s “Exploring Patients’ Experiences as a Primary Source of Meaning” from the same year marked the introduction of an “array of communicative behaviors that can enhance the quality of a relationship between the health care provider and patient, or the patient’s family” (Bekelja Wanzer, Booth-Butterfield & Gruber, 2004). The crux of these communicative behaviors relies on providers and patients challenging traditional healthcare communication practices and interrogating the power structures heretofore foundational to healthcare communication. It’s difficult to see the instructional methods participants described as teaching students to do this work in clinical settings because, as participants made clear, communication training does not seem to provide students adequate opportunities to evolve as culturally sensitive practitioners who are respectful of patients and their experiences, needs, and values while still providing good patient care and facilitating positive health outcomes. One explanation as to why such a disconnect exists could be due to a lack of standardized operating definition of PCC (Rathert, Wyrwich, & Boren, 2012). Conceptually, PCC has existed in healthcare literature since the 1960s and yet its processes remain ill-defined, even though there has been significant investment on the federal level with the creation of the Patient-Centered Outcomes Research Institute in 2010 (Gusamano, Maschke, & Solomon, 2019). It seems the theoretical notions of PCC are not being applied, uniformly or otherwise, when it comes to classroom or continuing education for the healthcare providers I spoke to.

While I do not believe it’s possible to teach communication of any kind in a one-size-fitsall model, it seems there may be too little consistency in patient communication instruction among healthcare provider programs in academic and clinical settings. In the early stages of their career, it seems vital that healthcare providers have access to relevant instruction that will carry them successfully through to the next stage in their practice as a medical professional.

Participants' Approach to Patient Communication

Participants described approaching patient communication, regardless of if a patient has a stigmatized condition, as a largely informative practice with some indication of sensitivity to patients' positionality and comfort. When asked how they broach communication with patients, for example, participants across the board stated they focused on being "clear," "direct," "avoiding euphemisms," and being "non-judgmental." For Joslyn, it's important that she "be able to approach [patients] in…vernacular that they're going to understand." Kathryn alluded "to us[ing] open-ended questions" during patient intake and assessment. Collin said realistic communication instruction should include "how [to] give the person like the top 10 [most important pieces of information] in 30 seconds or less?"

Several participants also described using non-verbal communication like maintaining eye-contact, sitting at the same height as their patient, and initiating therapeutic touch when appropriate with patients. Emily specifically mentioned having to develop her awareness of her body language once she understood how it was impacting patients, and Participant Two stated she is "cognizant that I have to keep my...face relaxed and my tone, try to keep it even" to help create the most effective communication experience for patients. Sari takes an "intentional design...approach to a patient's comfort" before attempting to disclose information to them. In her clinical setting, "many patients are admitted from a triage environment [and] arrive super hungry and cold, taking time to meet those needs, asking visitors to step out of the room, dimming the lights and returning to deliver news." Many of the strategies listed above, however, do not generally convey empathy to a patient, which often impacts how well a patient experiences their care (Yeary, et. al, 2015; Hashim, 2017). And even with their emphasis on providing information in what they intend to be unbiased ways, we know that "even well-intentioned providers who are motivated to be nonprejudiced may stereotype ... particularly under [certain workplace] conditions," which can leave patients feeling stigmatized (Burgess, Fu, van Ryn, 2004). Although I did not get the sense that participants had stereotyped patients, the literature in healthcare communication indicates the issue is at least somewhat common. Cultural sensitivity or lack thereof aside, one of the issues here is that the practices participants mentioned may or may not align with how patients best receive care or how they perceive their provider. It is difficult to say which is worse, having very little communication training at all or having what little communication training is provided not be effective for patients.

Based on information from participants, it also seems that this information driven approach to patient communication often results in a negative experience for the patient. For example, Joslyn recounted a recent patient interaction that resulted in the patient feeling "defeated when they left. And I think it was just the amount of information we talked about. It was a lot in one sitting." She felt the patient was "quite overwhelmed," stating "they left with just 'oh my gosh, I've got to get this done, I've got to take this drug,'" but also confided that she didn't "know how I could have approached it differently." When disclosing an alarming sounding diagnosis, Stefanie said she was "worried enough about [a patient] that I just said, 'I need to send you to the hospital, I need to call them right now, you need to go by ambulance.' And that poor family, they were so upset. They were thankful later on, but in that moment, Mom was tearful and Dad was kind of panicking...I have handled subsequent [disclosures] a bit more gently." These two examples in particular show that miscommunications can happen at any point in a provider's career and, importantly, that these participants are often reflective of their role in effective communication with patients. In fact, this seemed to be the case with all of the participants. And yet none of the participants mentioned anything about being taught to be self-reflective or that they were given opportunities to cultivate that practice during their medical training. Rather, introspection and empathy seem to be part of their character, something they do automatically. Kathryn, for instance, said that when communicating on sensitive topics she thinks to herself, "okay...I want to be a decent human being...how would I want to be approached if this was me or my family? So that's what I always try [to do]."

Most participants developed communication workarounds on the fly and/or over time with experience. Joslyn, for example, makes an effort to get to know patients and even offers up information about herself, such as where she went to college and sports teams she follows. Any solutions developed to help providers meet the communication and treatment needs of their patients need to be based on the specific context in which a provider practices in their field. Kathryn's work in community health, wherein patients might be homeless or in circumstances that do not afford them the ability to think about their health in the long-term, is an excellent example of the nuance needed in communication training. Patients who seek treatment at her facility may not have reliable access to the internet. In those cases, any written documentation she can provide about their condition and treatment plan is crucial to the patient's health and wellbeing.

Working Against Stigma

One approach participants took to communicating with patients was to identify their own solutions to address the gaps described above in the section on "Methods of Instruction." These include specialized training and opportunities for self-reflection, which may be more widely applicable to healthcare providers broadly. I discuss more concrete solutions based on these ideas in Chapter Five.

Training

Participants described a few interesting training scenarios or techniques that helped them develop as communicators generally and build empathy for their patients, though not directly related to stigma. Some of this training was part of their program requirements while others were something a participant voluntarily took part in. During her training to become a nurse's assistant, Emily participated in a class activity that involved being blindfolded and fed by another student to help the class cultivate empathy for patients in long-term care facilities. She told me that, "[These patients] need help being bathed, going to the bathroom, and eating…[the class activity] was a very sobering experience...that kind of changed the way a lot of us approached talking to patients and taking care of them." Role-playing in this instance seemed to be more effective than using Standardized Patients, perhaps because students themselves were required to experience being vulnerable (blindfolded) and reliant on another to fulfill a vital need (eating). Further, the program Stefanie was in required training or offered students additional instructional opportunities not offered in all programs. During their second year of medical school, students "were actually in the clinic with patients one day a week, which is a lot earlier than other medical schools." She "was allowed to have a second continuity clinic in residency," which enables her to speak more confidently on the topic of obesity to patients and their families in her pediatric practice. Additionally, Kathryn attended an optional training for Suboxone, an opioid replacement drug, that was hosted by the pharmaceutical company who created it. Despite this very real conflict of interest, it was through this training that she was finally able to understand patients' need for long-term opioid replacement therapy: "If you do heroin for years your brain doesn't release dopamine the same way as a person who's never done it” and people using this therapy who are “constantly hearing, ‘oh, no, you need to get off, you're not clean cuz you're still on something like that’...have a really high relapse rate.” It seemed this optional training gave her additional perspective on what patients who take this drug may be experiencing in their lives. Moreover, she seemed to have greater empathy for people who are not able to experience the full range of human emotion due to long-term drug use.

On the other hand, participants also told me that one of the things that they were not adequately trained to do was interact with patients from different parts of the country or world. Cross cultural communication is often fraught in the best of circumstances, and conversations about a patient’s health has much higher stakes than everyday conversations. Participant Two and Collin each referred to situations in which cultural differences impeded their ability to communicate effectively with patients. Concerningly, both told me that figuring out how to bridge the gap was often left up to them. Given the ever more connected world we live in, it seems that such training would benefit both providers and their patients. Participant Two said, “it really wasn’t until I came out to work in Minnesota [from Connecticut] that I just noticed that...I just did not know how to communicate with the people out here.” Collin stated he once had to “draw stick drawings” to help a Korean woman who spoke inadequate language for the situation understand how to use the vaginal suppositories prescribed to her.

It’s unrealistic to think medical programs or residencies can teach their students how to communicate with every culture. However, it’s not out of reach for employers to help providers who recently move to a new location or who are unfamiliar with a certain population a clinical setting serves learn how to successfully navigate those interactions, again for the benefit of both provider and patient.

Self-reflection

I mentioned in the previous section that most participants seem to be naturally inclined towards introspection and spend time reflecting on their role in attaining positive communication experiences and good health outcomes for patients. Emily, for example, retains her empathy for patients by remembering that to a patient, their medical concern “is super important at this moment in time....It’s hard enough to come in with something that’s stigmatized and then let alone have them feel bad about being there.” In his position as a pharmacy manager, Collin is in a position to help the people who report to him reframe some of their problematic assumptions: “My technicians will sometimes be like, ‘Ooh someone’s coming in for...azithromycin [usually used to treat STIs].’ I’m like, ‘Hey I’d much rather them get treated.’...I always try to be supportive of [patients] making a good health decision.”

Additionally, two participants mentioned that the way they or other providers interacted with patients and perceived stigmatized conditions often had to do with their experiences either with a loved one’s illness or their own. Such experiences seem to result in increased empathy through self-reflection, which could then translate into these providers feeling more empathy during patient interactions, an important implication for training. Sari told me that “life experience is one of the biggest developers of empathetic, genuine, honest communication” practices, especially when it comes to a nurse’s “personal experience in his or her life with difficult circumstances.” In Kathryn’s case, two close family members had bipolar disorder and her experiences of seeing medical professionals “laughing at [her sister] when she's yelling and saying talking about Jesus coming” made her reflect on “how did I feel when this was my family in this position?...I'm thankful for those experiences.”

None of the participants mentioned that their training provided opportunities to practice self-reflection, and yet doing so allowed these participants to empathize more effectively with their patients' experiences. Unbeknownst to them, research from *Military Medicine* indicates students also benefit from this serious thought as well: "self-reflection skills…can potentially predict long-term educational success" (Stephens, et al., 2012). As Cohan (2019) argues, "thoughts guide attention, and attention guides actions," and so cultivating opportunities and space for medical students and healthcare providers to meaningfully reflect on their influences seems to be a worthy pursuit, one that my interview data supports.

Conclusion

My study of these trends leads me to concur with the literature cited earlier in this chapter and throughout this dissertation: some patients experience poor health outcomes because of poor provider-patient communication which, I believe, can lead patients to feel as though they've been stigmatized by providers while under their care. I argue that these outcomes are due in large part to a lack of formal, systematic provider training on the how to approach complex and potentially stigmatizing topics with patients. This gap occurs during all stages of a provider's career no matter where they received their education or which healthcare field they've chosen to enter. A provider's disclosure of a new condition, especially a socially stigmatized one, is likely one of the most significant communicative moments a provider and patient can share. As such, I believe appropriate steps should be taken to ensure that providers have both robust training in how to disclose said diagnoses, and that an array of supplements and a network of support be available to providers and patients alike once the diagnostic disclosure has happened.

While this chapter has offered major themes related to provider communication and sets the stage for thinking about improving the education and communication of healthcare providers in the future (see Chapter 5), my next chapter focuses on the "next step" after communication breakdowns occur specifically for patients diagnosed with herpes, perhaps one of the most severely stigmatized health conditions a patient can be diagnosed with. Healthcare providers, despite their training or perhaps because of it, are just as prone to have erroneous or misaligned views from those they provide services for, which in turn affects their ability to communicate effectively, leaving newly diagnosed herpes patients in the lurch. The online community known as “herpblr” formed in response to the dire need for those diagnosed with herpes, particularly those newly diagnosed, to seek out support and information from others who have been diagnosed. The juxtaposition of these two chapters allows me to think about the rhetorical situation from the position of each of the rhetors and to imagine a greater range of possible solutions to communicative problems in healthcare settings that address both disclosure and stigma.

Chapter Four: Herpes + Tumblr = Herpblr: Co-opting Social Media for STI Support and Filling the Gap in Healthcare Provider Communication

> "The thing about glitter is, if you get it on you, be prepared to have it on you forever 'cause glitter is the herpes of the craft supplies." Demetri Martin

Introduction

As has been made clear in the previous chapters, sexually transmitted infections (STIs) are highly stigmatized in Western culture, perhaps none more so than herpes simplex virus (HSV), or genital herpes. The complex nature of our perceptions of sex, sexuality, and sexual health can make being diagnosed and diagnosing, i.e. the patient/doctor relationship, genital herpes fraught with issues that often bring about miscommunications and/or further stigmatization that negatively impact the wellbeing of newly diagnosed patients. As was shown in the previous chapter, healthcare providers receive little focused formal training on how best to communicate with patients in general, much less about how to communicate with patients regarding a stigmatized condition. Instead, healthcare providers learn to interact and communicate with patients through more experienced providers during internships, clinical rotations, and preceptorships. Providers need to attend a certain number of continuing education courses over the years to maintain their licensure, and several I interviewed mentioned having attended a mix of required courses and electives. Most if not all of the continuing education courses mentioned by interview participants dealt with updating providers on pharmacology, treatment procedures, and the like, and no participant could remember a continuing education course on communication being offered. Unfortunately, this gap in education means that the psychological issues many patients experience, as detailed in Chapter One, in the time following a diagnosis of a stigmatized condition go unaddressed. To fill the void, many patients recently diagnosed with herpes have found themselves on the social media platform Tumblr, which has become the home to a community known as Herpblr.

As of May 2019, the social networking and microblogging website Tumblr hosts 465 million blogs which contain 172 billion posts (“Tumblr.com Traffic Statistics”, “About”). Unlike Facebook, where users have one personal account and expect to see the real names and often faces of people they friend, or Twitter, which is more easily anonymized but limited to 280 characters per post, Tumblr allows users to create and access multiple personal blogs under one account, anonymize any or all of a user’s blogs, and the opportunity to engage with other users anonymously or otherwise via inbox or messaging. In addition, and given the microblog nature of the site, many Tumblr users are able to post text and media updates with easily searchable hashtags and their followers are able to reblog the post as is or add a comment to the post that their followers will be able to see automatically.

A combination of the words “herpes” and “Tumblr,” Herpblr is an online space wherein herpes positive Tumblr users provide information and support to each other and to those newly diagnosed with herpes. This digital space, anonymized and protected to some degree, provides users with valuable resources as well as a forum to exchange information and support that, for many, does not exist in the physical world as Gaby Dunn (2013) wrote in her article “The Strongest Herpes Support Group Is on Tumblr.” Aside from the basics of what exactly herpes is, individuals in the Herpblr community post supportive messages to their followers, and ask for and provide personal experiences and encouragement relating to topics not often covered in a doctor visit, like how to live with their diagnosis, disclose to potential sexual partners as well as friends and family, and how to manage the virus. This chapter leverages the unique liminal space—amateur/expert, social/medical, supportive/educational—that is Herpblr as an avenue for thinking about new and organic solutions to the challenges facing medical personnel as they communicate about stigmatized conditions.

Computer-Mediated Social Support/Social Media Use for Stigmatized Populations

Communication, as Manuel Castells (2012) states in *Networks of Outrage and Hope: Social Movements in the Internet Age*, is “the process of sharing meaning through the exchange of information” (6). The most significant advancements in communication have emerged as a result of new technology. Gutenberg's printing press, of course, sparked a dramatic increase in the quantity and circulation of printed materials which, in turn, lead to important shifts in thought throughout Western civilization. Radio, telephone, and television also mark notable moments in the expansion of human communication. The dawn of the Internet and personal computers has arguably transformed the communication environment of those with access to it to a greater degree than perhaps any other technological creation. Not since the printing press has human communication taken such large and speedy strides towards advancing our ability to produce, consume, and share information, and reach out to others and express ourselves. This rapid headway lead to a new branch of communication studies: computer-mediated communication (CMC), which was best defined by Denis McQuail (2005) as “any human communication that occurs through the use of two or more electronic devices” (5). With the advancement of social media, and especially its ability to aggregate information via hashtags, human communication can now happen between many people at one time and, depending on the context of such communication, can be classified as computer-mediated social support (CMSS).

According to Leland K. Ackerson and K. Viswanath (2009), all “social support exists in a number of forms including emotional support, such as love, caring, and sympathy; instrumental support, like assistance with tangible needs; and informational support, which includes the provision of advice or information” (p. 10). Further, they claim that there are numerous benefits to social support, such as “reducing the role of harmful psychological processes such as stress and depression ... improving health-related behaviors ... and allowing for the provision of health-conserving resources” (p. 10). Moreover, Heather J. Hether, Sheila T. Murphy, and Thomas W. Valente (2014) found in their research reported in “It's Better to Give Than to Receive: The Role of Social Support, Trust, and Participation on Health-Related Social Networking Sites,” that “the more highly involved support providers are, the more they benefit” (p. 1433). In the context of this research, which focuses on the need for people diagnosed with herpes to seek out information and support for their highly stigmatized disease, CMSS in the form of Tumblr has provided both an outlet and a haven for people with herpes to get and give information and support. Those characteristics unique to Tumblr in the social media world, i.e. optionally anonymous blogging, make the platform an ideal location for such a community.

“[B]logging ... seems to provide a unique deep communicative experience in terms of increased identification and empathy” and bloggers have the opportunity to “achieve empathy and unequivocally that often had been missing in their day-to-day, face-to-face lives” claims Amy Aldridge Sanford (2010) in her article, “‘I Can Air My Feelings Instead of Eating Them’: Blogging as Social Support for the Morbidly Obese” (p. 579-80). Brian D. Loader, Steve Muncer, Roger Burrows, Nicholas Pleace, and Sara Nettleton (2002) wrote about CMSS for people with diabetes in their article “Medicine on the Line? Computer-mediated Social Support and Advice for People with Diabetes.” They found that such groups provided people the chance to “share and provide support to others with a similar understanding of the social constraints of living a ‘normal’ existence with such a chronic condition. Rather than a rejection of evidenced-based clinical advice, it offers a secure space where such information can be assimilated and reflexively shaped to inform lifestyle choices – a space where discursive learning about one’s condition can be undertaken on a more equal basis" (p. 64). This line of inquiry makes apparent the how crucial it is for patients with conditions of all kinds to have access to support that they may or may not be getting from their healthcare provider.

