Literary Hypertext as Illness Narrative for Women and Nonbinary Individuals with Hyperandrogenism

by

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A thesis submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

in

Media and Cultural Studies

Department of Modern Languages and Cultural Studies

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Abstract

Illness narratives, or autobiographical accounts of the lived experience of pathology or disability, have been established as an effective therapeutic intervention for responding to emotional well-being related to illness (Couser, 1999, 2004, 2005, 2009; Frank; Hartman; Hawkins; Irvine & Charon; Kleinman; Mintz; Sontag). The scholarly field related to illness narratives is currently grappling with the genre's expansion from the traditional book to digital-born narratives, however, there is limited research analyzing illness narratives built through literary hypertext. Literary hypertext is a form of digital story writing that calls on the reader to participate in the narrative's unfolding by selecting hyperlink options which branch the narrative into nonlinear directions. There has been a revival of scholarly and public interest in literary hypertext in the past decade, owing to the genre's culture of free production and distribution. This culture has contributed to a steep rise in the popularity of literary hypertext tools, such as Twinery.org, amongst minority designers who are often excluded from male-dominated and white spaces of game development (Anthropy 90; Harvey 96). Turning towards the intersection of medical/health humanities, gender studies and digital humanities, this project questions how women and nonbinary individuals with the illness hyperandrogenism can use hypertext technology to write illness narratives that construct positive relationships between their identities and the world. Hyperandrogenism is a complex condition characterized by high levels of androgens in the female body. Ten participants with hyperandrogenism completed a two-hour pedagogical Twine module on hypertext illness narratives. Participants concluded the study by submitting a personal literary hypertext illness narrative and participating in a Closing Interview to detail their experience with the technology. The corpus of this research was analyzed through a feminist new materialist theoretical framework and a novel methodology called Critical

Discourse Analysis for Digital-Born Narratives developed for this project. The findings of this research suggest that literary hypertext technology was used by participants to visually map and manually chart experiences through the practice of hyperlinking in order to create a structure perceived as best suited for therapeutic reflection. Ultimately, participants argue that writing a single illness narrative, in any format, cannot produce a transformative, encompassing therapeutic result. The value in engaging in writing a literary hypertext illness narrative was found through the unique process of reflection on past experiences and knowledge dissemination to the wider community, in line with a narrative medicine framework. Participants believe that for literary hypertext illness narratives to cultivate true therapeutic value, they must be tools, not only for the author to reflect on illness, but for the wider social and medical community to read and learn about the experience of hyperandrogenism.

Preface

This thesis is an original work by Megan Perram. The research project, of which this thesis is a part, received research ethics approval as a human research trial from the University of Alberta Research Ethics Board under the name: “Click Here for Body Stories: Employing Literary Hypertext as a Form of Illness Narrative for Women with Hyperandrogenism”, ID Pro00098579, March 30, 2020 (Appendix A).

Sections of this dissertation have been previously published. A section of the Introduction chapter within the header “A Note on Language” has been published in the 2022 article “The Possibilities of Illness Narratives in Virtual Reality for Bodies at the Margins” co-authored with my supervisor Astrid Ensslin in the journal of *Digital Creativity*. This article was researched and written by myself. Dr. Ensslin contributed with theoretical framework consultation, subsequent research and editing.

Sections of the Literature Review and Introduction chapters, including fig. 5, are currently accepted for publication in a forthcoming article for *Interdisciplinary Digital Engagement in Arts & Humanities* called “Building Hypertext Literature Reviews for Qualitative Research.” This article is a solo publication.

Sections of the Methods and Protocol chapter and Abstract are accepted for publication as a chapter in the forthcoming book *EnTwine: A Critical and Creative Companion to Teaching with Twine* edited by Anastasia Salter and Stuart Moulthrop for Amherst College Press.

Dedication

For the ten authors who shared their stories for this research.

Acknowledgments

Thank you first and foremost to the ten authors who dedicated their time, stories and valuable perspectives to this project. You are every piece of this research.

Thank you to my incomparable supervisor, mentor and friend, Astrid Ensslin. Your unwavering support has guided me through the dizzying maze of a dissertation project. I am so glad I met you many years ago at the start of our Writing New Bodies project. The skills, experience, and opportunities you have afforded me through various research, conference and publication endeavours have been the foundation of this dissertation.

Thank you to my dissertation committee Daniel Laforest, Michelle Meagher and Astrid Ensslin, from whom I have had the honour to learn over the years. Dr. Laforest has been a pillar throughout my PhD studies, leading core courses and directed readings that have shaped my understanding of health humanities. Dr. Meagher has been my mentor and a great friend for many years at the University of Alberta. I met her many years ago as an undergraduate when I was a student in her women's and gender studies course. Later, Dr. Meagher became my supervisor during my master's degree in Gender and Social Justice. Her guidance in that project is the foundation of this dissertation.

I have a deep appreciation for the various funding bodies who have financially supported this research including the Social Sciences and Humanities Research Council of Canada, the Government of Alberta, the University of Alberta, the Intersections of Gender at the University of Alberta, and the Digital Humanities Summer Institute.

The reason I had the opportunity to do this research is because of my parents who have supported all my pursuits, always.

Thank you to my daughter, Townes, whose birth occurred in the middle of this research and added a spectacular dramatic effect.

Finally, thank you to my partner, Brian, who has been my most impactful mentor and supporter.