For CMSS that deals with health issues of a more sensitive nature like herpes, anonymous blogging is a way for people to avoid "felt stigma." Authors Vanessa Boudewyns, Itai Himelboim, Derek L. Hansen, and Brian G. Southwell (2015) discuss felt stigma in their article "Stigma's Effect on Social Interaction and Social Media Activity." They state that felt stigma "refers to fear of societal attitudes and potential discrimination arising from a particular undesirable attribute (e.g., being promiscuous), disease (e.g., HIV), or association with a particular group or behavior (e.g., homosexuality)" (p. 1337-8). In the context of their research on stigmatized topics on Twitter, the authors found that "those who perceived STDs as stigmatized were less likely to report talking with their sexual partners about the topic or engaging with others in a conversation about it" (p. 1342). Having access to a space wherein people with stigmatized illnesses can interact with others who have the same illness is beneficial, especially if anonymity is an option. For example, Stephen A. Rains (2013) writes in "The Implications of Stigma and Anonymity for Self-Disclosure in Health Blogs" that "anonymity appears to be a tool with the potential to enable those who feel illness-related embarrassment to disclose a range of information about their illness experience" (p. 30). Such disclosure, he contends, "is associated with salutary outcomes" unlike nondisclosure, which "can exacerbate aversive feelings, intensify physiological stress, and increase obsessive thinking" (p. 23-4). Rains goes on to claim that

> Some degree of anonymity may make it possible for individuals who perceive themselves to be stigmatized to publicly recognize stigma but keep it from disrupting

> interaction. The implications of being able to claim a stigmatized identity but not have it dominate or otherwise disrupt interaction are considerable. It seems possible that concealing part or all of one's identity may make stigma less salient in interaction. Individuals may even have the opportunity to share discrediting attributes of their condition without some of the deleterious consequences associated with stigmatization. (p. 29)

Herpblr

In action, individuals who make up the Herpblr community post a wide range of updates relating to herpes. It is common to see well-established and newly created herpes specific accounts alike indicate they founded or found the Herpblr community in order to fill a void of support and information, both medical and experiential, they did not get from either their non-electronic communities or from their healthcare provider during the diagnostic disclosure. The ubiquity of such a narrative across herpes specific accounts suggests that Herpblr is at least in part a result of earlier points of failed disclosure in clinical settings

There is enough data on Tumblr generally and Herpblr specifically to fill many a dissertation. For the purposes of this project, therefore, I conduct content and rhetorical analysis on two distinct groupings of Herpblr data. First, I examine the ten most popular[5] herpes posts found under the Herpblr tag[6] via Tumblr's search functionality. This serves to provide a snapshot of the community as it might be experienced by someone new to the community. In order to offer a more holistic sampling of posts and to get at some of the means through which Herpblr can provide useful informational and anti-stigma models for the medical community and society at large, I also include several examples of how individuals have used Tumblr to communicate

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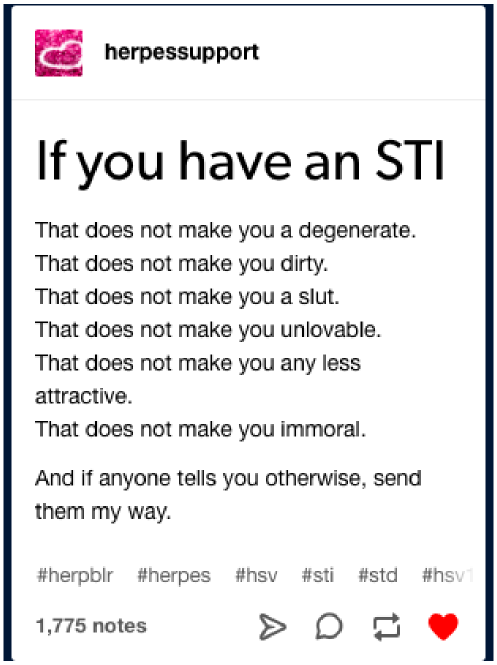
[5] As of May 2019 according to Tumblr metrics, i.e. likes, reblogs, comments, etc.
[6] Herpblr is also the tag used by herpetologists; hence the need for clarification.

technical information in innovative ways and in ways most conducive to how the platform functions. This second set of data, if you will, is included because of its relevance to the scope of my inquiry, rather than because I or a significant number of other users have found it to useful.

Top Ten Most Popular



herpessupport

If you have an STI

That does not make you a degenerate.
That does not make you dirty.
That does not make you a slut.
That does not make you unlovable.
That does not make you any less attractive.
That does not make you immoral.

And if anyone tells you otherwise, send them my way.

#herpblr #herpes #hsv #sti #std #hsv1

1,775 notes

Figure 1: First Most Popular Herpblr Post

Herpblr posts with the most engagement include characteristics like re-framing the stigma that STIs carry culturally, offering statistical research and other resources to help users better understand the realities of herpes, and personal narratives of user's experiences with their first outbreaks, getting diagnosed, and disclosing to loved ones and sexual partners. Interestingly, the most popular herpes related post on Herpblr is a textpost that refers to STIs broadly rather than herpes specifically. Posted by an account called @herpessupport, the post is written with a repeated negative sentence structure to affirm all of the character traits one does not possess should they have an STI. Among the traits listed are dirty, slut, unlovable, and unattractive. The end of the post states "And if anyone tells you otherwise, send them my way."

This post is representative of a few important patterns apparent in the Herpblr community. Though not immediately evident, this post suggests that many in this community seem to identify as female. As evidence, notice how many of the terms included are not generally considered gender neutral. Cis-gendered heterosexual men are rarely ever referred to as sluts, culturally speaking, just as they are not considered unlovable should they remain unmarried late in life, a courtesy few women enjoy. Some of these terms coincide with concepts often leveled at female identified persons in particular, usually with the intent to hurt or shut down said persons, e.g. how attractive and/or clean a woman is perceived to be is often based on how well she meets the standards set by patriarchal society. Women are often shamed for liking sex, having too high a "body count," and even accessing sexual and reproductive healthcare. Pregnancy and STIs are commonly framed as appropriate punishment for what happens to women when they have sex. When considered this way, the language used in this post is reflective of how society would perceive a woman who has been diagnosed with an STI and is, I would argue, a list of the words that could be used against her should she choose to disclose her status to another. Finally, as someone who has been an active consumer of Herpblr posts for several years now, I can confirm the implicit not-quite-threat in the final line is indicative of the ferocity with which Herpblrians advocate for themselves and others with HSV, provide all manner of advice and even disclosure and medical verbiage to those newly diagnosed who have reached out for help, and impart support and education to all comers on this platform.

To those who chose to reject someone simply because they disclosed their herpes status

You are entitled to leave if you want. But keep this in mind:

80-90% of the population has herpes. Of those, 85% of people who have herpes have no idea. Of those who are aware they have herpes only half will actually tell you. Edit: to be more specific roughly ¼ people under the age of 50 have hsv 1 and 1/6 have hsv 2.

So, when you reject someone who is honest enough to tell you they have herpes because you don't want to take that risk, just remember you are, in fact, taking a much larger risk with all the other people out there who may not know their status or be honest. Statistically speaking you are safer with someone who knows their status and is honest with you than with anyone else. And even those who claim they get tested regularly, herpes is not included in most STD panels unless you specifically ask.

So just keep that in mind when making your decision.

#herpblr #herpes #hsv #std #sti #hsv1 #hsv2 #cold sore #genital herpes #std stigma

1,561 notes

Figure 2: Second Most Popular Herpblr Post

The second most popular post provides statistics and information that most people are not aware of, e.g. that standard STI screenings do not include a test for herpes and also argues[7] that one would be "safer" with someone who knows their status than someone who does not. Though ostensibly written to someone who has

---

[7] Early in my herpes journey, I admit to finding the "safer" argument compelling both when working up the nerve to disclose to someone and after experiencing exactly the kind of rejection referenced in the post. Now I understand that that argument is problematic and work to dispel the notion that sexual activity is inherently "dangerous."

not been diagnosed with hers, this post is really written for an audience who is concerned about being rejected upon disclosing their status or who has been rejected because of their status. This post could be read as encouragement to disclose, which is not something everyone in the community agrees on, could function as a balm of sorts one might read after being rejected for disclosing, or could even be subliminally re-blogged to one's account similar to a subtweet[8].

Disclosing one's status is one of, if not the most discussed topic within the Herpblr community, with the recently diagnosed asking how to approach it and seasoned Herpblerians[9] describing how their own disclosures have gone and detailing the strategies that have worked for them in the past. Taken in context with the most popular post, it's easy to understand how these two feed into one another, addressing separate but related aspects of the concerns folks with HSV have: how to combat the stigma associated with having an STI, herpes specifically, and how to tell others that one has herpes. We know from shame research that disclosing is one way folks are able to potentially feel the effects of stigma less, depending upon whether they are accepted or not.

Third most popular post riffs off the Kubler-Ross grief framework as the poster, @talon-rose, identifies each stage (denial, anger, bargaining, depression, and acceptance) as they experienced it from the start of their first outbreak symptoms, to their diagnosis, and finally to their acceptance of what having herpes will mean for their life going forward. Part story, part stream of consciousness, @talon-rose paints a picture after the fact of their physical and emotional state, including vomiting and thoughts of suicide, during the ordeal that commonly

---

[8] When a Twitter user alludes to or references another Twitter user but does not use their username/handle; usually done to insult or criticize.

[9] The term I affectionately use to refer to Tumblr users in the herpblr community, similar to the term rhetoricians as its used to describe folks to study and apply rhetoric or the term Minnesotan as its used to describe folks who live or have lived in Minnesota.

talon-rose

The Stages of Grief (Herpes Edition)

Denial.
I woke up on a Monday morning; after a Sunday night of rough sex. I went to the bathroom and could barely get anything out. *Great, I have a UTI because I fell asleep right after.* *Eye-roll*
Days go by, I'm drinking tons of water, drinking sugar-free cranberry juice. My UTI is not letting up. I should go see a doctor.
Thursday comes along and I have to go to the ER because I am in so much pain when I do pee. Extreme burning. Extremely fatigued. My bladder is spasming - which is painful. I get some antibiotics, and some medication to help with the bladder spasming. I am informed that if I vomit, I need to come back.
Friday at 4AM, I projectile vomit all over the bathroom. I resort to peeing in the shower because water helps take away the sting. I cry. I touch my labia, and that's when I notice it… a bump. *What the fuck is this?* I take a picture (after getting out of the shower). *Fuck. Fuck. Fuck. I have herpes.*
Friday at 10PM, I work up enough courage to go back to the ER. I get the visual diagnosis, and swabs done to confirm.

Anger.
In the moments following the visual diagnosis. I am crying. *My life is ruined. No one will love me. My boyfriend is going to accuse me of cheating, and I have done nothing wrong! Why does this hurt so bad? I should go over to his house and confront him! How is he going to do this to me?! He told me he got checked for STD's and was clear! I shouldn't have trusted him.*

Bargaining.
Why can't I have chlamydia? What about gonorrhea? Why did I have to get something that's incurable? Why me? What did I do wrong?

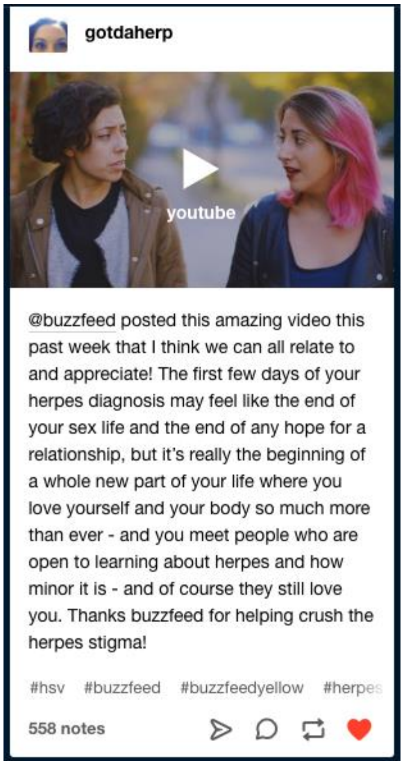
Depression.
I didn't move for days; with the exception of going to my partners house to inform him of my 2AM diagnosis. We cried together, and he apologized. I went home, called off work, and laid in bed. I cried. I wondered how I was going to tell my mom. *What was she going to think of my boyfriend that she already didn't like? Should I just commit suicide? Is life even worth living at this point?*

Acceptance.
This only came with research. Ninety percent of people have HSV. One in Five have genital herpes. I am not alone. I am not a minority. I can still have children. I can still live a normal life. I am a human being. I am not dirty. I did nothing wrong. Life is still worth living; it is beautiful, even when it's painful.
Not everyone is worthy to know of my diagnosis. My mom doesn't need to know. My gossipy friend does not need to know. The only person that needs to know is myself, my partner, and any future partners. Herpes does not change me, it does not make me.

Figure 3: Third Most Popular Herpblr Post

accompanies the first outbreak. Disclosing their story in this way, and so candidly, is likely one way they were able to combat the shame associated with a herpes diagnosis, and Tumblr makes doing so less risky by way of handles rather than names. And while placing their experience in line with the grief model may at first seem dramatic, it does align with how many other users have described the aftermath of their diagnosis: a herpes diagnosis often lands with the same impact as a death sentence would. This pattern occurs time and again across Herpblr posts and is further evidence of the immense stigma surrounding herpes.

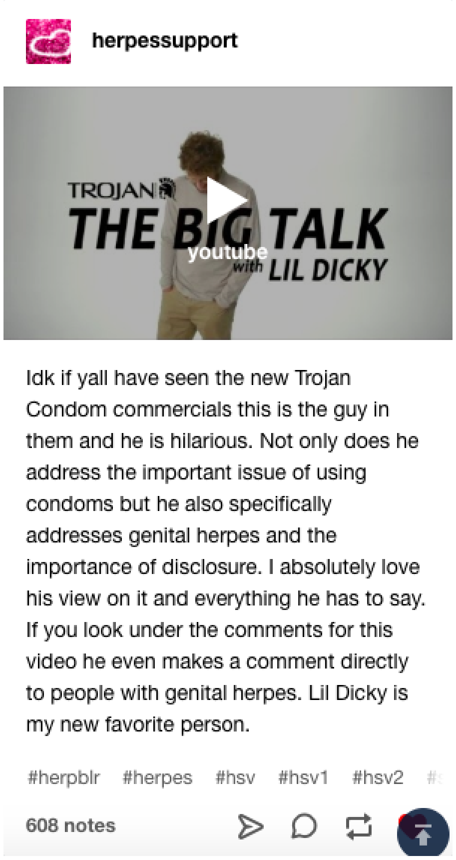
Fourth and fifth in popularity are examples of how the community shares resources and bonds over common experiences. Embedded within each post is a link to a video, one created by the news and entertainment website Buzzfeed and the other created by the condom manufacturer Trojan. As @gotdaherp notes, the Buzzfeed clip tackles the issue of having sex with herpes and they even write “Thanks buzzfeed for helping crush the herpes stigma!” at the end. In line with the previous post, @gotdaherp recalls how being diagnosed “may feel like the end,” in this case of hope for a relationship and implicitly a satisfying sex life, in a way similar to how the grief framework talon-rose references helps those mourn the loss of a loved one. In their post with the Trojan condom commercial, @herpessupport highlights that the spokesperson, Lil Dicky, specifically mentions the importance of condom use and disclosing to partners before engaging in sexual activity and is funny to boot.



@buzzfeed posted this amazing video this past week that I think we can all relate to and appreciate! The first few days of your herpes diagnosis may feel like the end of your sex life and the end of any hope for a relationship, but it’s really the beginning of a whole new part of your life where you love yourself and your body so much more than ever - and you meet people who are open to learning about herpes and how minor it is - and of course they still love you. Thanks buzzfeed for helping crush the herpes stigma!

Figure 4: Fourth Most Popular Herpblr Post

Although I haven’t personally shared either link on my own social media, I have shared several others I found on Tumblr. This kind of resource, especially one from a reputableish news organization like Buzzfeed and a well-known brand like Trojan, is invaluable in normalizing herpes because stigmatized or taboo topics are only that way because they are not openly disclosed or widely discussed. Moreover, the creation and posting of these videos present an important avenue for people with herpes to feel seen and supported on a bigger level than Tumblr.



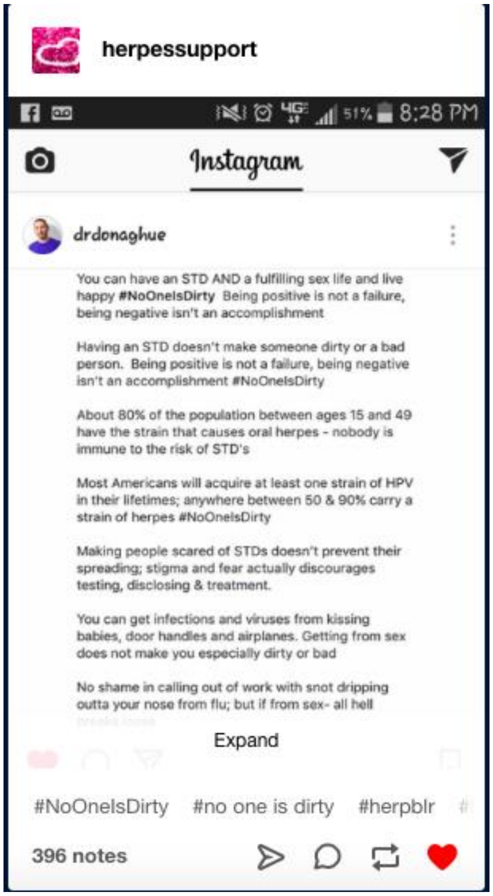
Idk if yall have seen the new Trojan Condom commercials this is the guy in them and he is hilarious. Not only does he address the important issue of using condoms but he also specifically addresses genital herpes and the importance of disclosure. I absolutely love his view on it and everything he has to say. If you look under the comments for this video he even makes a comment directly to people with genital herpes. Lil Dicky is my new favorite person.

Figure 5: Fifth Most Popular Herpblr Post

In sixth place for most popular, @herpessupport has cross-posted a screenshot from

Instagram of a text image from the account @drdonaghue. Similar to the most popular post above, this text image seems to refer to STIs in general, although herpes and HPV are named, and the unwelcome, stigmatizing feelings associated with a diagnosis. In addition to some statistical information, the text makes the argument that contracting an STI is no different than contracting the flu, that it is only our cultural hang ups around sexual activity that cause us to see these illnesses differently. What makes this post conceivably more credible is the original Instagram post seems to be coming from the account of a doctor, which is likely the reason why @herpessupport posted the screenshot in the first place.

Most popular post number seven is an example of the kind of technical slash medical communication that Herpblr can provide, especially for the newly diagnosed. This post offers a recipe for a topical ointment that can be used to relieve the pain and length of an outbreak, according to the poster, complete with pictures and tips for how to use the ointment. What strikes me as interesting about this post is that it does not contain any explicit message of support or argument as the previous posts do; it simply provides ingredients, instructions, and reference pictures. I would, however, argue that it still does work to dispel herpes stigma by way of the direct tone and lack of additional commentary. The account that posted this is presenting it as commonplace that one would be interested in an all-natural herpes ointment recipe from the Internet in the same way that others create and/or look for concoctions



You can have an STD AND a fulfilling sex life and live happy **#NoOneIsDirty** Being positive is not a failure, being negative isn't an accomplishment

Having an STD doesn't make someone dirty or a bad person. Being positive is not a failure, being negative isn't an accomplishment #NoOneIsDirty

About 80% of the population between ages 15 and 49 have the strain that causes oral herpes - nobody is immune to the risk of STD's

Most Americans will acquire at least one strain of HPV in their lifetimes; anywhere between 50 & 90% carry a strain of herpes #NoOneIsDirty

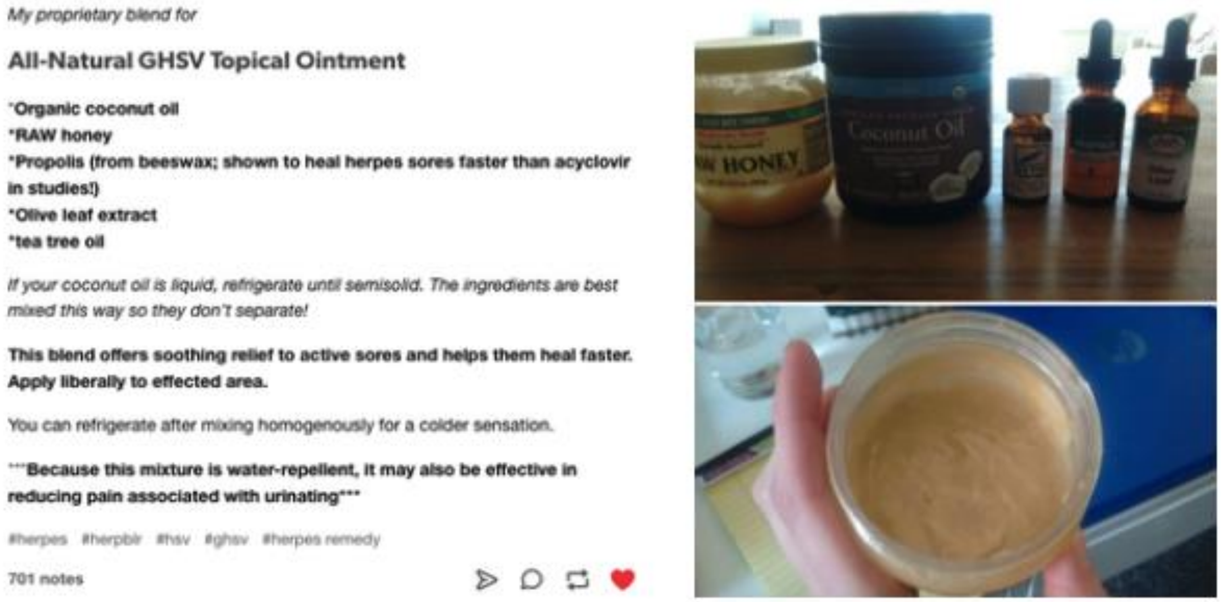
Making people scared of STDs doesn't prevent their spreading; stigma and fear actually discourages testing, disclosing & treatment.

You can get infections and viruses from kissing babies, door handles and airplanes. Getting from sex does not make you especially dirty or bad

No shame in calling out of work with snot dripping outta your nose from flu; but if from sex- all hell

Figure 6: Sixth Most Popular Herpblr Post

to take care of sunburn or a pimple. Again, the importance of seeing a post that approaches how to treat an herpes outbreak with everyday products in the same perfunctory tone as many other (non-stigmatized) ailments cannot be discounted.



My proprietary blend for

All-Natural GHSV Topical Ointment

***Organic coconut oil**
***RAW honey**
***Propolis (from beeswax; shown to heal herpes sores faster than acyclovir in studies!)**
***Olive leaf extract**
***tea tree oil**

If your coconut oil is liquid, refrigerate until semisolid. The ingredients are best mixed this way so they don't separate!

This blend offers soothing relief to active sores and helps them heal faster. Apply liberally to effected area.

You can refrigerate after mixing homogenously for a colder sensation.

*****Because this mixture is water-repellent, it may also be effective in reducing pain associated with urinating*****

#herpes #herpblr #hsv #ghsv #herpes remedy

701 notes

Figure 7: Seventh Most Popular Herpblr Post

In some corners of the Herpblr community, particularly those corners very concerned with how to reintroduce sexual activity into one's life once diagnosed, herpes is sometimes referred to as a "wingman/woman." A wingperson is someone who attends social events usually for the sole purpose of helping a friend approach a potential romantic/sexual partner. One's wingperson is supposed to provide encouragement, support, and sometimes help their friend make informed decisions on the appropriateness or compatibility of said potential partner. It's

herpessupport

An anonymous writer shared these inspiring words:

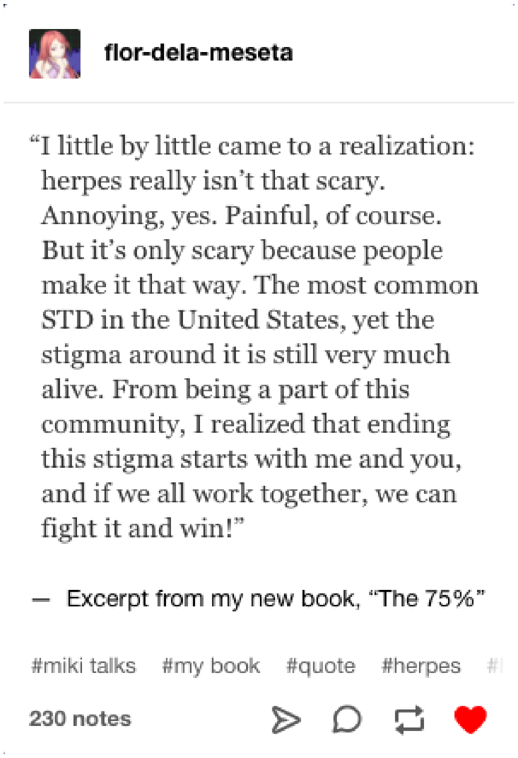
In a world full of infinite partner choices, herpes had narrowed mine to the understanding, the open minded, the risk takers. I am now confined to partners who think my awesomeness eclipses my cellular flaw — so instead of killing my love life, herpes has weirdly deepened it.

#herpblr #herpes #hsv1 #hsv #hsv2

278 notes

Figure 8: Eighth Most Popular Herpblr Post

not uncommon for those with herpes to post about how having herpes, and the attendant need to disclose, has stopped them from engaging in potentially risky, both physically and emotionally, sexual activity that they would have had they not been diagnosed. In this way, herpes can sometimes function as a wing person, figuratively protecting the host from harm. The writer of popular post number eight alludes to a similar sort of discretion without directly referring to herpes as a wing person, explaining that herpes has "deepened" their love life by way of "narrowing" their choices to "the understanding, the open minded, the risk takers," presumably because such individuals would be more accepting of someone with herpes and thus better partners. Disclosing can be intense and, should the discloser be accepted by the disclosee, the bond created can be especially meaningful. Of course, disclosing deeply personal information early in any kind of relationship can be manipulative, but that does not seem to be what this post in particular is about nor does that align with the conversations I have witnessed on Herpblr. Notable, too, is the writer's use of the word "killing" in reference to their love life, which continues the grief allusion mentioned in previous posts.



flor-dela-meseta

"I little by little came to a realization: herpes really isn't that scary. Annoying, yes. Painful, of course. But it's only scary because people make it that way. The most common STD in the United States, yet the stigma around it is still very much alive. From being a part of this community, I realized that ending this stigma starts with me and you, and if we all work together, we can fight it and win!"

— Excerpt from my new book, "The 75%"

Figure 9: Ninth Most Popular Herpblr Post

Popular post nine broadly tracks the process many people diagnosed with herpes go through, based on my own personal experience and those I have seen recounted on Herpblr: thinking herpes is scary, doing some research, and finally realizing that truly the worst part of having herpes is the stigma. @Flor-dela-meseta presents this post as an excerpt from a (hypothetical) book (which I have not been able to find) likely about herpes. The writer of this excerpt mentions the role the Herpblr community has had in the evolution of their understanding of herpes stigma and that addressing the stigma is up to those who have herpes, according to my reading of the text. Such a revelation is significant to this project because one of the most effective ways to end the stigma is to disclose one’s status.

In the final popular post included in my analysis, we see a picture of the woman behind @herpessupport and read about their decision to post a picture of themselves to their blog despite their fear of being outed, which they concede is a “dumb” fear. Given that the photo depicts them in a graduation cap and gown, we can assume that they lead a busy life outside out Tumblr. And yet this account is one of the most active on Herpblr currently, as you can see by the number of their posts included in this list. Such dedication from Herpblrians is not at all uncommon, while their comment about their fear of being outed illustrates just how insidious and difficult to shake herpes stigma can be, even for the most outspoken and informed. These moments of victory and vulnerability documented in various ways were and continue to be incredibly important for all of us across Herpblr to read and see.

I haven’t posted a picture of myself in forever because I have had this dumb fear of somehow being outed if I do so. But I am pretty damn proud of all that I have accomplished since starting college and simultaneously contracting herpes. I have nothing to be ashamed of. This is the face of herpes. This is the face of a woman who has accomplished so much and still has much more to accomplish.

I have gone through a lot to get here. So, nevertheless I have persisted.

#herpes #herpblr #hsvhotties #neverth

208 notes

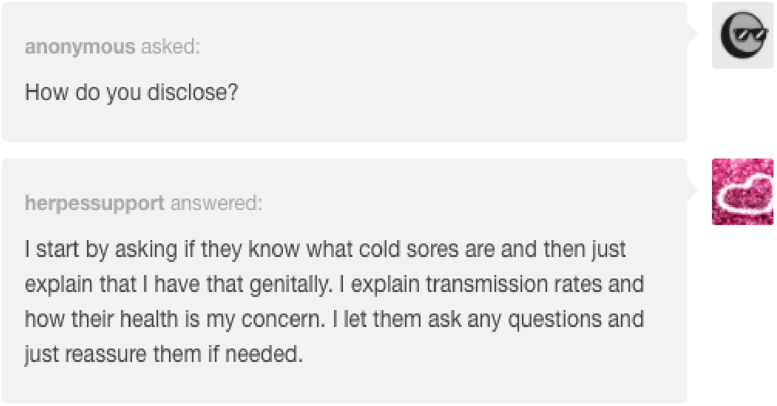
Figure 10: Tenth Most Popular Herpblr Post

Notable Posts

I include the following posts because they are notable in one of several ways: the post is relevant to disclosure rhetorics; the post is technical communication composed by folks not generally considered "experts," i.e. doctors or other healthcare professionals or technical communicators/writing scholars; the post speaks to the negative psychological trauma associated with a herpes diagnosis and, usually implicitly, the lack of support offered to the newly diagnosed by healthcare providers; or the post is an example of a healthcare provider doing anti-stigma work by communicating with their patient and the impact it had; the post is an example of other discussions happening in the community not already covered. These posts are important to include in this project because one of my research goals is to provide a content analysis of posts within the Herpblr community, and because such posts may more directly provide insight into strategies medical professionals could extrapolate into their practice—implications which I will discuss more in my final chapter.

Disclosure

These posts are examples of how Herpblrians talk about disclosure with the newly diagnosed, which usually happen by way of the Ask feature on Tumblr. In every instance I could find, these disclosure Asks are about how someone with herpes would disclose to a friend, loved one, or current or potential sexual partner, as opposed to the diagnostic disclosures that happen between a healthcare provider and their patient. These kinds of disclosures are different from those in clinical settings in that the discloser may have limited experience in disclosing potentially stigmatizing information, especially about themselves, and


anonymous asked:

How do you disclose?

herpessupport answered:

I start by asking if they know what cold sores are and then just explain that I have that genitally. I explain transmission rates and how their health is my concern. I let them ask any questions and just reassure them if needed.

Figure 11: Example Disclosure Ask

the risk of negative social repercussions are much higher than that of a healthcare provider. Unlike other social media platforms, Tumblr does not have a way for users to post things on others' accounts. Instead, the ask feature allows users to send questions to other users, usually anonymously, which are then answered via a public post on the askee's blog. Again, being able to create a Tumblr account, which does not require using a first or last name, and asking someone with insider knowledge and experience with herpes a question is likely one of the reasons why this platform in particular is the home for people with a highly stigmatized condition. Asks about disclosure are sometimes short and to the point while others might be longer and give some insight into the asker's state of mind. Even though these examples were posted from the same account, @herpessupport, they are representative of the responses to such asks: detailed, actionable advice that acknowledges the asker's apparent state of mind and, I would argue, makes them feel seen.

Technical Communication

herpessupport

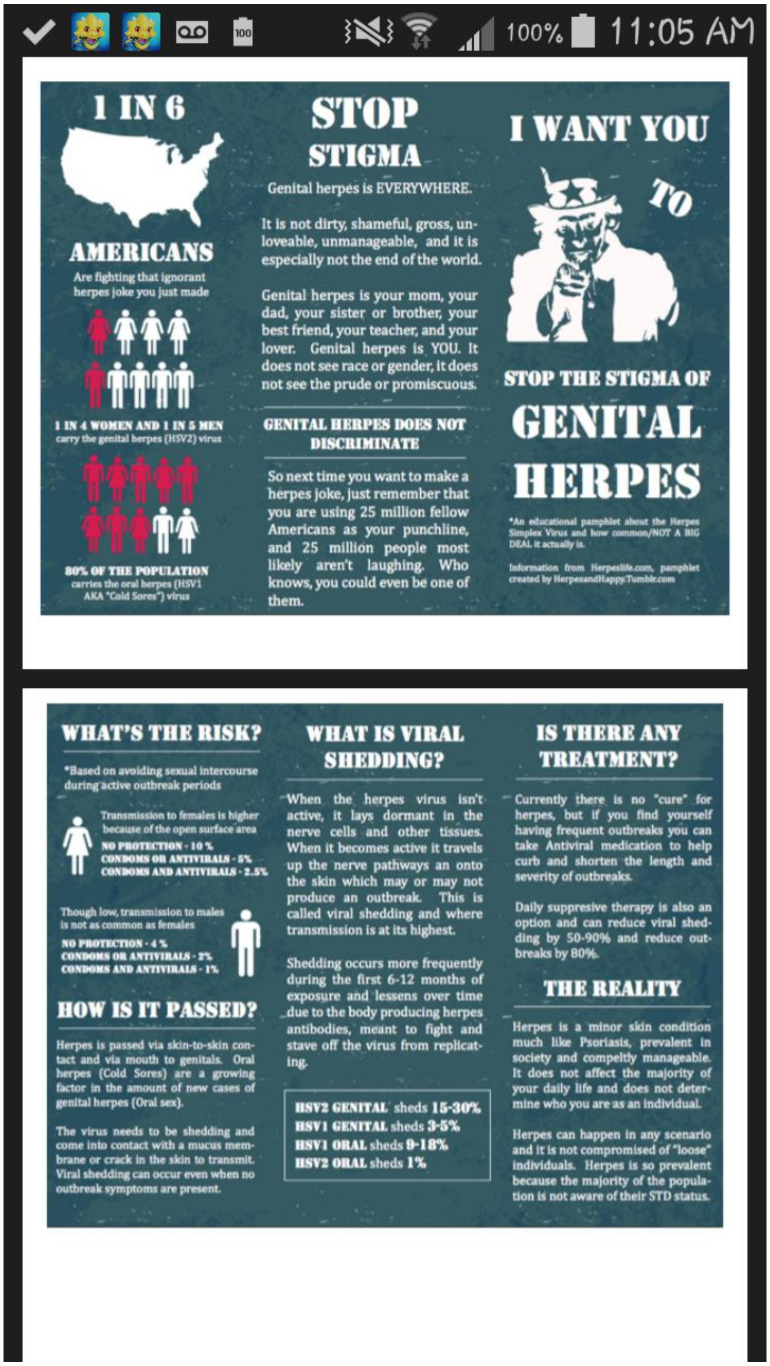
anonymous asked:

Hey, I found out I have herpes a couple of weeks ago. I have a really hard time dealing with it. I am the type of girl that was really straight forward with guys. I felt confident and now I don't anymore.. If guys approach me I turn them down because I don't want to tell them my secret. Also I don't have the courage to step up to guys like I used to because I am afraid that they will turn me down in the long run. Do you have any tips? Right now feeling like I will never be the same again..

So something that really helped me when I wasn't feeling very confident was to fake it till I made it. I did this by creating a tinder and disclosing in my bio. And if you're scared about doing that and having people see, I did not include my face in any of the pictures and still got a ton of matches. And I would say 95% of responses I got were "Wow your honesty is so hot" and it really boosted my confidence. Or if you don't want to disclose directly in the bio just match with people and then disclose to them by playing 2 truths and a lie and then segwaying that into educating them.

Figure 12: Example Disclosure Ask

Herpblrians are often doing the work of technical communicators, evidence that personal experience and expertise should sometimes be valued over more culturally accepted kinds of expertise like the kind healthcare providers often acquire. For example, several users have created pamphlets and posted them as pdfs to their blog for others to use while others have shared a resource from the website herpesopportunity.com, which is essentially an online support group that helps people cope with their herpes diagnosis. The examples provided represent a range of design skills and prioritizing of information, follow genre conventions of a pamphlet or brochure, and are directed at different audiences. Other users have put the platforms blogging nature to good use by including things like gifs into their posts. The Glitter Stick example features gif bookends of Marilyn Monroe and kitten Marie from the film *The Aristocats* along with the word “pussy,” choices which further the assertion that the Herpblr community is comprised largely of women.



1 IN 6

AMERICANS

Are fighting that ignorant herpes joke you just made

1 IN 4 WOMEN AND 1 IN 5 MEN
carry the genital herpes (HSV2) virus

80% OF THE POPULATION
carries the oral herpes (HSV1 AKA "Cold Sores") virus

STOP
STIGMA

Genital herpes is EVERYWHERE.

It is not dirty, shameful, gross, unloveable, unmanageable, and it is especially not the end of the world.

Genital herpes is your mom, your dad, your sister or brother, your best friend, your teacher, and your lover. Genital herpes is YOU. It does not see race or gender, it does not see the prude or promiscuous.

GENITAL HERPES DOES NOT DISCRIMINATE

So next time you want to make a herpes joke, just remember that you are using 25 million fellow Americans as your punchline, and 25 million people most likely aren't laughing. Who knows, you could even be one of them.

I WANT YOU

TO

STOP THE STIGMA OF

GENITAL HERPES

*An educational pamphlet about the Herpes Simplex Virus and how common/NOT A BIG DEAL it actually is.

Information from Herpeslife.com, pamphlet created by HerpesandHappy.Tumblr.com

WHAT'S THE RISK?