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Chapter I: Introduction

In *The Wounded Storyteller*, Arthur Frank wrote that major illness has the potential to disrupt the map that once guided our life. We have plans, aspirations, and goals when suddenly, in the wake of an unexpected diagnosis, we no longer can forge the path we once imagined because illness exposes the ableism in the lives we chart and narrate for ourselves. In the place of our former path, we become well acquainted with clinic waiting rooms, researching symptoms, and prescription drug side effects. It is when we are claimed by a new "ill" identity that we are required to relinquish our narrative to the medical institution in ways that, Frank argues, reinforce the Cartesian dualism of a modern experience of being ill (6). In this modern experience, according to Frank, we are categorized in a binary of *sick* or *well*, and, through an objectifying process, our bodies become separate from our *selves* as we are required to share our narrative through the language of the institution.

Scholars of illness narratives argue that it is through the practice of writing about one's experience of illness that the capacity for telling one's story is reclaimed (Frank 1). Illness narratives – autobiographical accounts of the experience of illness or disability – can be particularly transformative for marginalized groups as an accessible way to bring agency and voice to the body (Couser, *Signifying Bodies* 16). Positioned at the intersection of gender studies, medical/health humanities and digital humanities, this dissertation questions how innovative digital tools, particularly hypertext, can reimagine the traditional illness narrative in ways that better enable access to therapeutic responses to illness for marginalized people. I will consider the following: how can hypertext be utilized to hone in on the transformative, therapeutic aspects of the illness narrative? How might these tools offer an effective and purposeful means for subjugated bodies to write a path to health liberation? What is innovative or inventive about digital capability that advances the potential of illness narratives? In order to explore these questions, I turn to the case study of hyperandrogenism, a disorder diagnosed in individuals, labelled in clinical diagnosis typically as women,[1] who experience natural levels of "elevated" testosterone. Guided by these research questions, my project considers how we might "code" health liberation[2] into the digital for women and nonbinary people with hyperandrogenism through literary hypertext technology.

Brief Project Overview

This project evaluates how literary hypertext can be used as an avenue for women and nonbinary people with hyperandrogenism to write illness narratives. Literary hypertext is a form of digital story writing that calls on the reader to participate in the narrative's unfolding by selecting hypertext options that branch the narrative into nonlinear directions. There has been a resurgence of scholarly and public interest in literary hypertext in the past ten years, owing to the genre's steep rise in popularity amongst minority game designers (Anthropy 21). Concentrated in the discipline of game studies, there is limited scholarly research on the potential for literary hypertext as a tool for writing therapeutic illness narratives. Turning towards the intersection of digital humanities, health/medical humanities, and gender studies, my project questions how women and nonbinary people with hyperandrogenism can use hypertext technology as a method of narrative therapy to write illness narratives that construct positive relationships between their

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[1] A clarification of sexed language in the diagnosis of hyperandrogenism will be clarified in a section below entitled "A Note on Language."

[2] I refer to health liberation as a concept of the liberation health framework (see Martinez and Fleck-Henderson) that comes out of social work theory. Liberation health is a method of practice that understands that the seemingly individualized experiences of mental health and illness are, in fact, created in the intersection between social, institutional, economic, and political power relations. Overall, health liberation seeks to challenge traditional power structures within, parallel to, and outside of the healthcare system that contribute in destructive ways to the experience of illness. Health liberation, then, is a pursuit to address individualized experiences of illness through the targeting of structural impacts.

identities and the world. This research will lead to the concrete realization of a novel pathway to inform therapeutic approaches for emotional well-being related to gendered illness.

In March 2020, I began working closely with a group of women and nonbinary participants who self-identify[3] as having hyperandrogenism. Hyperandrogenism is an endocrine disorder characterized by "excessive" levels of male hormones (androgens), such as testosterone which, when identified in the female body, are associated with "masculinizing" symptoms including excess body and facial hair, male-pattern baldness, infertility, elevated sex drive, increased muscle mass and absence of menstrual bleeding (Bazarganipour et al. 371). Terms such as "excessive" and "masculinizing" are included in quotation marks as this project will question their perceived cohesiveness. Participants are English speakers who are at least 18 years old and have at least two clinical symptoms of hyperandrogenism. Participants were recruited from Facebook support groups for polycystic ovarian syndrome,[4] Instagram, email listservs and public online health forums. The recruitment method was chosen in order to connect with individuals who may have been seeking support or information on their disease, digitally. Informed by my experience supporting a related research design (Ensslin et al. *Writing New Bodies*), I recruited ten participants as this size is expansive representationally but narrow enough for focused engagement. Potential participants first encountered a general call for participants, or the Recruitment Poster (Appendix B), where they are asked to send an email to the Principal Investigator (PI) to express interest. From there, I shared an Informational Email (Appendix C) with the potential participants explaining the details of the study and eligibility. If

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[3] See section below entitled "A Note on Language" regarding the language choice of "self-identify" rather than "diagnosed".

[4] The decision to centre the disease polycystic ovarian syndrome over hyperandrogenism in the recruitment of this study is explained in depth in the Methods and Protocol chapter within the section titled "Participant Recruitment and Research Process."

potential participants were interested and eligible, they were invited to a Zoom Screening Interview (Appendix D) with me that confirmed eligibility and recorded diversity markers. Following the Screening Interview, potential participants were given a Consent Form (Appendix E) that detailed expectations of participation, ethical procedures, and data management. If the potential participant signed the Consent Form, they were invited to take part in the study.