*Based on avoiding sexual intercourse during active outbreak periods

Transmission to females is higher because of the open surface area
NO PROTECTION - 10 %
CONDOMS OR ANTIVIRALS - 5%
CONDOMS AND ANTIVIRALS - 2.5%

Though low, transmission to males is not as common as females
NO PROTECTION - 4 %
CONDOMS OR ANTIVIRALS - 2%
CONDOMS AND ANTIVIRALS - 1%

HOW IS IT PASSED?

Herpes is passed via skin-to-skin contact and via mouth to genitals. Oral herpes (Cold Sores) are a growing factor in the amount of new cases of genital herpes (Oral sex).

The virus needs to be shedding and come into contact with a mucus membrane or crack in the skin to transmit. Viral shedding can occur even when no outbreak symptoms are present.

WHAT IS VIRAL SHEDDING?

When the herpes virus isn't active, it lays dormant in the nerve cells and other tissues. When it becomes active it travels up the nerve pathways an onto the skin which may or may not produce an outbreak. This is called viral shedding and where transmission is at its highest.

Shedding occurs more frequently during the first 6-12 months of exposure and lessens over time due to the body producing herpes antibodies, meant to fight and stave off the virus from replicating.

HSV2 GENITAL sheds **15-30%**
HSV1 GENITAL sheds **3-5%**
HSV1 ORAL sheds **9-18%**
HSV2 ORAL sheds **1%**

IS THERE ANY TREATMENT?

Currently there is no "cure" for herpes, but if you find yourself having frequent outbreaks you can take Antiviral medication to help curb and shorten the length and severity of outbreaks.

Daily suppresive therapy is also an option and can reduce viral shedding by 50-90% and reduce outbreaks by 80%.

THE REALITY

Herpes is a minor skin condition much like Psoriasis, prevalent in society and compeltly manageable. It does not affect the majority of your daily life and does not determine who you are as an individual.

Herpes can happen in any scenario and it is not compromised of "loose" individuals. Herpes is so prevalent because the majority of the population is not aware of their STD status.

Figure 13: Disclosure Brochure One

Some Statistics

- GENITAL HERPES -

1 IN 4
WOMEN

1 IN 5
MEN

- ORAL HERPES (AKA COLD SORES) -

80% OF THE POPULATION

Chances are, you probably already carry some form of this virus. Lucky for you that means you have built up antibodies to protect you from contracting the other kind!

What's the Risk?

If we use NO PROTECTION
4% chance of transmission

If we use CONDOMS
2% chance of transmission

CONDOMS AND ANTIVIRALS
>1% chance of transmission

It is extremely hard to pass herpes to males, as you can imagine, there's not as much open surface area.

YOU ARE MORE LIKELY TO DIE in a car crash, get run over, get cancer, have a stroke or a heart attack THAN GET HERPES.

GOLDEN!

How Bad Is My Herp?

EASY PEASY LEMON SQUEEZY

I rarely get outbreaks, it's been over a year and still nada. I was in a three year relationship and we DIDN'T use condoms or antivirals, the dude is still Herpes free (At least when I left him).

Now, I take Acyclovir twice daily to reduce the risk of passing it on to you, sexy pants. That's right, you're getting this pamphlet because I deemed you bangworthy and trusted you enough to share this information about me.

Consider yourself lucky my man, not everyone gets the chance to fuck Rachel.

So....

HOW DID THIS HAPPEN TO ME?

★ I was 19
★ Liked a guy
★ Lost my virginity
★ Bing, bang, boom
★ HERPES
★ Guy didn't own/fess up
★ Then blamed me
★ FUCKED RIGHT?!

BUT HONESTLY, HERPES AIN'T THAT BAD

READ ON MY SEX MUFFIN...

You made it!

STILL INTERESTED?

I know this was probably awkward as fuck, but feel free to do your own research and seriously, no pressure. I will do everything in my power to protect the D. Since I know my status and am taking literally EVERY precaution possible, you have LESS THAN 1% chance of catching herpes.

You are more likely to catch herpes from that side chick who says she's "clean" when she probably isn't. Most STD panels don't test for herpes unless you ASK.

ALSO...CHECK OUT MY STD SUPPORT BLOG

HerpesandHappy.Tumblr.com

NOW, ARE WE DOING THIS OR WHAT?

Surprise!

YOUR GIRL HAS HERPES

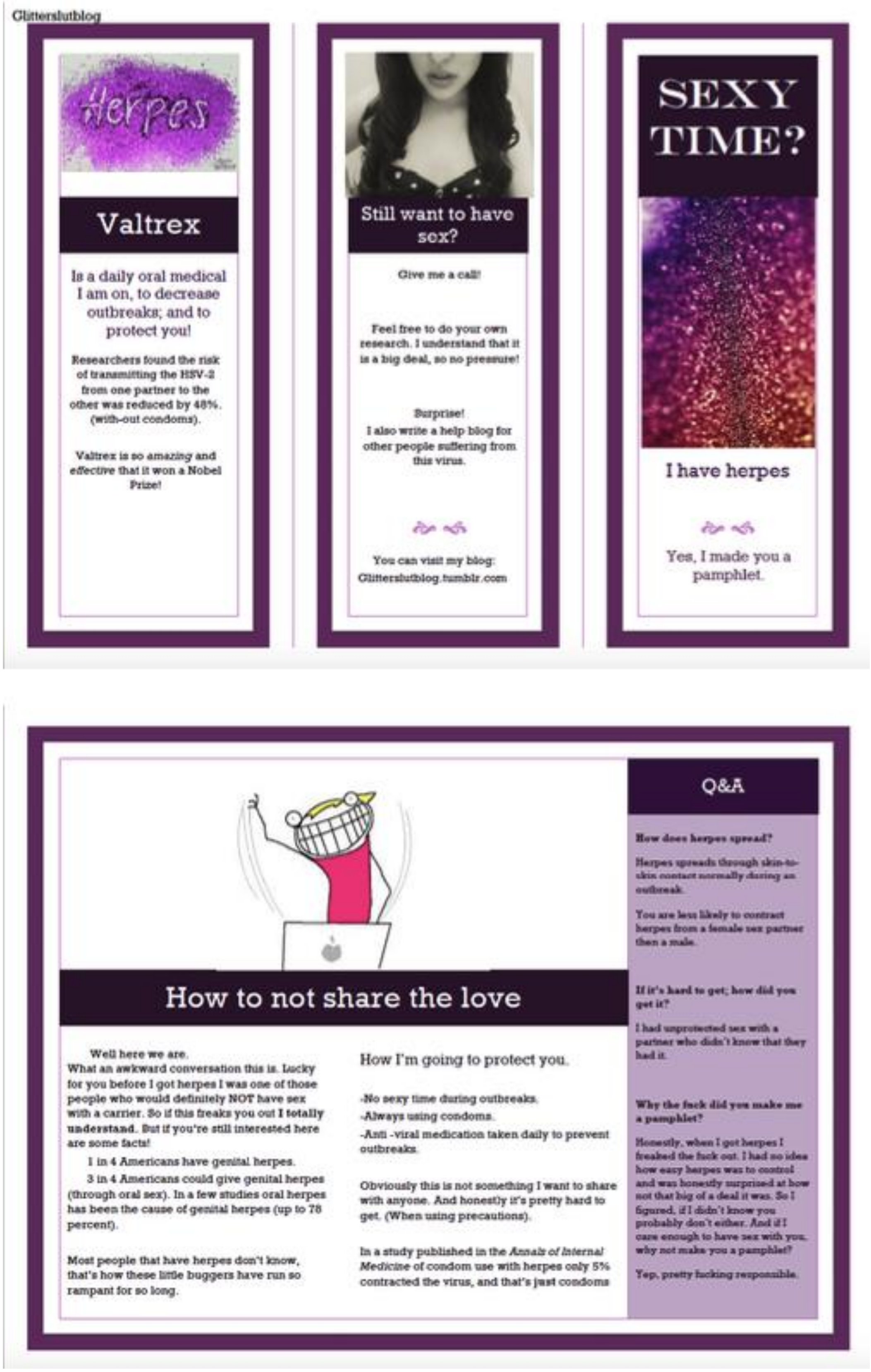
HERE IS EVERYTHING YOU NEED TO KNOW BEFORE

A) Freaking Out

- or -

B) Doing the Dirty

Figure 14: Disclosure Brochure Two



Glitterslutblog

Herpes

Valtrex

Is a daily oral medical I am on, to decrease outbreaks; and to protect you!

Researchers found the risk of transmitting the HSV-2 from one partner to the other was reduced by 48%. (with-out condoms).

Valtrex is so *amazing* and effective that it won a Nobel Prize!

Still want to have sex?

Give me a call!

Feel free to do your own research. I understand that it is a big deal, so no pressure!

Surprise!
I also write a help blog for other people suffering from this virus.

* * *

You can visit my blog:
Glitterslutblog.tumblr.com

SEXY TIME?

I have herpes

* * *

Yes, I made you a pamphlet.

How to not share the love

Well here we are.
What an awkward conversation this is. Lucky for you before I got herpes I was one of those people who would definitely NOT have sex with a carrier. So if this freaks you out I totally understand. But if you're still interested here are some facts!

1 in 4 Americans have genital herpes.

3 in 4 Americans could give genital herpes (through oral sex). In a few studies oral herpes has been the cause of genital herpes (up to 78 percent).

Most people that have herpes don't know, that's how these little buggers have run so rampant for so long.

How I'm going to protect you.

-No sexy time during outbreaks.
-Always using condoms.
-Anti -viral medication taken daily to prevent outbreaks.

Obviously this is not something I want to share with anyone. And honestly it's pretty hard to get. (When using precautions).

In a study published in the *Annals of Internal Medicine* of condom use with herpes only 5% contracted the virus, and that's just condoms

Q&A

How does herpes spread?

Herpes spreads through skin-to-skin contact normally during an outbreak.

You are less likely to contract herpes from a female sex partner then a male.

If it's hard to get; how did you get it?

I had unprotected sex with a partner who didn't know that they had it.

Why the fuck did you make me a pamphlet?

Honestly, when I got herpes I freaked the fuck out. I had no idea how easy herpes was to control and was honestly surprised at how not that big of a deal it was. So I figured, if I didn't know you probably don't either. And if I care enough to have sex with you, why not make you a pamphlet?

Yep, pretty fucking responsible.

Figure 15: Disclosure Brochure Three

JUST DIAGNOSED?

you'll be **just fine**. promise.

Most of the suffering from herpes happens in your head — in your beliefs about yourself. Shift these beliefs, accept yourself, shift your life. Who you are is more important than what you have.

"It's really important for people to understand how common herpes is, and how little problem it causes ..."
— Dr. Anna Kaminski (PP)

16.2%
>25,000,000

1 out of 6 Americans* have genital herpes.

The virus "down under"

The amount of Americans* with the genital herpes virus is millions more than the entire population of Australia (21.5 million).

*Americans ages 14-49 years. Herpes data per CDC. Population data per 2010 US Census & 2009 American Community Survey. Source of all data on this page comes from the research pages to the right.

THE BASICS

- **Over 25 million Americans*** **(16.2%)** have genital herpes.
- **776,000** new herpes cases annually (2,000/day).
- **80%** have oral HSV-1

80% of the 16.2% with genital herpes don't know they have it.

Herpes is transmitted via **skin-to-skin contact** in a warm/moist environment (mostly genitals/mouth). Herpes is transmitted <u>only</u> when the contagious area of the skin contacts the mucous membrane or a crack in the surface of the skin.

Over time you will probably have **fewer outbreaks** and they will be easier to handle as your body builds up natural immunity. Good diet, enough rest and sleep, and managing stress may help prevent herpes recurrences.

15-20% of people who have an initial outbreak never have another outbreak. The average number of outbreaks is **4-6/yr**. Initial outbreaks can last up to **2-4 weeks**.

Prodrome symptoms? Tingling. Itching. Burning. Any could be your body telling you an outbreak or viral shedding is about to happen. Get to know your body and how it interacts with herpes to avoid outbreaks and protect partners. The more you know your herpes prodrome symptoms, the less risk of you passing herpes to your partner. Knowledge creates more safety.

WHAT IS VIRAL SHEDDING?

On average, **5-10%** of the time, herpes sheds virus on the skin around the site of your outbreaks even when you are not having an outbreak.

Certain medications can help manage herpes when you have an outbreak or you can take daily suppressive therapy.

Daily suppressive antiviral medication can reduce shedding by **50-90%** and reduce the frequency of outbreaks by **up to 80%**. Over time, your body will naturally build up immunity (naturally having less outbreaks in frequency & intensity).

DISCLOSURE E-BOOK

How to have "the herpes talk"

- Download the free e-book to shift your whole perspective on the herpes talk — from one of fear to one of opportunity: www.eepurl.com/b4IPP

WHERE DOES THIS INFO COME FROM?

(just search for these terms in google)

- **Planned Parenthood's herpes page**
- **ASHA Herpes Resource Center**
- **WebMD herpes page**
- **CDC: Genital Herpes Fact Sheet**
- **NYT Health Guide: Genital Herpes**
- **Westover Heights Herpes Handbook**

Note: There is always a risk of passing this skin condition known as herpes. But with knowledge, care and communication, the risk of passing it to your partner can be lessened. See the Herpes Opportunity Disclosure Handout for more on that: http://bit.ly/h-opp-disclosure-handout

Spread knowledge and facts. Live fully. Love fully. **Begin now.**

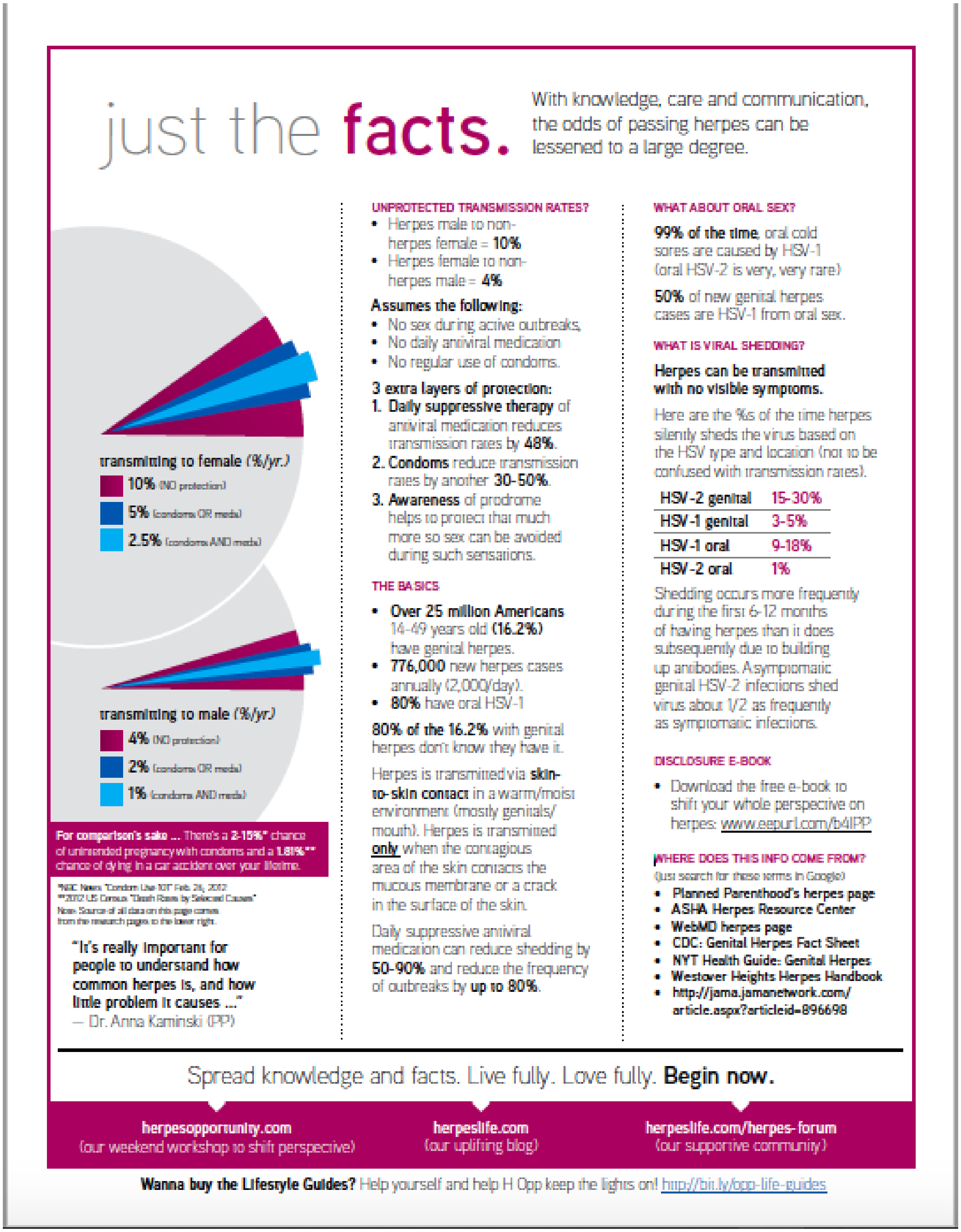
herpesopportunity.com
(our weekend workshop to heal shame)

herpeslife.com
(our uplifting blog)

herpeslife.com/herpes-forum
(our supportive community)

Wanna buy the Lifestyle Guides? Help yourself and help H Opp keep the lights on! http://bit.ly/opp-life-guides

Figure 16: Herpes Informational Brochure Page One



just the **facts.**

With knowledge, care and communication, the odds of passing herpes can be lessened to a large degree.

transmitting to female *(%/yr.)*

- 🟥 **10%** (NO protection)
- 🟦 **5%** (condoms OR meds)
- 🟦 **2.5%** (condoms AND meds)

transmitting to male *(%/yr.)*

- 🟥 **4%** (NO protection)
- 🟦 **2%** (condoms OR meds)
- 🟦 **1%** (condoms AND meds)

For comparison's sake ... There's a **2-15%*** chance of unintended pregnancy with condoms and a **1.81%**** chance of dying in a car accident over your lifetime.

*NBC News "Condom Use 101" Feb. 28, 2012
**2012 US Census "Death Rates by Selected Causes"
Note: Source of all data on this page comes from the research pages to the lower right.

> **"It's really important for people to understand how common herpes is, and how little problem it causes ..."**
> — Dr. Anna Kaminski (PP)

UNPROTECTED TRANSMISSION RATES?

- Herpes male to non-herpes female = **10%**
- Herpes female to non-herpes male = **4%**

Assumes the following:

- No sex during active outbreaks.
- No daily antiviral medication
- No regular use of condoms.

3 extra layers of protection:

1. **Daily suppressive therapy** of antiviral medication reduces transmission rates by **48%**.
2. **Condoms** reduce transmission rates by another **30-50%**.
3. **Awareness** of prodrome helps to protect that much more so sex can be avoided during such sensations.