Participants were sent a link to a two-hour digital module that they could complete in a location where they felt most comfortable, and at their own pace. The module was designed using Twine, a freely accessible, open-source tool for creating literary hypertexts. The module includes information on, and a political framing of, hyperandrogenism, a story-boarding exercise, a Twine software tutorial, and a final writing prompt that participants used to build their own literary hypertext stories rooted in their illness experiences. When participants completed their illness narratives, they uploaded them to a personalized, secure Google Drive folder. From there, I invited the participant to a Closing Interview (Appendix F) over Zoom that was recorded and transcribed by myself. The interview engages the participant on their experience using literary hypertext to write an illness narrative and a reflection on what kind of changes, if any, the participant experienced after writing. This completed the participants' involvement in the study. Following the Closing Interview, participants were invited to submit their Twine stories to a private, secure Google folder to which only myself and the other participants had access. It was explained to participants that this folder would act as a community-building space where participants could read each other's illness stories. Participants were informed that submitting their story to this folder was optional, did not affect their participation in the study (if they chose not to share, I would still use their data), and that their submission would remain anonymous. All ten participants chose to share their stories.

This Introduction chapter will be separated into the following meta topics: a background on illness narratives and narrative therapy, electronic literature as a foundation of literary hypertext, literary hypertext and nonfiction, the Twine Revolution, a description of Twinery.org, an analysis of the cultural take-up, clinical diagnosis, and treatment of hyperandrogenism, and a brief overview of my master's work on which this project expands. My intention for this introduction is to provide a comprehensive contextual overview of the major topics addressed in my research, where the Literature Review will develop these topics in further depth by incorporating their theoretical backgrounds.

A Note on Language

When you are working on a project that looks at embodied experience that is typically pathologized as a medical disorder that interferes with normative ways of understanding biological sex, categories of defining gender and illness become muddy. In this project, I require a term to define my participants. Clinical guidelines in North America for defining people with hyperandrogenism use the term *woman* (Yildiz 167), however, it became apparent that this term is gravely insufficient to describe all individuals who experience the disease. Hyperandrogenism, a disorder diagnosed in "female" bodies that produce "excess" male hormones is complex because it diagnostically relies on binary language that does not reflect the population of people who experience it. For example, I have a nonbinary participant who took part in this study who self-identifies as having hyperandrogenism. From here it may logically lead to a conclusion that the phrase I should use to define my population would be *women and nonbinary people*. This is the phrase I do employ in this project and it does, in fact, define my population of ten participants. However, this phrase does not represent all individuals who identify as having hyperandrogenism. A transgender man may, for example, have extensive experience, even in the healthcare system, with hyperandrogenism. From here, it may appear using the phrase *assigned female at birth* could represent the population of individuals who identify as having hyperandrogenism. Though, I began to wonder if this is universally true.

Hyperandrogenism is closely tied to, and even at times understood as, a diagnosis of intersex (Davis and Preves 80). It is plausible that an individual who identifies as having hyperandrogenism may not have been assigned female at birth and may, in fact, have been assigned differently (male, or in some jurisdictions a "third" sex classifier). This fact leads to the obvious solution that I should refer to the population in a general way, such as *individuals* or *people* (terms which I do employ at times). However, the glaring issue with this solution is that it works to erase the very gendered implications of the disease of hyperandrogenism. The issues of hyperandrogenism that this project explores are the ways in which, medically and culturally, the disease is viewed as a condition that masculinizes the "female" body. Many of the issues that individuals with hyperandrogenism face, including many of my participants, are issues around perceptions of not being able to embody an idea of femininity and the kinds of psychological impacts that may have. Further, the disorder raises issues for individuals around the ways in which their gender is read, or misread, in society (see Fausto-Sterling; Stryker and Whittle). At the same time, nonbinary people and transgender men's relationship to the illness may be different from femme-identifying folks. A lot of the distress surrounding hyperandrogenism is around the "masculinizing symptoms" and these symptoms may or may not induce similar distress in transgender men or nonbinary people. However, for my participant pool, anxiety around not meeting a standard of femininity was a central theme.

Because of this reality, and what I would argue is the most significant aspect of hyperandrogenism for this project, it is imperative for me to maintain language around constructed femininity and womanhood. However, I want to do this by also including those who may not identify with these terms directly. The solution I have chosen is three-fold. First, I will refer to my participants by the gender terms they have identified within Screening Interviews: *women* and *nonbinary people*. Second, I will refer to the larger population as *individuals* with hyperandrogenism, as this is the only terminology that captures all identities. Third, the exclusionary phrase *women with hyperandrogenism* will only be used when referring directly to the language of others whom I am discussing (for example, diagnostic language or language a participant includes in their story).

The label of pathologized illness has historically and is contemporarily used to categorize what some emerging identity communities would now call *differing embodiments*, *ways of being*, or *identity categories* (nuances of biological sex embodiments[5], fat bodies, disability, madness, etc.) (Kelly and Orsini 288; Svenaeus, "The Body Uncanny" 125; Sulik 463). Pathologized identities are complex. Some individuals or communities may view *a way of being* as an illness in the traditional sense and others may find the label reductive or subjugating. Further, these same communities or individuals who may find these labels harmful in some sense (it defines their embodiments as abnormal, for example) may seek pathologized labels for the resources they can afford (particular healthcare procedures, medications, insurance coverage, etc.). For those who embrace illness labels for their embodiments, this too can be a liberatory act. Defining oneself as ill may be a step toward validation of experience and following a treatment path within the normative healthcare system[6] may be extremely beneficial for some.

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[5] I use the phrase "nuances of biological sex embodiment" to refer to the experience of sex as a spectrum in regard to nonbinary manifestations of chromosome patterns, hormones, external genitalia and internal organs (at times referred to as intersex disorders).

[6] I use the term "normative" healthcare system to refer to the standard systems and practices that are institutionalized (privately or publicly) to respond to the health of individuals and communities. In a

This project will use the terms *pathologized identities* or *illness* to describe individuals with hyperandrogenism and the disease, respectively, for three reasons. First, these terms speak to difference as an identity category, however, they do not erase the ways in which these *ways of being* are pulled into diagnostic criteria of illness, or are descriptors of the illness themselves. Second, *pathologized* as a verb form works to represent how some people's bodies are pulled into a discourse of pathology with or without their consent or desire. Some pathologized identities experience the act of the pathologizing of their identity and this act is without a value judgment. Third, *pathologized identities* allows for a thematic connection to illness narratives as a responsive action. The history of the practice of illness narratives is rooted in a desire to push back against the perceived omnipotence of the healthcare system and reposition illness as a sociohistorical experience rather than merely a bodily state (see Couser; Frank; Hawkins; Kleinman). However, the term *illness* in *illness narratives* is retained. Perhaps *illness* can be seen as both a restrictive and generative label. Like *illness, pathologized identity* is fluid as there is no set of experiences or embodiments that always occupy the category for everyone, but the term can be used as a tool to think more critically about the processes of diagnosing and treating illness as historically situated and sociopolitically constituted.

Illness Narratives as Performative

Life writing, and particularly life writing of illness, according to G. Thomas Couser, is a literary genre of autobiography that centres the bodily experience and subjectivity of the author (“Disability, Life Narrative, and Representation” 604). Couser argues that life writing has potential as a tool to empower authors to reclaim authority over their bodies by diminishing the

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Canadian context, the normative healthcare system includes institutions such as hospitals and health ministries, healthcare providers, patients, and policies that govern the relations between these entities..

cultural omnipotence of statistics or diagnostic criteria (*Recovering Bodies* 4). Canvassing the scholarly field of life writing, which centres disability and illness, has illuminated two identifying aspects of the practice. First, life writing is rooted in naming one's embodied subjectivity as authoritative, and second, life writing *does* something. This *doing* is performative, as in it works to create a form of cultural change through the act of writing in various ways. This is done by perhaps building a community, initiating self-care, organizing a resistance, embodying a transgressive act, or coming to understand one's own subjectivity in a more profound way.

Couser's work makes evident why a significant section of scholarly texts on life writing intersect with illness and disability theory. Specifically, Couser offers the key term *autopathography* to describe autobiographical narratives of illness or bodily dysfunction (*Recovering Bodies* 5). Couser seeks to conceptualize autopathography and considers how life writing becomes a therapeutic, community-building, or transgressive process. Ultimately, bodily dysfunction works to provoke autopathography by intensifying one's mindfulness of mortality, aggregating introspection, threatening one's sense of identity, and dislocating the perceived plot of one's life (Couser, *Recovering Bodies* 5). This phenomenon occurs for several reasons, including that illness tends to heighten anxiety of our somatic self and imminent mortality, that illness is deeply entwined in identity politics, and that one becomes disillusioned with their experience in the medical institution (Couser, *Recovering Bodies* 8). Couser's analysis makes clear the ways in which illness incites life writing, particularly regarding the threat to identity.

Thinking critically about impending mortality, Couser argues that illness narratives are positioned against a postmodern backdrop as a method to push back against lingering modern biomedical and technological advancements that code "healthy" as "natural". The same technological development that has advanced diagnosis and treatment has, paradoxically, “diverted doctors’ attention toward disease and away from illness, toward the laboratory and away from the bedside, toward curing and away from healing” (Couser, *Recovering Bodies* 10). Couser suggests that when our medical standard is to cure, anything less than an ideal of bodily function is coded as failure. The advancement of medical discourse has allowed individuals to live longer, but patients feel demoralized in the process (*Recovering Bodies* 10). Couser argues that “Bodily dysfunction is perhaps the most common threat to the appealing belief that one controls one's destiny. Perhaps, then, narratives of disability and illness serve to expose and dramatize what we would prefer to ignore most of the time, to arouse and (ideally) assuage our anxiety about our somatic selves” (*Recovering Bodies* 9). Illness and disability, in this sense, are not read as natural phenomena, but rather as inexcusable and catastrophic events that are both remarkable and narratable (Couser, *Recovering Bodies* 9).

Further, Couser echoes Frank's argument that illness is postcolonial, meaning that the experience of illness rouses a certain reclaiming of the body from hegemonic medical discourse (Couser, *Recovering Bodies* 10). In the process of diagnosing and treating illness, a narrative collaboration is ignited between the physician and the patient where a “life text” is generated. When an individual is in the process of diagnosis, often they must “offer up” a description of their family medical history and give a testimonial of their symptoms and bodily sensations. From this place, Couser argues, their story is no longer their own. The physician now interprets this information, commonly in ways inaccessible or shielded from the patient, and reconfigures “the sick person’s illness as the patient’s disease” (Couser, *Recovering Bodies* 10). Couser warns that although this process is what we generally expect and even want to happen, it is not without repercussions. This process often involves surrendering authority over one’s own body and one’s narrative in a way that is objectifying. Here, life writing or illness narratives become tools to repossess one's own body and life story from hegemonic discourse.