THE BASICS

- **Over 25 million Americans** 14-49 years old **(16.2%)** have genital herpes.
- **776,000** new herpes cases annually (2,000/day).
- **80%** have oral HSV-1

80% of the 16.2% with genital herpes don't know they have it.

Herpes is transmitted via **skin-to-skin contact** in a warm/moist environment (mostly genitals/mouth). Herpes is transmitted **only** when the contagious area of the skin contacts the mucous membrane or a crack in the surface of the skin.

Daily suppressive antiviral medication can reduce shedding by **50-90%** and reduce the frequency of outbreaks by **up to 80%**.

WHAT ABOUT ORAL SEX?

99% of the time, oral cold sores are caused by HSV-1 (oral HSV-2 is very, very rare)

50% of new genital herpes cases are HSV-1 from oral sex.

WHAT IS VIRAL SHEDDING?

Herpes can be transmitted with no visible symptoms.

Here are the %s of the time herpes silently sheds the virus based on the HSV type and location (not to be confused with transmission rates).

HSV-2 genital	**15-30%**
HSV-1 genital	**3-5%**
HSV-1 oral	**9-18%**
HSV-2 oral	**1%**

Shedding occurs more frequently during the first 6-12 months of having herpes than it does subsequently due to building up antibodies. Asymptomatic genital HSV-2 infections shed virus about 1/2 as frequently as symptomatic infections.

DISCLOSURE E-BOOK

- Download the free e-book to shift your whole perspective on herpes: www.eepurl.com/b4IPP

WHERE DOES THIS INFO COME FROM?

(just search for these terms in Google)

- **Planned Parenthood's herpes page**
- **ASHA Herpes Resource Center**
- **WebMD herpes page**
- **CDC: Genital Herpes Fact Sheet**
- **NYT Health Guide: Genital Herpes**
- **Westover Heights Herpes Handbook**
- **http://jama.jamanetwork.com/article.aspx?articleid=896698**

Spread knowledge and facts. Live fully. Love fully. **Begin now.**

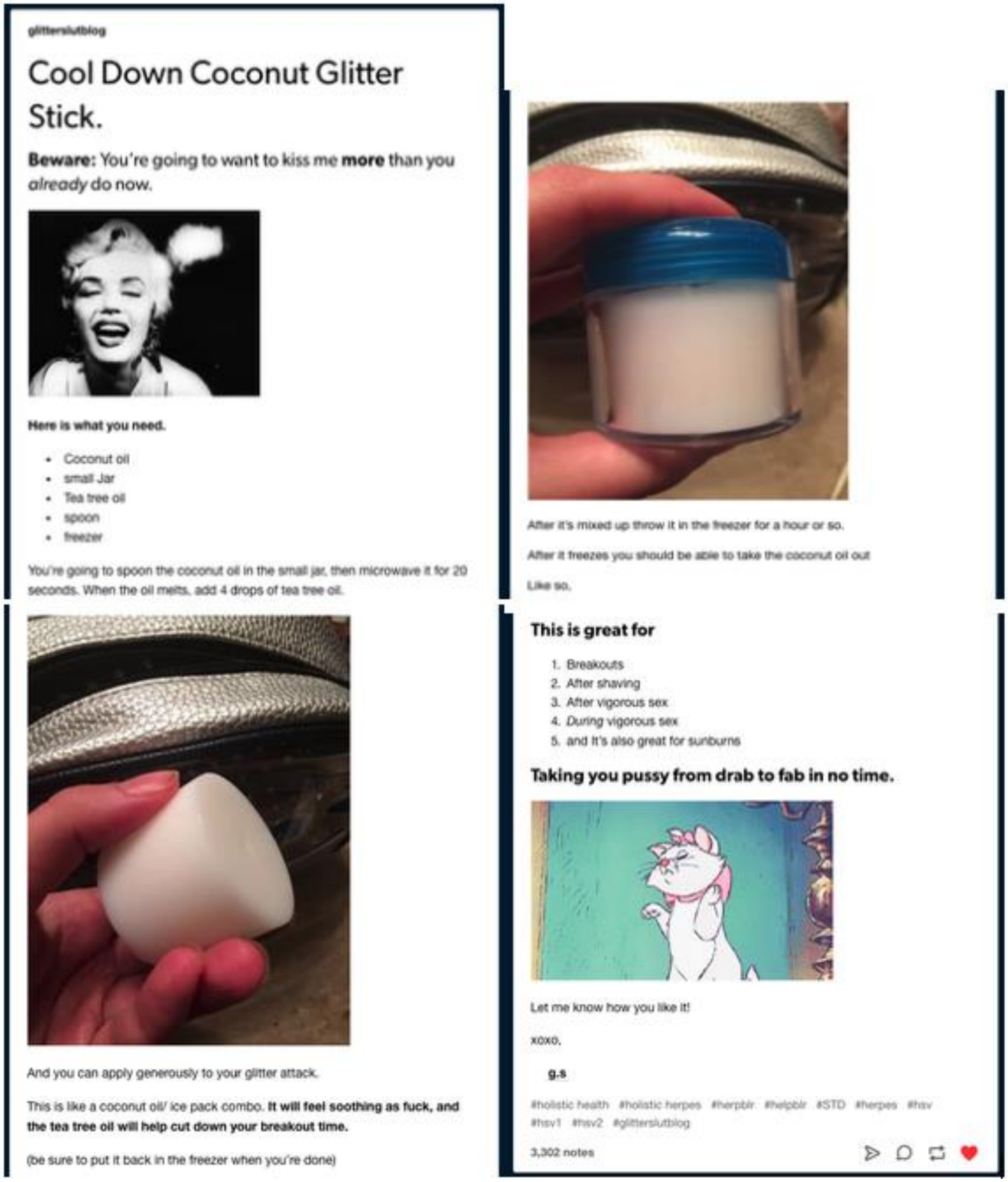
herpesopportunity.com
(our weekend workshop to shift perspective)

herpeslife.com
(our uplifting blog)

herpeslife.com/herpes-forum
(our supportive community)

Wanna buy the Lifestyle Guides? Help yourself and help H Opp keep the lights on! http://bit.ly/opp-life-guides

Figure 17: Herpes Informational Brochure Page Two



glitterslutblog

Cool Down Coconut Glitter Stick.

Beware: You're going to want to kiss me **more** than you *already* do now.

Here is what you need.

- Coconut oil
- small Jar
- Tea tree oil
- spoon
- freezer

You're going to spoon the coconut oil in the small jar, then microwave it for 20 seconds. When the oil melts, add 4 drops of tea tree oil.

After it's mixed up throw it in the freezer for a hour or so.

After it freezes you should be able to take the coconut oil out

Like so.

And you can apply generously to your glitter attack.

This is like a coconut oil/ ice pack combo. **It will feel soothing as fuck, and the tea tree oil will help cut down your breakout time.**

(be sure to put it back in the freezer when you're done)

This is great for

1. Breakouts
2. After shaving
3. After vigorous sex
4. *During* vigorous sex
5. and it's also great for sunburns

Taking you pussy from drab to fab in no time.

Let me know how you like it!

xoxo,

g.s

#holistic health #holistic herpes #herpblr #helpblr #STD #herpes #hsv #hsv1 #hsv2 #glitterslutblog

3,302 notes

Figure 18: Cool Down Glitter Stick Instructions

Negative Psychological Trauma

As made clear in previous paragraphs and chapters, herpes stigma has very real effects on people who are diagnosed. Even the Centers for Disease Control recommends against testing people for herpes unless they are showing signs of an active outbreak. Here is one example of how discussions of stigma happen on Tumblr. Notice that the response includes actionable steps as well as personal reassurance based on the personal experience/expertise of someone living with herpes. Disclosing our status is important not just for our own processing of a herpes diagnosis, but also because doing so provides others with a model and a place to reach out to.


herpessupport

anonymous asked:

I don't want to live anymore

Please please please go talk to a counselor or therapist. Or call 1-800-273-8255. Herpes is so minimal and I know you can't see that right now but I promise you if you push through this, which I know you can, you will eventually see this too. Herpes is like the wizard of oz, this seemingly big giant thing, but once you look behind the curtain you realize it's nothing more than a measly virus.

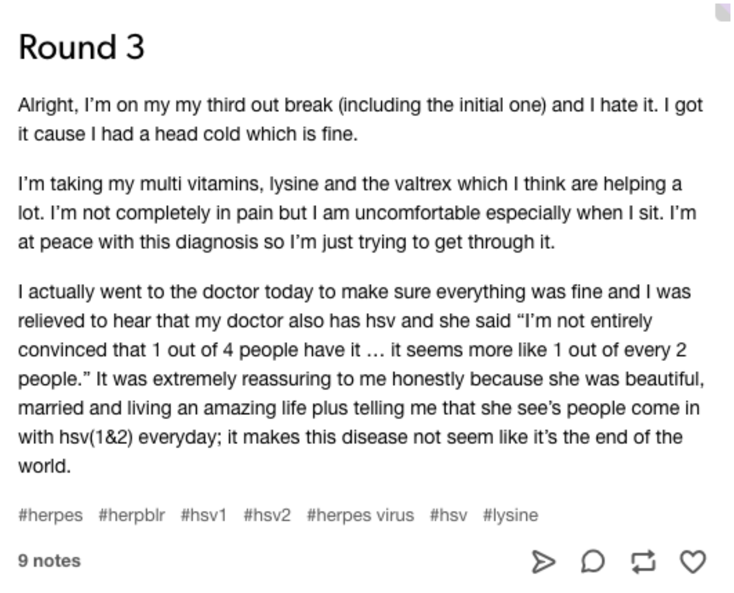
Ask herpessupport a question

7 notes

Figure 19: Psychological Trauma Ask

Anti-Stigma Work from Healthcare Providers

In their positions of power and prestige, I argue that healthcare providers have a responsibility to not only not perpetuate stigma but to be actively anti-stigma. This post is one example of how that work might happen and the positive impact such work can have on patients. Again here, the act of disclosing on the part of the healthcare provider and subsequent conversation brought a measure of relief to the person who posted this and obviously helped them dispel some of the negative


Round 3

Alright, I'm on my my third out break (including the initial one) and I hate it. I got it cause I had a head cold which is fine.

I'm taking my multi vitamins, lysine and the valtrex which I think are helping a lot. I'm not completely in pain but I am uncomfortable especially when I sit. I'm at peace with this diagnosis so I'm just trying to get through it.

I actually went to the doctor today to make sure everything was fine and I was relieved to hear that my doctor also has hsv and she said "I'm not entirely convinced that 1 out of 4 people have it … it seems more like 1 out of every 2 people." It was extremely reassuring to me honestly because she was beautiful, married and living an amazing life plus telling me that she see's people come in with hsv(1&2) everyday; it makes this disease not seem like it's the end of the world.

#herpes #herpblr #hsv1 #hsv2 #herpes virus #hsv #lysine

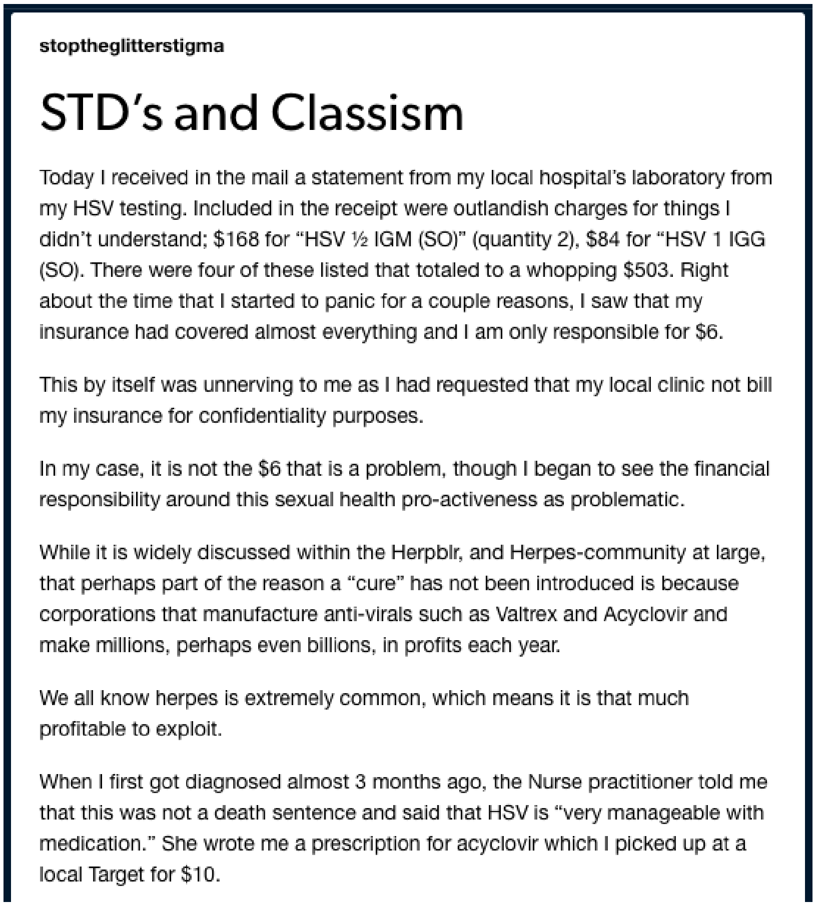
9 notes

Figure 20: Anti-Stigma Post

affects stigma can have.

Miscellaneous But Important

The following posts represent some of the larger, cultural conversations on socioeconomic status, consent, medical encounters, and/or dealing with STI myths happening within the Herpblr community that concern issues beyond the localized concerns of the newly diagnosed and more experienced Herpblrians. It seems important to include such examples in this project so as to truly represent the entirety of the community, but also to suggest that nuanced discussions of complex issues are not only relegated to academic or otherwise elitist circles.



stoptheglitterstigma

STD's and Classism

Today I received in the mail a statement from my local hospital's laboratory from my HSV testing. Included in the receipt were outlandish charges for things I didn't understand; $168 for "HSV ½ IGM (SO)" (quantity 2), $84 for "HSV 1 IGG (SO). There were four of these listed that totaled to a whopping $503. Right about the time that I started to panic for a couple reasons, I saw that my insurance had covered almost everything and I am only responsible for $6.

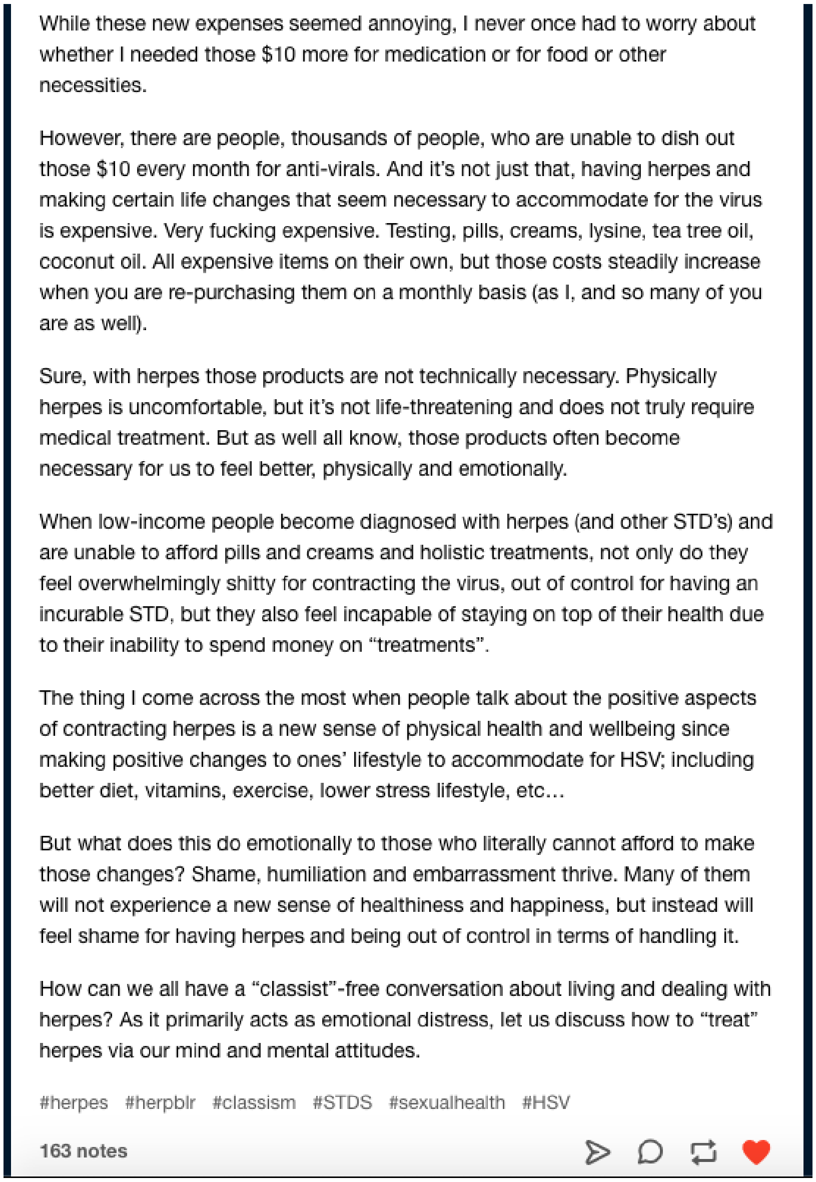
This by itself was unnerving to me as I had requested that my local clinic not bill my insurance for confidentiality purposes.

In my case, it is not the $6 that is a problem, though I began to see the financial responsibility around this sexual health pro-activeness as problematic.

While it is widely discussed within the Herpblr, and Herpes-community at large, that perhaps part of the reason a "cure" has not been introduced is because corporations that manufacture anti-virals such as Valtrex and Acyclovir and make millions, perhaps even billions, in profits each year.

We all know herpes is extremely common, which means it is that much profitable to exploit.

When I first got diagnosed almost 3 months ago, the Nurse practitioner told me that this was not a death sentence and said that HSV is "very manageable with medication." She wrote me a prescription for acyclovir which I picked up at a local Target for $10.


While these new expenses seemed annoying, I never once had to worry about whether I needed those $10 more for medication or for food or other necessities.

However, there are people, thousands of people, who are unable to dish out those $10 every month for anti-virals. And it's not just that, having herpes and making certain life changes that seem necessary to accommodate for the virus is expensive. Very fucking expensive. Testing, pills, creams, lysine, tea tree oil, coconut oil. All expensive items on their own, but those costs steadily increase when you are re-purchasing them on a monthly basis (as I, and so many of you are as well).

Sure, with herpes those products are not technically necessary. Physically herpes is uncomfortable, but it's not life-threatening and does not truly require medical treatment. But as well all know, those products often become necessary for us to feel better, physically and emotionally.