A Note on Therapy

The scholarly take-up of illness narratives situates the genre as one form of intervention for narrative therapy, a method of psychotherapy developed in the early 1990s by Michael White and David Epston. Narrative therapy, which is discussed in depth in the Literature Review, is an interdisciplinary approach to therapy that encourages meaning-making by constructing one's life as a story. At the centre of narrative therapy practice is nonjudgment by the practitioner where they work with the patient to deconstruct, then externalize harmful story aspects from the patient's identity. In the place of counterproductive story elements, generative perspectives are inserted. At the crux of this form of therapy is the role of the therapist as significant but ultimately decentred (Panina-Beard et al.).

Narrative therapy scholars Brown and Augusta-Scott argue that narrative therapy emerged from a Foucauldian critique of perceived "modernist" forms of therapy that work through practices of surveillance, regulation, and an assessment of morality (8). Narrative therapy refutes perspectives of former therapy frameworks that function from the belief that there is an untouched, true essence of the self and that therapy is the practice of emancipating this self. Narrative therapy situates the self, in contrast, as a subject constructed through, and inseparable from, historical, political, and social forces. Brown and Augusta-Scott argue that narrative therapy is emerging from this vantage point that "modernist" perspectives of therapy are flawed as they are uncritical of their discursive practice that reinforces dominant ideologies regarding morality: it is universally right to be a certain way and adhering to this will mandate emotional well-being.

Brown and Augusta-Scott write that “discourse of the therapeutic idea pervades daily life” in that it shapes how we interact with the world and forms our identities (8). Through “modernist” therapeutic perspectives, this shaping makes ideological decisions regarding how we function in a social order and what we deem as appropriate behaviour in a cultural context. The authors note that narrative therapy is mirroring former methods of therapy in that it claims it will “help” a patient feel better. However, the disruption of narrative therapy comes from its departure from “modernist” forms of therapies’ stance that therapy is ahistorical and apolitical. The authors note: “We believe that while therapy can indeed invoke conservatizing, normalizing, and regulating processes of self in its operation as a social strategy of power, it can also be an effort to challenge the discursive practices of power and knowledge that have become problematically embedded within people's lives” (9). In narrative therapy, it is believed that modifying an individual's life story can bring about change in their actual life. This involves challenging dominant social narratives that emerge in the patient’s problem-laden stories about themselves and their lives. It is acknowledged within this therapeutic approach that all personal narratives are also social narratives and are not the sole product of a single author (9). When dominant social relations of power go unchallenged within these self-narratives, the prevailing assumptions about truth and power are reinforced. Narrative therapy aims to disrupt these dominant discourses which serve to maintain the existing social reality.

From this starting point, the research question of this project is considering how women and nonbinary people with hyperandrogenism can use hypertext technology as a method of narrative therapy to write illness narratives that construct positive relationships between their identities and the world. The role of therapy in this question, and within the scope of this project, is nuanced. This project employs the terms *therapy* and *therapeutic* within the context of the practice of narrative therapy as described above and in depth in the Literature Review. I use Catrina Brown and Tod Augusta-Scott's description of therapy as "a social construction with a particular kind of social agenda and role" (8). This project will turn to insight from some aspects of the theoretical framework of narrative therapy to inform the design of the illness narrative module, discussed further in the Methods and Protocol chapter.

This project, however, resists labelling aspects of the research as any form of formal, active therapy. This is because therapeutic illness narratives hold an affinity with counter-practice to traditional forms of medical treatment (Couser, *Recovering Bodies* 4). The method is taken up in spaces that lack traditional healthcare resources by individuals who, at times, are seeking alternative methods to address emotional well-being, organize political action, and take up space as an identity tied to an "abject" body. Participants in this study did not have contact, at any point during the study, with a psychologist or therapist in relation to the project. Due to illness narrative's sociohistorical marking as a method of political action, it would be inaccurate and a disservice to participants to tie the practice to any formal therapeutic method. This is not to say that formal therapeutic practices are not or would not be beneficial for individuals with hyperandrogenism. This research will merely turn to participants to guide the meaning-making practice following the illness narrative process.

This research is the legacy of women and individuals sitting at their computer screens, writing their illness stories in blog posts, comment sections, health forums and status updates, in order to individually, or with feedback from the anonymous internet, make meaning from their experiences. A dominant perspective in the literature on narrative therapy, in contrast, understands the practice as a method of psychotherapy administered by a trained therapist (Combs and Freedman 1034). It is significant in this project to uphold the notion of accessibility of illness narratives as a practice of self-expression that can be beneficial inside or beyond institutional walls. Therefore, this project will draw on some aspects of narrative therapy as one theoretical backdrop to the method of illness narratives, however, the intention will be for illness narrative to remain as counter-practice.

Electronic Literature

The literature on illness narratives as a reclaiming tool is powerful, however, I wonder what we might consider as forms of illness narrative. Do we categorize the genre as specifically published books – or is there room to expand beyond normative notions of narrativity? Specifically, I wonder how different forms and mediums for writing about one's experience of illness can shape the process in differing ways. In my master's project, which I detail later in this Introduction, I began researching online health forums for women with polycystic ovarian syndrome as instances of illness narrative. From this place, I saw the possibility of digital narrativity become expansive and wanted to explore this further. Through a research assistantship I was exposed to literary hypertext technology, and here is where I found a way into researching how the multiplicity of the digital space can be a valuable alternative to writing one's story on paper.

In this project, I am turning to literary hypertext, a genre of digital-born writing situated within a larger field known as electronic literature. Electronic literature is described by Scott Rettberg in his book *Electronic Literature* as "new forms and genres of writing that explore the specific capabilities of the computer and network – literature that would not be possible without the contemporary digital context" (11). The genre has grown significantly from the 1990s to the present day as the capabilities of technology expand and grow. The term electronic literature has been contested in the field for decades, with scholars offering alternatives that they believe capture the essence of the described works more accurately. As Rettberg argues, scholar John Cayley put forward “writing in networked and programmable media” (11) whereas other scholars value narrower adherences such as *hypertext* (Nelson; Landow), *cybertext* (Aarseth), or *e-poetry* (Glazier). Nevertheless, electronic literature as a descriptor has prevailed likely due to its generality and ability to represent newer modes of digital storytelling. Rettberg defines forms of electronic literature in expansive ways including hypertext fiction and poetry, digital art installations, and even narratives generated by AI or conversational characters known as chatterbots (Rettberg 13). As we see, the first category encompasses the medium of this project. Yet, electronic literature can account for a robust collection of modalities and approaches to literary creation.

Today, the dominant understanding of electronic literature is refined to include the notion of, N. Katherine Hayles’ term *born-digital* creations. Electronic literature, at its core, is difficult to reproduce or distribute on the print page because its origins are within the dynamic space of the digital. Works of electronic literature tend to rely on code, digital interactivity, or computer generation, to tell a story whereas the confines of print media are typically unable to produce the same results. But more significantly, at the root of electronic literature is a disruption of print conventions. Not only is electronic literature unable to be translated into print, but it also challenges the boundaries of the static medium. For instance, electronic literature’s affinity with the term reader/player to describe the agent who engages with the text speaks to the genre’s resistance to the boundaries of long-standing axioms where a text can be a game, a narrative, a work of art, etc. Where print media may rely on linearity, electronic literature turns to the malleability of the digital to explore multiplicity, interactivity and rhizomatic structures. We see this in the electronic literature projects of UK-based artist Christine Wilks that utilize multimodality in the form of text and images to explore autobiographical undercurrents of pressurized normative femininity with harmful expectations of gender roles enforced through society and family. Wilks' Flash fiction *Underbelly* (2010) is influenced by the sociohistorical landscape of northern England. In her work, Wilks explores her sister's identity as a stone-carving artist through the setting of a former colliery's industrial past. Auditory and textual elements of 19th-century female coal miners weave together with a storyline of a contemporary woman sculptor. As the reader/player, you soon plunge into the world of *Underbelly*, an underworld of female-gendered anatomy where you may shift through a uterus canal or play a Wheel of Fortune-style game of pregnancy fate. A textual element bombards you to "Choose! Choose!" as "Time is running out." You may play the game multiple times and never receive the same outcome. But in all versions, the story urges the reader/player to confront internalized perceptions of gender roles, compulsory motherhood, and fertility.

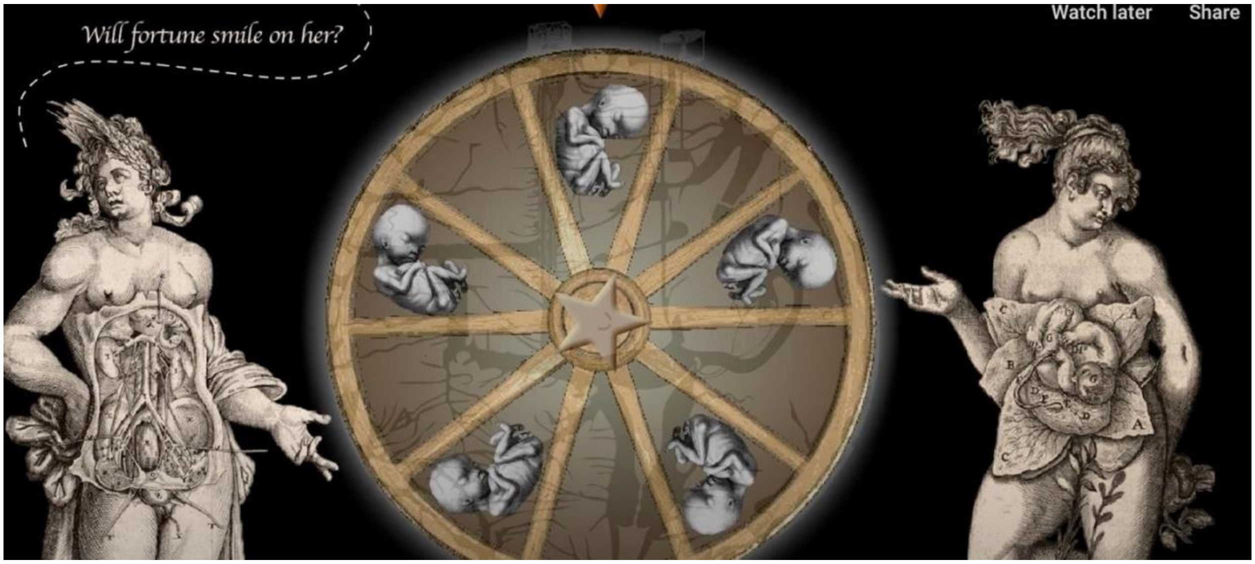


Fig. 1. Screenshot from Wilks, Christine. *Underbelly*. Interactive Game, 2010, https://crissxross.net/elit/underbelly.