When low-income people become diagnosed with herpes (and other STD's) and are unable to afford pills and creams and holistic treatments, not only do they feel overwhelmingly shitty for contracting the virus, out of control for having an incurable STD, but they also feel incapable of staying on top of their health due to their inability to spend money on "treatments".

The thing I come across the most when people talk about the positive aspects of contracting herpes is a new sense of physical health and wellbeing since making positive changes to ones' lifestyle to accommodate for HSV; including better diet, vitamins, exercise, lower stress lifestyle, etc…

But what does this do emotionally to those who literally cannot afford to make those changes? Shame, humiliation and embarrassment thrive. Many of them will not experience a new sense of healthiness and happiness, but instead will feel shame for having herpes and being out of control in terms of handling it.

How can we all have a "classist"-free conversation about living and dealing with herpes? As it primarily acts as emotional distress, let us discuss how to "treat" herpes via our mind and mental attitudes.

#herpes #herpblr #classism #STDS #sexualhealth #HSV

Figure 21: Classism in the Herpes Community

livingpositive2019 glitterxmessx

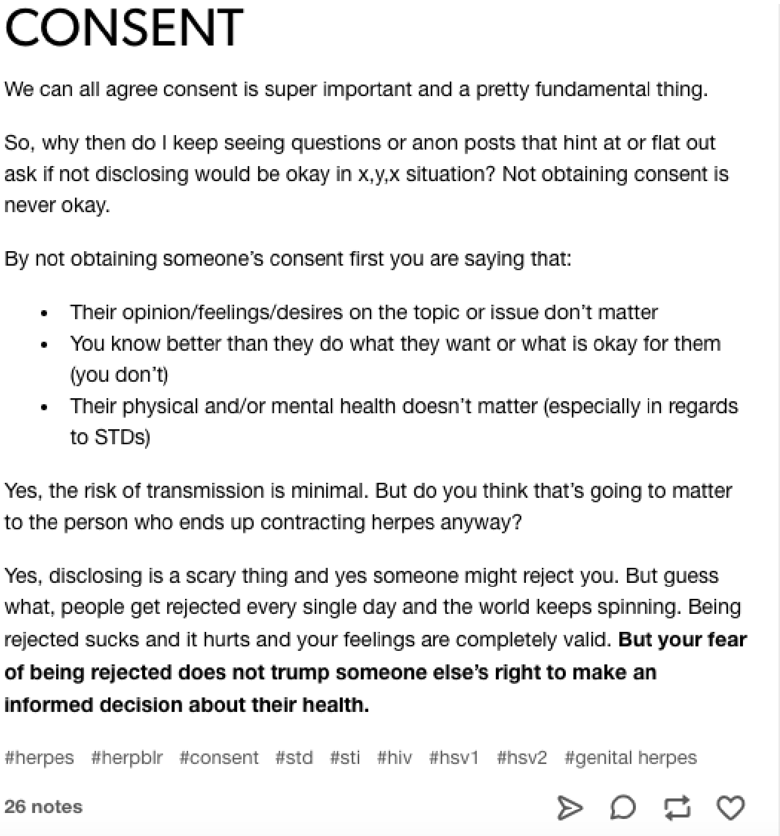
unfriendlyhsvhottie

you can't have body positivity with STI shaming
you can't have sex positivity with STI shaming

Source: unfriendlyhsvh…

256 notes

Figure 22: Body Positive Critique



CONSENT

We can all agree consent is super important and a pretty fundamental thing.

So, why then do I keep seeing questions or anon posts that hint at or flat out ask if not disclosing would be okay in x,y,x situation? Not obtaining consent is never okay.

By not obtaining someone's consent first you are saying that:

- Their opinion/feelings/desires on the topic or issue don't matter
- You know better than they do what they want or what is okay for them (you don't)
- Their physical and/or mental health doesn't matter (especially in regards to STDs)

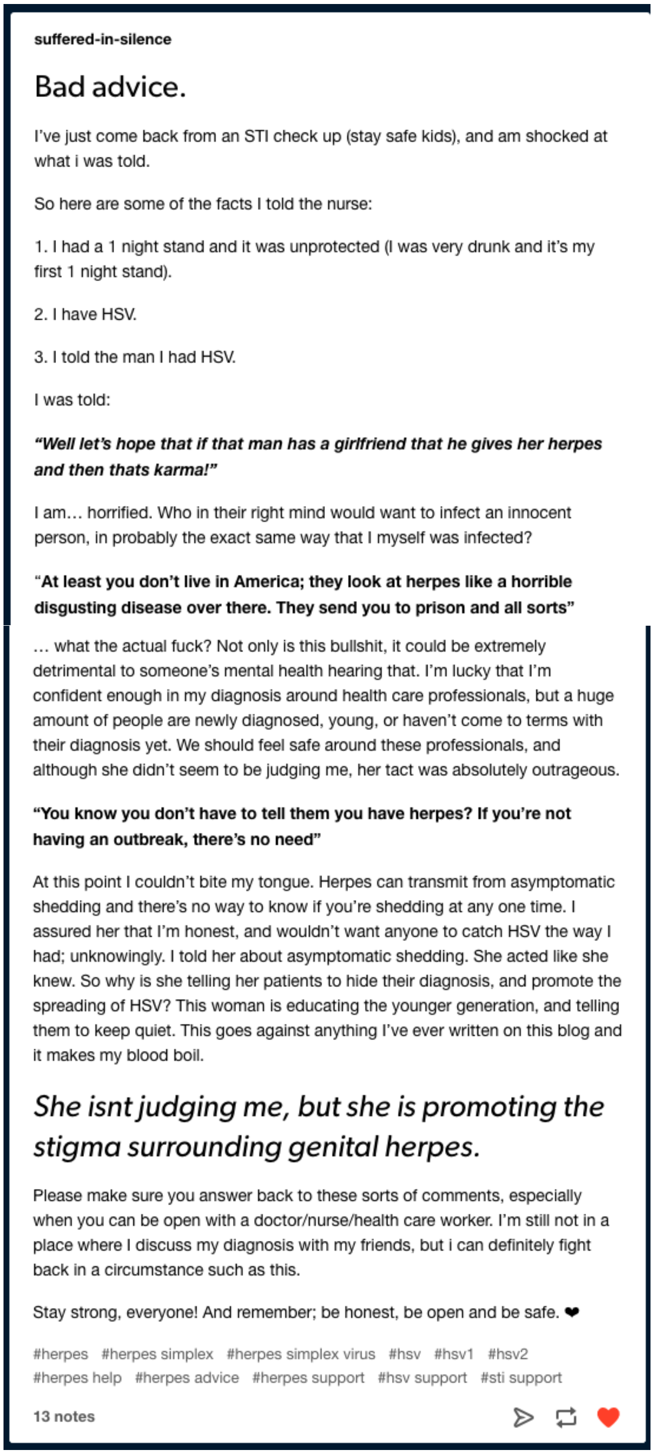
Yes, the risk of transmission is minimal. But do you think that's going to matter to the person who ends up contracting herpes anyway?

Yes, disclosing is a scary thing and yes someone might reject you. But guess what, people get rejected every single day and the world keeps spinning. Being rejected sucks and it hurts and your feelings are completely valid. **But your fear of being rejected does not trump someone else's right to make an informed decision about their health.**

#herpes #herpblr #consent #std #sti #hiv #hsv1 #hsv2 #genital herpes

26 notes

Figure 23: Intersection of Disclosure and Consent Post



suffered-in-silence

Bad advice.

I've just come back from an STI check up (stay safe kids), and am shocked at what i was told.

So here are some of the facts I told the nurse:

1. I had a 1 night stand and it was unprotected (I was very drunk and it's my first 1 night stand).

2. I have HSV.

3. I told the man I had HSV.

I was told:

"Well let's hope that if that man has a girlfriend that he gives her herpes and then thats karma!"

I am… horrified. Who in their right mind would want to infect an innocent person, in probably the exact same way that I myself was infected?

"**At least you don't live in America; they look at herpes like a horrible disgusting disease over there. They send you to prison and all sorts**"

… what the actual fuck? Not only is this bullshit, it could be extremely detrimental to someone's mental health hearing that. I'm lucky that I'm confident enough in my diagnosis around health care professionals, but a huge amount of people are newly diagnosed, young, or haven't come to terms with their diagnosis yet. We should feel safe around these professionals, and although she didn't seem to be judging me, her tact was absolutely outrageous.

"You know you don't have to tell them you have herpes? If you're not having an outbreak, there's no need"

At this point I couldn't bite my tongue. Herpes can transmit from asymptomatic shedding and there's no way to know if you're shedding at any one time. I assured her that I'm honest, and wouldn't want anyone to catch HSV the way I had; unknowingly. I told her about asymptomatic shedding. She acted like she knew. So why is she telling her patients to hide their diagnosis, and promote the spreading of HSV? This woman is educating the younger generation, and telling them to keep quiet. This goes against anything I've ever written on this blog and it makes my blood boil.

She isnt judging me, but she is promoting the stigma surrounding genital herpes.

Please make sure you answer back to these sorts of comments, especially when you can be open with a doctor/nurse/health care worker. I'm still not in a place where I discuss my diagnosis with my friends, but i can definitely fight back in a circumstance such as this.

Stay strong, everyone! And remember; be honest, be open and be safe. ❤

#herpes #herpes simplex #herpes simplex virus #hsv #hsv1 #hsv2 #herpes help #herpes advice #herpes support #hsv support #sti support

13 notes

Figure 24: Negative Healthcare Communication Post

In summary, the top 10 posts and the notable posts explained above provide a multifaceted snapshot of a complex and highly technical community—a community that discusses a stigmatized condition frankly and that interfaces social and medical aspects of health.

I argue that this unlikely source provides avenues forward in relationship to the challenges discussed in Chapter 3. Conclusions from this analysis and further implications will be provided in the next chapter, along with a more robust discussion of disclosure rhetorics.

Chapter Five: Disclosure Rhetorics and Solutions

theessenceofcatherine
dulect Follow

methhomework
when i was a kid i thought herpes was a greek god

nishlo
is this a macklemore lyric

361,635 notes

Introduction

So far in this dissertation, I have argued that the symbiotic relationship between stigma and disclosure can and often does cause communication to breakdown between healthcare providers and their patients. I have focused especially on STIs because of their particularly taboo status in Western culture and because of the lack of empirical reasoning for this stigma. Interviews with practicing healthcare providers revealed a dearth of authentic, rhetorically sound communication training required of or available to providers at all stages of their careers. In the previous chapter, my analysis of the Tumblr community herpblr illustrates what happens when patients are left in the communicative lurch. Lacking some combination of comprehensive sexual and reproductive health education, a compassionate provider who took the time to undo some of the trauma we know is associated with a herpes diagnosis, and a robust social network to help cope with a herpes diagnosis, these patients created an online community to share information based on personal experiences, and offer support and resources to those newly diagnosed with herpes. In this final chapter, Chapter Five, I fully articulate disclosure rhetorics and provide an array of solutions that technical communicators are especially well-equipped to carry out.

Disclosure Rhetorics

Disclosure rhetorics are bounded by the considerations an individual has to make as they determine whether or not to disclose information to a particular person or group of people that may or may not lead to said individual being regarded in a negative light or stigmatized. They are the persuasive techniques available to an individual as they navigate systems of value that govern how people may respond to potentially stigmatizing information that has been disclosed to them. Returning to Johnson's (2010) definition of stigma from Chapter One, i.e. the active rhetorical propagation of community norms and values coupled with the demand for visibility, disclosure goes hand in hand with risk since an individual risks stigmatization by openly deviating from the norms and values of a given community. The decision to disclose potentially stigmatizing information, and how to do so, often requires that an individual consider possible outcomes carefully. For example, a person's social identity is an important contributor to their psychological state (Haslam 2009), with social ostracism resulting in negative psychological consequences. Psychological consequences are not the only outcome one has to weigh when disclosing. Being stigmatized can lead to any number of negative material outcomes as well, such as homelessness and physical violence experienced by those who identify as part of the LGBTQ community. Further, the act of disclosure itself can bring up feelings of shame or embarrassment (Sankar & Jones, 2005) for the person disclosing. These and many other considerations are taken into account as one determines if, when, how, and to whom they disclose potentially stigmatizing information.

Perhaps the most accessible example of robustly articulated disclosure rhetorics is the LGBTQ concept of "coming out," wherein a person who identifies as being part of the gay community discloses their orientation to others. As Matthew B. Cox (2019) and others have written, coming out as gay is an ongoing practice that can happen in a multitude of ways over time and the techniques used in doing so often depend upon one's audience. For example, I co-taught two classes with Cox in the spring of 2015 and witnessed him disclosing to students by mentioning his now-husband. I think it’s important to note that in Cox’s case, he chose to disclose in a rhetorical environment in which he held a certain amount of cultural capital (Bourdieu, 1991). The classes were both business writing classes that are offered at East Carolina, located in Greenville, North Carolina. Further, he used techniques like casually mentioning proposing to his boyfriend on Valentine’s Day rather than explicitly stating “I’m gay” during class time. Business writing classes are usually populated predominantly with students who are white and male from the College of Business, and ours was no exception. Though Cox is gay, he is also white, male, cis-gendered, tall, and sports an impressive beard. These factors, along with the southern cultural context that historically values respecting authority figures like professors, likely contributed to what I would consider a successful disclosure, i.e. no overt shaming or ostracizing, students continued to respect his authority as the professor, and he still received positive student evaluation scores. In other words,

In my case, I disclosed my STI status to a few close friends at first and then to all of my Facebook friends several months later after reading an article about a herpes-only dating site that implied people with herpes should only use that dating site so as not to contaminate the rest of the population. The disclosure rhetorics bounding my choice to disclose on that platform included how I use that medium to create a community for myself and what other information I make available about myself to said community. For example, I am discerning who I allow to friend me on Facebook; I decline requests from people I do not know personally and even then, I only accept or send friend requests from and to people who are, say, not overly religious or loudly Republican. I do this so as to ensure this particular social media platform does not become a place where I might regularly have to justify my bodily autonomy, for example. Had I been less selective in sending and accepting friend requests, it’s likely that I would not have chosen

Facebook as the platform on which to disclose my STI status because the risk of being stigmatized would have been too great for me to bear. In addition, as the social media platform I have participated in the longest, Facebook makes it easy to let a wide swath of friends know that I obtained my Master's degree before being diagnosed and am pursuing a PhD as well. Because of who I allow into this community, on Facebook, my education carries with it a certain amount of credibility still widely accepted outside of anti-intellectual circles, again because of the judiciousness with which I created this network of friends. I'm also a white woman from the Midwest, and therefore less likely to be shamed for my sexual behaviors than women of color, at least to my face. I used my vast rhetorical expertise to craft a message that was direct and informative, with a tone that offered compassion to others with herpes while chastening those who would regard me (and other herpes-havers) differently now that they knew my Big Secret, including the author of the herpes dating site article I read. These are just some of the things I considered before I disclosed and techniques I used to do so on such a public platform.

Healthcare Providers

Disclosure in the field of healthcare has been a topic of concern for decades. However, most research on the issue has focused on patients disclosing pertinent information to their healthcare provider rather than on how a provider might approach disclosing a diagnosis to a patient under their care (Fanslow & Robinson, 2011; Durso & Meyer, 2013; Bradford & Rickwood, 2015). But healthcare providers have to disclose diagnoses and information to patients in clinical settings on a regular basis. Our cultural bias toward believing in professional objectivity may have prevented researchers from thinking about diagnosis as a moment of disclosure, but the act of a healthcare provider communicating a diagnosis to a patient meets all the criteria for disclosure rhetorics as defined above. As far as diagnosing herpes, for example, providers know the diagnostic disclosure will likely be taken as bad news, even though they understand that herpes is very common and medically a non-issue for the vast majority of people who have it. Providers though must also take care to avoid making light of the condition, since herpes is a virus and they are duty bound to prevent the spread of illness and disease. Providers must then determine which rhetorical techniques they will use when disclosing a diagnosis to a patient based on these and many other factors, such as the impersonal setting of an exam room, their level of familiarity with the patient to whom they must disclose a diagnosis.

Terri Warren states a herpes diagnosis “never seems to get easier” to disclose to patients (2004). Conclusions from many studies regarding how healthcare providers can best help patients following a herpes diagnosis suggest offering counseling, educating patients, and having “a higher degree of ... sensitivity,” as Katie A. Ports, Diane M. Reddy and Jessica L. Barnack-Tavlaris state in their article “Sex Differences in Health Care Provider Communication During Genital Herpes Care and Patients’ Health Outcomes” (2013). As we saw in Chapter Three, however, communication and especially disclosure does not seem to be an explicit part of a provider’s academic training, with participants’ most authentic instruction on how to communicate and disclose happening during live interactions with patients as a matter of chance rather than systematic education.

Patients

Based on my own experience and that of folks in the herpblr community, disclosing is among the top concerns newly diagnosed patients have. I believe one reason for this has to do with the fact that disclosing successfully, i.e. without negative psychological or physical effects, tends to erode the shame one feels alongside their stigmatizing condition (Brown, 2003). As I described above, the concerns and techniques involved in disclosure rhetorics can vary widely across topic, audience, access to information, and abilities, among others. My experience disclosing my STI status, as frightening as it was, was one that I was equipped particularly well to pull off successfully. My degrees in English and rhetoric, my skills as a researcher, my ability to write in ways that are valued in society, and my discretion in choosing Facebook friends cumulatively all but guaranteed I could successfully, i.e. without being stigmatized, disclose. Ultimately, disclosure rhetorics are informed by societal norms and values. There are a number of places technical communicators can intervene to reframe these norms and values regarding disclosure of STI status for the good of providers and patients alike.

Solutions

As technical communicators, we can and should begin intervening ourselves at the classroom and clinical level. Traditionally academic and clinical settings are ideal avenues for intervention for technical communicators because of the direct link to the key players: healthcare providers and patients under their care. The following solutions are not exhaustive and will likely change and evolve over time and can lay the foundation for the larger and more sustainable interventions that follow.

In Healthcare

Students pursuing a career in healthcare would benefit from communication training 1) that is rhetorically sound and delivered by communication specialists, such as technical communication scholars and instructors, 2) that incorporates communication curriculum from related health fields such as counseling or psychology early in career and often in continuing education, and 3) that offers support for conference attendance and other resources. Program administrators in technical communication, science writing, as well as those in departments participating in writing in the discipline curriculum should consider how their writing intensive courses can interrupt the perpetuation of various social stigmas through thoughtfully designed learning outcomes and correspondingly carefully constructed assignments. Students in the undergraduate courses we teach that focus on the kinds of writing that happens in the health sciences, for instance, would benefit from building on their abilities to be productively introspective even before they reach advanced healthcare curriculum. Since my training is in rhetoric, the following example(s) address the first solution.