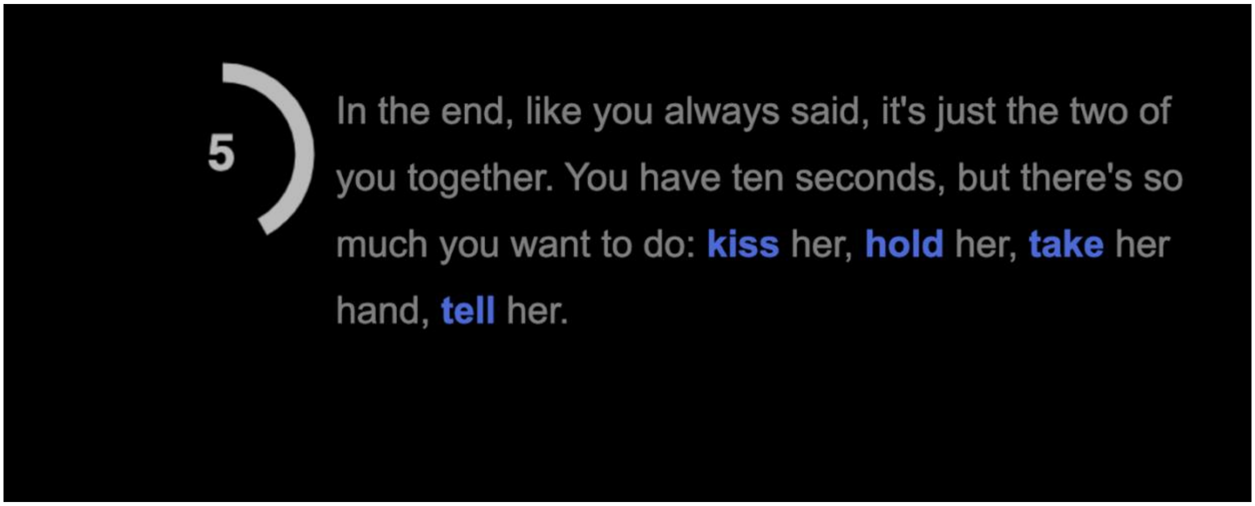
The future of electronic literature is expansive. As this project argues, there are dynamic and novel capabilities for one of the more traditional subgenres of electronic literature, literary hypertext, especially when looking at therapeutic, digital illness narratives. However, other more innovative adaptations of electronic literature are moving away from storytelling through a computer screen or a smartphone to the virtual reality (VR) visor. VR technology is in its infancy, however recently, more accessible, wearable VR technology, such as the Oculus Quest (Meta Platforms), is opening up the medium for the common consumer. Amongst VR video games, social connection spaces, virtual movie screenings, and virtual workspaces is a budding medium of VR electronic literature. *Down the Rabbit Hole* is a 2019 VR game developed by Cortopia Studios. As the reader/player, you navigate immersive tableaus, familiar to the world of Lewis Carroll's 1865 *Alice's Adventures in Wonderland*, that wrap around your body through VR graphics. You play as a young girl who is in search of her lost pet. Where *Down the Rabbit Hole* differs from some VR video games is through its textual and story-based choose-your-own-adventure plot. As you solve various riddles and puzzles to gain access to the next setting, the narrator of the story will show you a selection of cards imprinted with choices. The narrator may ask your name, what type of animal your lost pet is, or how you should interact with certain characters. Selecting a card drives the story in diverging directions which gives the reader/player differing outcomes. The experience of *Down the Rabbit Hole* reinforces most drastically electronic literature's disruption of the conventions of print media and the genre's embracing of new technological developments. Electronic literature is an expansive and growing field that encompasses a multitude of forms. In the next section, I will discuss the topic of this research and one subgenre of electronic literature: literary hypertext.

Literary Hypertext and Rhizomatic Multiplicity

In the 1990s, as hypertext technologies began to grow, so too did the practice of literary hypertext and games that utilize hypertext features. In 1993, Macintosh released one of the most successful computer games of the time, *Myst*. The puzzle adventure game was written using Hypercard, a hypermedia system that predates the emergence of the World Wide Web. *Myst* was built using the intricate layering of a series of Hypercard stacks. *Myst* became one of the most popular interactive fiction games of the time and has now been reimagined in virtual reality as a newly released Oculus Quest game. Near the end of the millennium, literary hypertext technology was becoming increasingly accessible to game developers, scholars, and individuals as a media artifact to study and create with. Today, there is a plethora of literary hypertext software available to everyday consumers, most notably Twine - the tool utilized in this study which will be discussed in depth below.

Literary hypertext is a form of rhizomatic digital story writing that calls on the reader to participate in the narrative's unfolding by selecting different hypertexts which branch the plot into diverging paths. The medium holds imminent potential as a therapeutic tool for body-based concerns due to its ability to foster unique and helpful connections between ideas, encourage integrative thought, and support collaborative learning (Ensslin et al., "Exploring Digital Fiction" 5). Digital hypertext responds to disillusionment in static, linear digital writing, such as online articles and e-books. As hypertext scholars McAdams and Berger argue, an innovative process for both reading and writing is required for narratives born in the online space to match the notion of multiplicity inherent in the digital medium. Dominant conceptualizations of literary hypertext, however, tend to make structural assumptions that the medium exclusively represents rhizomatic, fictional narratives. For example, McAdams and Berger suggest that when the structure of online writing becomes a fixed copy of that which can be produced on a piece of paper, we lose the digital capability of agency in navigation. The reader, then, has no choice but to follow the path of the narrative as it has been revealed to them. In contrast, the authors argue that hypertext literature can embody a myriad of narrative paths for the reader/player to explore. These assumptions of narrative multiplicity, however, fail to represent all forms of literary hypertext as many do, in fact, follow a linear path.