One common teaching tool interview participants mentioned, and which several critiqued, was the use of simulations and role playing in classroom settings to teach students how to communicate with patients. Participants' issues with such training tools echo those of researchers in the field, i.e. that standardized patients and role play especially are often considered "exaggerated, suggesting that they [are] aimed at fulfilling the assessment criteria rather than being actions that would take place" in actual interactions (Pilnick et al. 2018). Instead, Pilnick et al. (2018) suggest using conversational analysis to more authentically replicate provider-patient communication. Their process is to record and transcribe real exchanges between providers and patients and transfer those conversations into classroom settings that utilize simulations like Standardized Patients. While Pilnick's work is evidence of progress towards more authenticity in simulation pedagogy, a rhetorician's perspective and influence on simulation pedagogy can add important depth and nuance. Campbell's (2018) work to "challenge stereotypical portrayals" and "take a critical view of social forces" in medical simulation pedagogy has led to productive collaborations with healthcare scholars (p. 17). It is her hope, and mine too, that more scholars who engage in this kind of work will be able to "build more humanistic and patient-centered curriculum" (p. 17). Steps like this, in addition to rhetorically based communication focused classes available throughout a healthcare provider's career, are likely to equip providers with a more complete set of rhetorical skills that will benefit them and their patients.

Communication training should also make room in the curriculum for students and practitioners to experience in some way the instabilities or vulnerabilities faced by the populations they serve. Similar to the blindfolded eating exercise Emily shared in Chapter Three, students at East Carolina University recently participated in an exercise designed to help them understand the day-to-day concerns for people with low incomes (Rusk, 2019). Small groups of students, who were public/pre-health or social work majors, spent an afternoon attempting to navigate realistic scenarios in which they were not able to afford housing and other needed services. With local volunteers playing the role of debt collectors, banks, and employers among others, student groups faced, for example, unscrupulous lending practices that forced them into "paying" double their monthly mortgage and led to their inability to pay for eyeglasses for the granddaughter they were raising in the simulation. According to organizer Tamra Church, events like this and the debriefing that followed helps students grasp the realities experienced by populations they will serve in their future careers (Rusk, 2019).

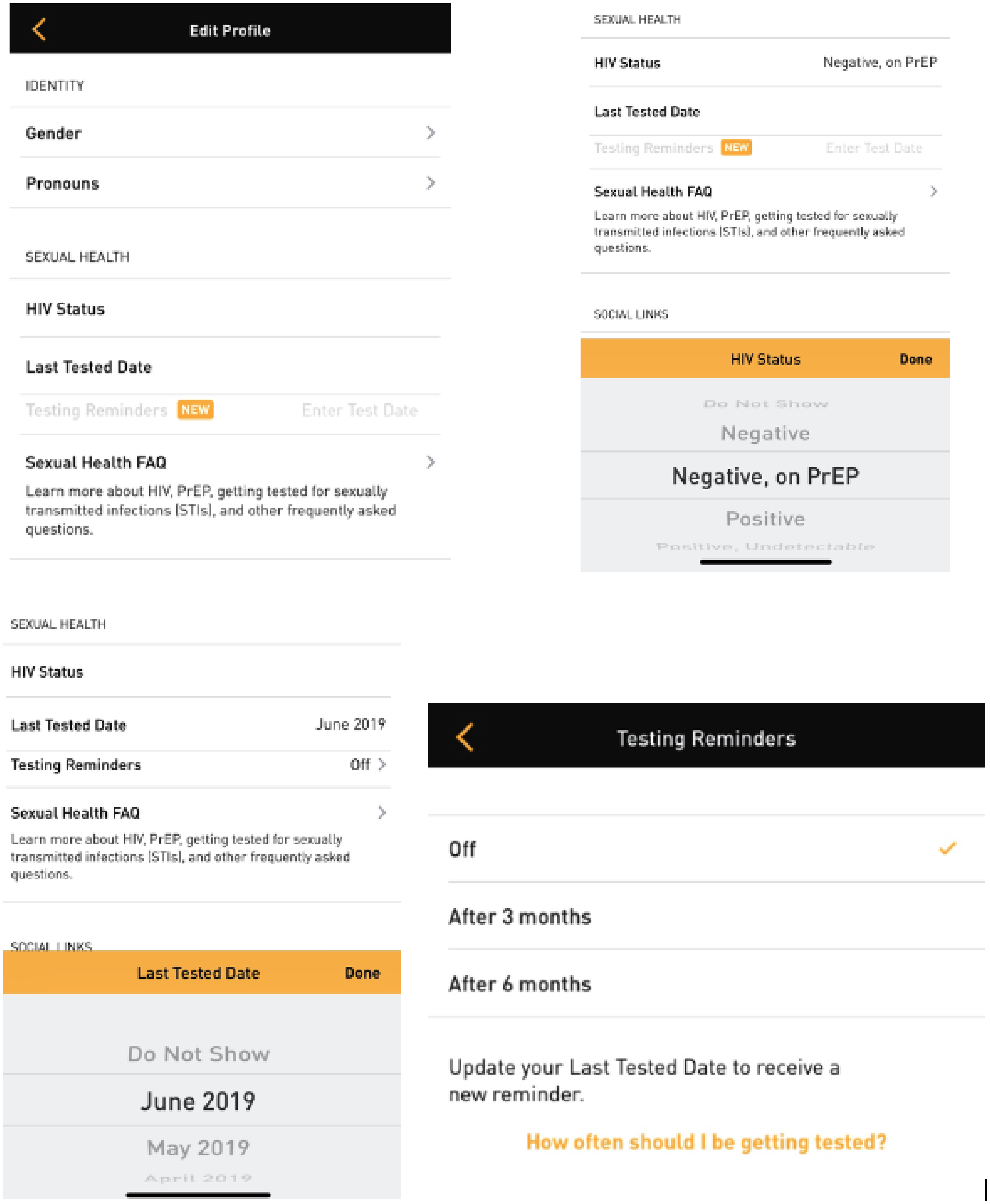
As academics, we can reach out to or establish connections with healthcare providers or administrators in larger healthcare programs and systems. Offering to partner with folks in these institutions affords the opportunity to reorient the communication instruction taking place in these spaces towards a more authentic, equitable, and rhetorically aware pedagogy and more robust resources for patients. Non-academic technical communicators could easily market themselves as brokers for hospital systems to act as advocates for healthcare providers and patients alike and create empathy-based training initiatives and documentation for patients.

It's imperative to understand providers cannot be responsible for covering every communication base with every patient every day that they practice. While an admirable goal, provider burnout is a real concern in the field, as Emily mentioned in her interview. Patients diagnosed with stigmatized conditions need access to resources beyond what many healthcare providers can offer, and it is incorrect to assume that all patients have access to the internet and/or can find their own resources. As Sari mentioned in her interview, the documentation patients get during their visit speaks for the healthcare provider once they leave the clinical setting and can be referred to time and again. For example, documentation that addresses the stigma head on and provides realistic instruction in accessible language for how patients can move forward with their lives now that they have a stigmatized illness. One example I have found that tackles complex and deeply personal topics are brochures published by the University of Illinois at Urbana-Champaign. Their selections on Self-Confidence and Recovering From Shame, as examples, provide easy-to-understand explanations along with actionable strategies to address these difficult topics.

In Western Society

Technical communicators designing mobile applications should consider how STI disclosure, and possibly discussions of other stigmatized topics, could be made much easier is by way of technology. Take mobile applications, for instance. Grindr, the popular dating and hookup mobile application marketed specifically to the LGBT community, has already worked disclosure into their dating profiles. There is a Sexual Health section built into a user’s profile that covers HIV status, the date a user was last tested, and a reminder for users to get tested again in either three or six months. Additionally, Grindr has included a Sexual Health FAQ section to help their users understand various aspects of sexual health by offering more than twenty sexual health articles answering common sexual health questions. This section could very easily add more information on disclosure and how users can work against stigma within and against their community.

Grindr is an especially good example for two reasons. First, Grindr is providing space for more advanced discussions of sexual and reproductive health in addition to being a dating and hookup app. In other words, the developers of the application see value in providing an easy yet direct way for its users to disclose their status, stay on top of their sexual healthcare needs, and cultivate a more robust understanding of sexual health topics in the same space where it is relevant. This concern for this particular population of users corresponds with the second reason: the gay community has been having conversations about disclosure of highly stigmatized conditions for decades (Scott, 2014). Stigma and disclosure are already embedded in the subculture.



Edit Profile

IDENTITY

Gender

Pronouns

SEXUAL HEALTH

HIV Status

Last Tested Date

Testing Reminders NEW Enter Test Date

Sexual Health FAQ

Learn more about HIV, PrEP, getting tested for sexually transmitted infections (STIs), and other frequently asked questions.

SEXUAL HEALTH

HIV Status Negative, on PrEP

Last Tested Date

Testing Reminders NEW Enter Test Date

Sexual Health FAQ

Learn more about HIV, PrEP, getting tested for sexually transmitted infections (STIs), and other frequently asked questions.

SOCIAL LINKS

HIV Status Done

Do Not Show
Negative
Negative, on PrEP
Positive
Positive, Undetectable

SEXUAL HEALTH

HIV Status

Last Tested Date June 2019

Testing Reminders Off

Sexual Health FAQ

Learn more about HIV, PrEP, getting tested for sexually transmitted infections (STIs), and other frequently asked questions.

SOCIAL LINKS

Last Tested Date Done

Do Not Show
June 2019
May 2019
April 2019

Testing Reminders

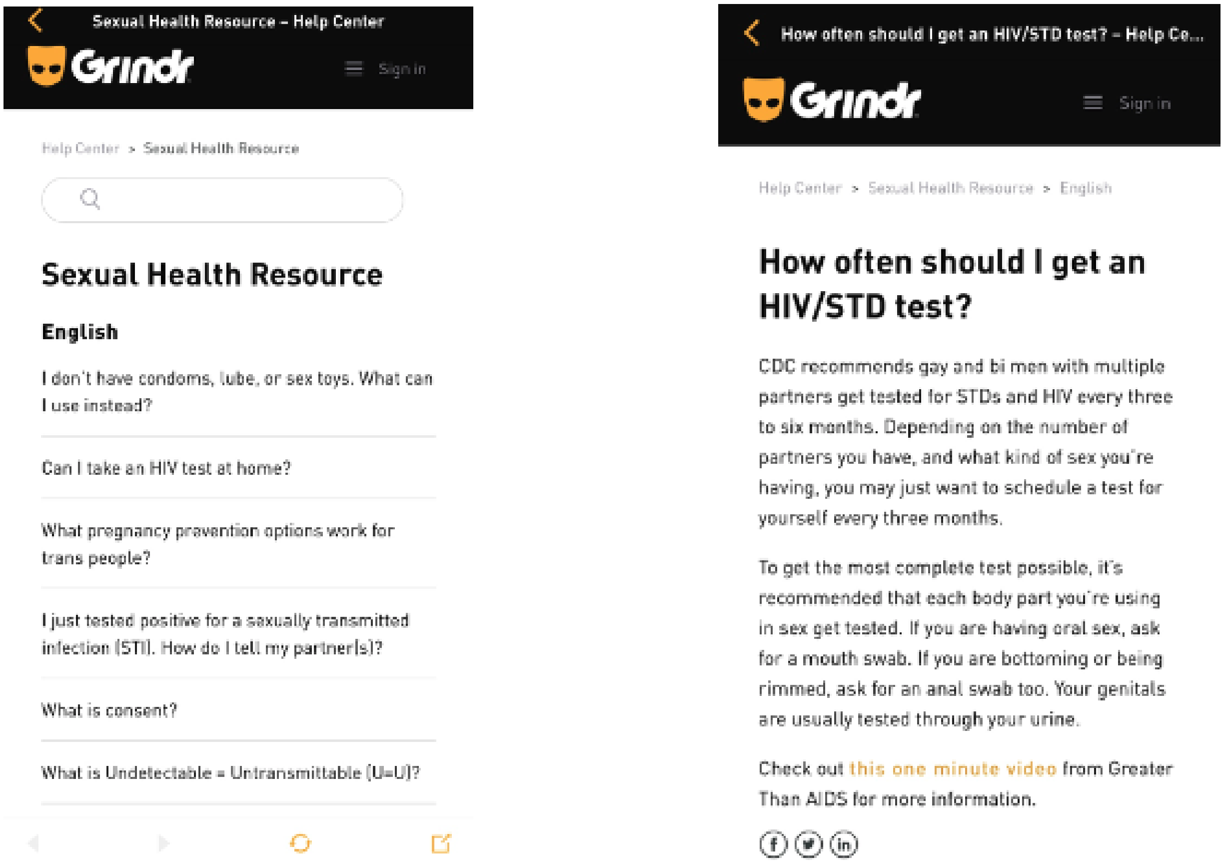
Off ✓
After 3 months
After 6 months

Update your Last Tested Date to receive a new reminder.

How often should I be getting tested?

Figure 25: Grindr Screenshots

The more normalized these discussions become beyond the LGBTQ community, the less arduous are the disclosure rhetorics one has to consider and employ. What society at large can learn from the LGBTQ community is that open conversations help dispel stigma and make disclosure much less of a harrowing experience, which will likely result in more disclosures overall. More disclosures mean more acceptance, fewer negative psychological effects, better healthcare, and the list goes on.



Sexual Health Resource

English

I don't have condoms, lube, or sex toys. What can I use instead?

Can I take an HIV test at home?

What pregnancy prevention options work for trans people?

I just tested positive for a sexually transmitted infection (STI). How do I tell my partner(s)?

What is consent?

What is Undetectable = Untransmittable (U=U)?

How often should I get an HIV/STD test?

CDC recommends gay and bi men with multiple partners get tested for STDs and HIV every three to six months. Depending on the number of partners you have, and what kind of sex you're having, you may just want to schedule a test for yourself every three months.

To get the most complete test possible, it's recommended that each body part you're using in sex get tested. If you are having oral sex, ask for a mouth swab. If you are bottoming or being rimmed, ask for an anal swab too. Your genitals are usually tested through your urine.

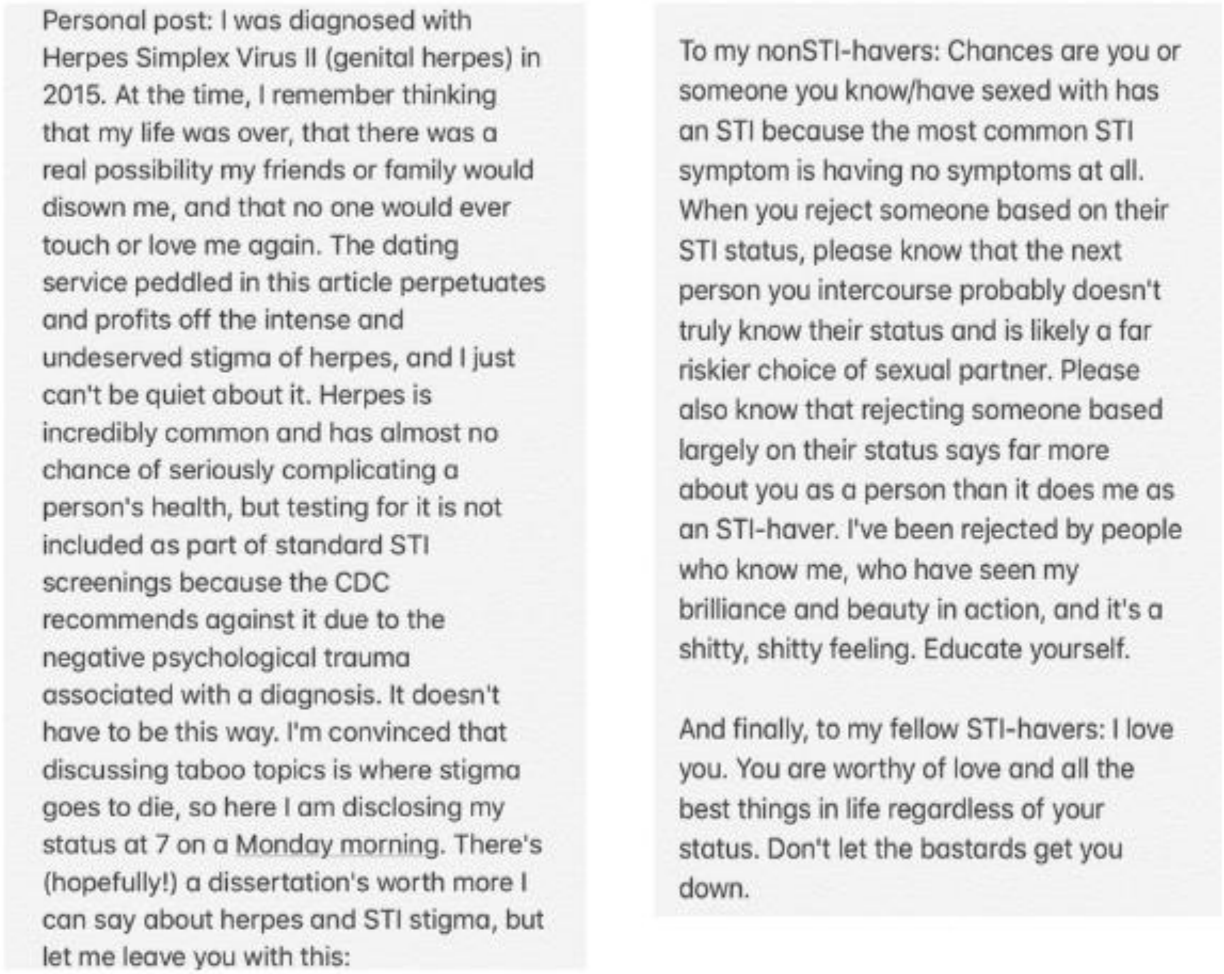
Check out this one minute video from Greater Than AIDS for more information.

Figure 26: Grindr Sexual Health Resources

In Interpersonal Communication

Disclosure rhetorics encompasses the rhetorical considerations and techniques that determine when, how, and to whom an individual might successfully disclose information to another so as to avoid being rejected or stigmatized. My definition of disclosure rhetorics productively contributes to the body of scholarship in technical communication. One area of inquiry within modern technical communication scholarship are the tools that communities use to negotiate and communicate risk and crisis. Disclosure rhetorics are one such tool. They give a multi-dimensional way of thinking about the effects of communication in times of crisis, and ways to convey stigmatizing information that mitigates risk to ourselves, socially, emotionally, and sometimes physically, as well as current or potential sexual partners.

Technical communicators are also humans with subjectivities and leading by example is perhaps one of the most impactful things we can do. In Chapter One of this dissertation, I disclosed my own STI status and alluded to my desperate search for information about how to cope and live with my diagnosis. In reality, by December of that year I began taking antidepressants to help me cope with this new normal. Being diagnosed with herpes was deeply traumatic not only because herpes is horribly and unjustly stigmatized in our culture but also because of the way in which I was diagnosed. I had my first symptoms late on a Friday evening, so I had to wait for student health to open on Monday morning to see a doctor. By the time the exam was over, the swab labeled for testing and the prescription for Valtrex written, I was openly weeping and asking questions like, “Can I ever hug my mother again?” My doctor, a woman who I had seen and had positive experiences with on two previous visits, answered in short responses from across the room, her hand on the doorknob. Should you determine through disclosure rhetorics that you might safely share information that is potentially stigmatizing, I encourage you to do so. Walking the walk is vital to this work, something I did not realize until I did it myself.



Personal post: I was diagnosed with Herpes Simplex Virus II (genital herpes) in 2015. At the time, I remember thinking that my life was over, that there was a real possibility my friends or family would disown me, and that no one would ever touch or love me again. The dating service peddled in this article perpetuates and profits off the intense and undeserved stigma of herpes, and I just can't be quiet about it. Herpes is incredibly common and has almost no chance of seriously complicating a person's health, but testing for it is not included as part of standard STI screenings because the CDC recommends against it due to the negative psychological trauma associated with a diagnosis. It doesn't have to be this way. I'm convinced that discussing taboo topics is where stigma goes to die, so here I am disclosing my status at 7 on a Monday morning. There's (hopefully!) a dissertation's worth more I can say about herpes and STI stigma, but let me leave you with this:

To my nonSTI-havers: Chances are you or someone you know/have sexed with has an STI because the most common STI symptom is having no symptoms at all. When you reject someone based on their STI status, please know that the next person you intercourse probably doesn't truly know their status and is likely a far riskier choice of sexual partner. Please also know that rejecting someone based largely on their status says far more about you as a person than it does me as an STI-haver. I've been rejected by people who know me, who have seen my brilliance and beauty in action, and it's a shitty, shitty feeling. Educate yourself.

And finally, to my fellow STI-havers: I love you. You are worthy of love and all the best things in life regardless of your status. Don't let the bastards get you down.

Figure 27: My Personal Social Media Disclosure

References

"About | Tumblr." *About | Tumblr*. Tumblr, 12 Dec. 2016. Web. 02 Jan. 2017.

Ackerson, L. K. & Viswanath, K. (2009). "The social context of interpersonal communication and health." *Journal of Health Communication*, 14.Sup1, 5-17.

Adorno, T. W., Frenkel-Brunswik, E., & Levinson, D. J., & Sanford, R. N. (1950). *The authoritarian personality.* New York: Harper.

Ahmed, Sara. (2006). *Queer phenomenology: Orientations, objects, others*. Durham: Duke University Press.

Angeli, E. L., & Johnson-Sheehan, R. (2017). Introduction to the special issue: Medical Humanities and/or the Rhetoric of Health and Medicine. *Technical Communication Quarterly*, 27(1), 1-6.

Apatow, J., Robertson, S., & Rothman, R. (Producer), & Stoller, N. (Director). (2008). *Forgetting Sarah Marshall* [Motion picture]. United States: Universal Pictures.

Arntfield, S.L., Slesar, K., Dickson, J., & Charon, R. (2013). Narrative medicine as a means of training medical students toward residency competencies. *Patient Education and Counseling*, 91(3), 280-286.

Barton, E. (2005). Introduction to the special issue. *Journal of Business and Technical Communication*, 19(3), 245–248.

Bekelja Wanzer, M., Booth-Butterfield, M., & Gruber, K. (2004). Perceptions of health care providers' communication: Relationships between patient-centered communication and satisfaction. *Health Communication,* 16(3), 363-384.

Bennett, K. C., & Irwin, H. (1997). Shifting the emphasis to 'patient as central': Sea change or ripple on the pond? *Health Communication*, 9(1), 83-93.

Bennett, J. A. (2015). *Banning Queer Blood: Rhetorics of Citizenship, Contagion, and Resistance*. Tuscaloosa: U of Alabama.

Berman, R. (1992). From Aristotle's Dualism to materialist dialectics: Feminist transformation of science and society. In A. M. Jagger & S. Bordo (Eds.), *Gender/Body/Knowledge: Feminist reconstructions of being and knowing*, (pp. 224-255). Rutgers University Press.

Blair, K., & Takayoshi, P. (1999). Feminist cyberscapes: Mapping gendered academic spaces. Stamford, CT: Ablex Publishing.

Boudewyns, V., Himelboim, I., Hansen, D. L., & Southwell, B. G. (2015). "Stigma's effect on social interaction and social media activity." *Journal of Health Communication,* 20(11), 1337-345.

Bourdieu, P., & Thompson, J. B. (1991). *Language and symbolic power*. Cambridge, MA: Harvard UP.

Bradford, S., & Rickwood, D. (2015). Acceptability and utility of an electronic psychosocial assessment (myAssessment) to increase self-disclosure in youth mental healthcare: A quasi-experimental study. *BMC Psychiatry*, 15, 1-13.

Brooks, P., Handelman, M., & Banks, E. (Producer), & Moore, J. (Director). (2012). *Pitch perfect* [Motion picture]. United States: Universal Pictures.

Brown, B. (2006). Shame Resilience Theory: A Grounded Theory study on women and shame. *Families in Society*, 87(1), 43-52.

Browne, K. & Nash, C. J. (2016). *Queer methods and methodologies: Intersecting queer theories and social science research*. Routledge, New York, NY.

Burgess, D.J., Fu, S.S., & van Ryn, M. (2004). Why Do Providers Contribute to Disparities and What Can Be Done About It? *Journal of General Internal Medicine*, 19(11), 1154–1159.

Campbell, L. (2018). The rhetoric of health and medicine as a "Teaching Subject": Lessons from the medical humanities and simulation pedagogy. *Technical Communication Quarterly*, 27(1), 7-20.

Castells, M. (2012). *Networks of outrage and hope: Social movements in the internet age*. Cambridge, UK: Polity.

Cohan, D. (2019). Racist like me — A call to self-reflection and action for white physicians. *New England Journal of Medicine*, 380, 805-807.

Collins, P. H. (1989). The social construction of Black Feminist Thought. *Signs: Journal of Women in Culture and Society, 14*(4), 745-773.

Conley, T. D., Jadack, R. A., & Shibley Hyde, J. (1997). Moral dilemmas, moral reasoning, and genital herpes. *Journal of Sex Research*, 34(3), 256-66.

Connor-Greene, P. A. (1986). The role of counseling in the treatment of genital herpes. *Journal of American College Health*, 34(6), 286-87.

Cox, M. B. (2019). Working closets: Mapping queer professional discourses and why professional communication studies need queer rhetorics. *Journal of Business and Technical Communication*, *33*(1), 1–25.

Derkatch, C. (2016). *Bounding biomedicine: Evidence and rhetoric in the new science of alternative medicine.* University of Chicago Press.

Dunn, G. (2013). "The strongest herpes support group Is on tumblr." *The Daily Dot*. The Daily Dot.

Durso, L.E. & Meyer, I.H. (2013). Patterns and predictors of disclosure of sexual orientation to healthcare providers among lesbians, gay men, and bisexuals. *Sexual Research and Social Policy*, 10(1), 35-42.

Ehrenreich, B. & English, D. (1973). *Witches, Midwives, and Nurses: A History of Women Healers*. Old Westbury, NY: Feminist.

Ellingson, L. L. (2000). Style, Substance, and Standpoint: A Feminist Critique of Bernie Siegel's Rhetoric of Self-Healing. *Women's Studies in Communication*, *23*(1), 63–90.

Fanslow, J. L., & Robinson, E. M. (2011). Physical injuries resulting from intimate partner violence and disclosure to healthcare providers: Results from a New Zealand population-based study. *Injury Prevention*, 17(1), 37.

Foss, S. K., Griffin, C. L., & Foss, K. A. (1997). Transforming rhetoric through feminist reconstruction: A response to the gender diversity perspective. *Women's Studies in Communication,* 20(2), 117-136.

Foucault, M., & Sheridan, A. (1994). *The birth of the clinic: An archaeology of medical perception*. New York: Vintage.

Fountain, T. K. (2014). *Rhetoric in the flesh: Trained vision, technical expertise, and the gross anatomy lab*. New York: Routledge, Taylor & Francis Group.

Frost, E. (2012). *Apparent feminism: Technical communication's obligation to intervene in public rhetorics*. Council for Programs in Scientific and Technical Communication, Houghton, MI.

Goffman, E. (1986). *Stigma: Notes on the management of spoiled identity*. NY, NY: Simon & Schuster.

Gusmano, M.K., Maschke, K. J., & Solomon, M.Z. (2019). Patient-centered care, yes; Patients as consumers, no. *Health Affairs*, 38(3).

Halberstam, J. (2011). *The Queer Art of Failure*. Durham: Duke University Press.

Haraway, D. (2006). A cyborg manifesto: Science, technology, and socialist-feminism in the late 20th century. *The International Handbook of Virtual Learning Environments*, 14(1), pp. 117=158.

Harding, S. (1995). "Strong Objectivity": A response to the New Objectivity question. *Feminism and Science*, *104*(3), 331-349.

Hashim, M.J. (2017). Patient-centered communication: Basic skills. *American Family Physician*, 95(1), 29-34.

Haslam, S. A., Jetten, J., Postmes, T., & Haslma, C. (2009). Social identity, health and well-being: An emerging agenda for applied psychology. *Applied Psychology: An International Review*, 58(1), 1–23.

Hausman, B. L. (2003). *Mother's milk: Breastfeeding controversies in American culture*. New York: Routledge.

Hayles, N. K. (1999). How we became posthuman: Virtual bodies in cybernetics, literature, and informatics. Chicago, IL: University of Chicago.

Heifferon, B., & Brown, S. C. (2008). *Rhetoric of healthcare: Essays toward a new disciplinary inquiry*. Cresskill, NJ: Hampton.

Hertough, Lori Beth. (2018). Feminist Digital Research Methodology for Rhetoricians of Health and Medicine. *JBTC, 32*(4), 480-503.

Hether, H. J., Murphy, S. T., & Valente, T. W. (2014)."It's better to give than to receive: The role of social support, trust, and participation on health-related social networking sites." *Journal of Health Communication* 19(12), 1424-439. Print.

Holm, A. L., Gorosh, M., Brady, M. & White-Perkins, D. (2017). Recognizing Privilege and Bias. Academic Medicine, 92 (3), 360–364.

Hubbard, R. (1990). *The Politics of Women's Biology*. New Brunswick: Rutgers UP.

Hubbard, R. (2003). Using pregnancy to control women. In A. Kesselman, L. D. McNair, & N. Schniedewind (Eds.), *Women: Images and realities: A multicultural anthology*, (pp. 360-364). Burr Ridge, IL: McGraw Hill.

Hubbs, N. (2014). *Rednecks, queers, and country music*. Berkeley and Los Angeles, CA: University of California Press.

Jensen, R. E. (2010). *Dirty words: The rhetoric of public sex education, 1870-1924*. Urbana: U of Illinois.

Johnson, B., & Quinlan, M. M. (2017). Insiders and outsiders and insider(s) again in the (in)fertility world. *Health Communication, 32*, 381-385.

Johnson, J. (2010). The skeleton on the couch: The Eagleton affair, rhetorical disability, and the stigma of mental illness. *Rhetoric Society Quarterly*, 40(5), 459-78.

Jordanova, L. (1999). Natural facts: A historical perspective on science and sexuality. In J. Price & M. Shildrick (Eds.), *Feminist theory and the body: A reader* 157-68). New York:

Routledge.

Jourard, S. M. (1971). *The transparent self*. Litton Educational Publishing.

Kleinman, S. S. (1998). Overview of feminist perspectives on the ideology of science. *Journal of Research in Science Teaching*, 35(8), 837-844.

Koerber, A. (2000). Toward a feminist rhetoric of technology. *Journal Business and Technical Communication*, 14(1), 58-73.

Koerber, A., & Still, B. (2008). Guest editors' introduction: Online health communication. *Technical Communication Quarterly*, 17(3), 259–263.

Kramarae, C. (1981). Women as a muted group. In Karen A. Foss, Sonja K. Foss, & Cindy L. Griffin (Eds.), *Readings in Feminist Rhetorical Theory* (19-26). Long Grove, IL: Waveland, 2006.

Lather, P. & Smithies, C. (1997). *Troubling the Angels: Women Living with HIV/AIDS*. Boulder, CO: Westview.

Lay, M. (1991). Feminist Theory and the redefinition of technical communication. *Journal of Business and Technical Communication 5*(4), 348-70.

Lichtenstein, B., Hook, E. W., Sharma, A. K. (2005). Public tolerance, private pain: Stigma and sexually transmitted infections in the American Deep South. *Culture, health & sexuality*, 7(1), 43-57.

Loader, B. D., Muncer, S., Burrows, R., Pleace, N., & Nettleton, S. (2002). "Medicine on the line? Computer-mediated social support and advice for people with diabetes." *International Journal of Social Welfare*, 11(1), 53-65.

Mara, M., & Scott, J. (2010). Spreading the (Dis)ease: Gardasil and the Gendering of HPV. Feminist Formations, 22(2), 124-143.

McCune Jr., J. Q. (2014). *Sexual discretion: Black masculinity and the politics of passing*. Chicago, IL: University of Chicago Press.

McIntosh, P. (1989). White privilege: Unpacking the invisible knapsack. *Peace and Freedom Magazine July/August*, 10-12.

McQuail, D. (2005). *McQuail's Mass Communication Theory*. London: Sage Publications.

McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York, NY: New York University Press.

Mark, H., Gilbert L., & Nanda, J. (2009). Psychosocial well-being and quality of life among women newly diagnosed with genital herpes. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 38(3), 320-26.

Meloncon, L., & Frost E. A. (2015). Special issue introduction: Charting an emerging field. *Communication Design Quarterly Review*, 3(4), 7–14.

Neuberg, S. L., Smith, D. M., & Asher, T. (2000). Why people stigmatize: Toward a biocultural

framework. In T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma* (pp. 31–61). New York: Guilford Press.

Pilnick, A., Trusson, D., Beeke, S., O'Briend, R., Goldburg, S., & Harwood, R. H. (2018). Using conversation analysis to inform role play and simulated interaction in communications skills training for healthcare professionals: identifying avenues for further development through a scoping review. *BMC Medical Education*. 18.1.

Ports, K. A., Reddy, D. M., & Barnack-Tavlaris, J. L. (2013). Sex differences in health

care provider communication during genital herpes care and patients' health outcomes. *Journal of Health Communication*, 18(12), 1436-448.

Rains, S. A. (2013). "The implications of stigma and anonymity for self-disclosure in health blogs." *Health Communication*, 29(1), 23-31.

Rapp, R. (1999). *Testing women, testing the fetus: The social impact of amniocentesis in America*. Routledge.

Rathert, C., Wyrwich, M. D., & Boren, S. A. (2013). Patient-Centered Care and Outcomes: A Systematic Review of the Literature. *Medical Care Research and Review*, *70*(4), 351–379.

Reinharz, S. (1992). *Feminist methods in social research*. Oxford University Press.

Roberts, R. E. L. (1997). Power/knowledge and discredited identities: Media representations of herpes. *The Sociological Quarterly*, 38(2), 265-84.

Rusk, K. (2019). Walk in their shoes: Poverty simulation builds understanding, empathy. *East Carolina News Services.*

Sanford, A. A. (2010). "'I can air my feelings instead of eating them': Blogging as social support for the morbidly obese." *Communication Studies*, 61(5), 567-84.

Sankar, P. & Jones, N. L. (2005). To tell or not to tell: Primary care patients' disclosure deliberations. *Archives of Internal Medicine*, 165(20), 2378-83.

Sauer, B. A. (1994). Sexual dynamics of the profession: Articulating the *ecriture masculine* of science and technology. *Technical Communication Quarterly*, 3(3), 309-323.

Scott, J. B. (2014). *Risky rhetoric: AIDS and the cultural practices of HIV testing*. Carbondale: Southern Illinois UP.

Scott, J. B., Longo, B., & Wills K. V. (2006). *Critical power tools: Technical communication and cultural studies*. Albany, NY: SUNY Press.

Segal, J. Z. (2005). *Health and the rhetoric of medicine*. Southern Illinois University.

Smith, R. A. (2007). Language of the Lost: An explication of stigma communication. *Communication Theory*, 17, 462–485.

Sontag, S. (2001). *Illness as metaphor: AIDS and its metaphors*. 1st Picador USA ed. New York: Picador USA.

Stephens, M. B., Reamy, B. V., Anderson, D., Olsen, C., Hemmer, P. A., Durning, S. J., & Auster, S. (2012). Writing, Self-Reflection, and Medical School Performance: The Human Context of Health Care. *Military Medicine*, 177, 26–30.

Tannen, D. (1996). Gender gap in cyberspace. In V. J. Vitanza (Ed.) *CyberReader*, (pp. 141-143). Needham Heights: Allyn & Bacon.

Thompson, I. (1999). Women and Feminism in Technical Communication A Qualitative Content Analysis of Journal Articles Published in 1989 through 1997. *Journal of Business and Technical Communication, 13*(2), 154-178.

"Tumblr.com Traffic Statistics." (2019). *Tumblr.com Traffic, Demographics and Competitors - Alexa*.

Turkle, S. (2007). *Evocative objects: Things we think with*. Cambridge, MA: MIT Press.

Vanderford, M. L., Jenks, E. B., & Sharf B. F. (1997). Exploring patients' experiences as a primary source of meaning." *Health Communication*, 9(1), 13-26.

Wajcman, J. (1991). *Feminism confronts technology*. Penn State University Press.

Wanzer, M. B., Booth-Butterfield, M., & Gruber, K. (2004). Perceptions of healthcare providers' communication: Relationships between patient-centered communication and satisfaction. *Health Communication*, 16(3), 363-83.

Warren, T. (2004). Importance and practicalities of patient counseling in the prevention and management of genital herpes. *Medscape Infectious Diseases > Expert Column, Faculty and Disclosures*, 6(2), 1-3.

Wells, S. (2010). *Our Bodies, Ourselves and the Work of Writing*. Stanford, CA: Stanford UP.

Yeary, K., Stewart, M.K., Lensing, S., Dockter, N., Bachelder, A. et al. (2015). Women's perceptions of provider empathy in the context of healthcare disparities. *Race, Gender & Class*, 22(3/4), 154-171.

APPENDIX

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board
4N-64 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** · www.ecu.edu/ORIC/irb

Notification of Initial Approval: Expedited

From: Social/Behavioral IRB
To: Gina Kruschek
CC:
Michelle Eble
Date: 1/11/2018
Re: UMCIRB 17-002663
You Have Herpes. Now What?: Stigma in Healthcare Systems and the Rhetoric of Disclosure

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 1/10/2018 to 1/9/2019. The research study is eligible for review under expedited category #6, 7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

Name	Description
Interview Consent	Consent Forms
Interview Questions	Interview/Focus Group Scripts/Questions
Prospectus	Study Protocol or Grant Application

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418