Further, most scholarly contribution to literary hypertext has been concentrated in the realm of fiction. Classified as forms of digital fiction, hypertexts can tell a story in ways that play with the reader's sense of intervention. Hypertextual forms of digital fiction tend to exhibit characteristics of games and for this reason, have been taken up thoroughly in scholarly game studies. Stemming from its accessibility in creation and counterhegemonic form, hypertext digital fictions have been both taken up and pioneered by subjugated communities to share stories that are typically veered to the margins. For example, the critically significant digital fiction *Queers in Love at the End of the World* by Ana Anthropy tells a ten-second story of a world being catapulted into emptiness. As the reader/player, you are up against a clock with a series of hypertext choices describing how you wish to interact with your lover before the whole world is "wiped away". *Queers in Love* uses multilinear narrativity in ways that foreground tenderness and compassion against a backdrop of impending destruction. Similarly, *Known Unknowns* is a hypertext digital fiction that tells the story of Nadia Nazari, a high school student dealing with the motivations of her ex-best friend, hunting for ghost raccoons, and contemplating queer desire. Found at the core of both fictions is the desire to give narrative voice to a subjugated identity through reflexive interaction between the story and the reader.



In the end, like you always said, it's just the two of you together. You have ten seconds, but there's so much you want to do: **kiss** her, **hold** her, **take** her hand, **tell** her.

Fig. 2. Screenshot from Anthropy, Anna. *Queers in Love at the End of the World*. itch.io, March 12, 2016, https://w.itch.io/end-of-the-world.

As noted above, much of the scholarly work on literary hypertext is focused on the medium as rhizomatic, fictional narrative. As Ensslin argues in *Canonizing Hypertext*: "Essentially, the abstract idea of 'hyper-text' is based on the rhizome metaphor (Deleuze and Guattari, 1987), characterized by a ramifying, horizontally organized root structure, which is, unlike arborescent structures, decentralized, i.e. there is no core, or 'trunk', and no visible hierarchy" (11). It is significant for my research to first question what we mean when we label a narrative as rhizomatic. Mainly, does this assume different plot options that can be realized through the choices of the reader, or are there novel ways we can interpret multiplicity in a relatively "linear" hypertext narrative? As discussed in the Analysis and Discussion chapter, the Twine illness narratives that participants designed in this study embodied the rhizome in different ways. Every story, though, has a single opening passage. Many narratives had a hierarchical, linear structure, as well. Despite this, there is something about the concept of the rhizome in connection to hypertext that allows for a deeper consideration of different kinds of ways to read multiplicity in the narratives.[7]

Further, I consider the potential of literary hypertext as a tool to write stories of nonfiction - particularly illness narratives. McAdams and Berger argue that innovative digital writing practices are "not only desirable but also necessary to move journalistic, nonfiction, and even scholarly writing in a direction made possible by hypertext." The authors suggest that hypertext should be more comprehensively adopted in nonfiction communities because it improves the reading experience of those engaging with the work. McAdams and Berger argue that unilinear storytelling becomes saturated in value judgments. Here, the author becomes the gatekeeper of meaning by choosing the structure of ideas and in "a well-crafted hypertext, readers immediately select what matters most to them" (McAdams and Berger). Meaning can be coded in multiple ways but includes the order of ideas, the amount of text devoted to a topic, or the author's decisions about which ideas to omit. Further, meaning is cultivated through a normative story structure that steers a course through a beginning, middle and end. In the limitless story space of literary hypertext, there can be multiple paths to both enter and exit the story with a rhizomatic internal structure. However, it becomes evident that the structure of hypertext literature does not resist every limitation of linear writing, as described by McAdams and Berger. I would argue that even with hypertext choice for the reader, literary hypertext is still confined to the structure and boundaries created by the author of the text.

Some hypertext scholars, such as Astrid Ensslin and Alice Bell, have noted that reading literary hypertext in isolation does not produce empowerment or freedom for the reader in itself.

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[7] A deeper analysis of the concept of the rhizome embodied in the participant narratives of this study is outlined in the Analysis and Discussion chapter under the headings "Designing Hypertext" and "Mapping the Illness Narrative".

In fact, the consumption of literary hypertext removed from the creation process may render notions of restriction (Ensslin, *Canonizing Hypertext* 3). It is through the process of collaborative reading, discussion, and creation of literary hypertext, Ensslin argues, where empowerment in narrative multiplicity is born (*Canonizing Hypertext* 3). It seems, that when we break down normative, hegemonic practises of writing for the purpose of empowerment, we must also consider deconstructing the binary of *reader* and *writer*. Perhaps it is when the identity of *reader* becomes amalgamated with that of *creator* that the restrictive structure of linear narrativity breaks down.

From a place situating literary hypertext as a subversion to normative ways of both reading and writing, I intend to begin my research considering where illness narratives can be taken up in the medium. It will be significant for this research to explore why literary hypertext might be beneficial, particularly for women and nonbinary people with hyperandrogenism. Perhaps, when being coded as an "abnormally" sexed body in our world becomes an act of subverting binaries of biological sex, responses that aim to empower these individuals must match this undermining of institutional and societal norms. These norms may include our standard practices of writing and reading illness narratives.

Twinery.org

Twine is one software for literary hypertext design. There is a legacy of hypertext systems, though, that has preceded the development of Twine and other current tools for building hypertext stories. These programs tend to adopt a similar scheme called a *directed path*, reminiscent of a rhizome of boxes and lines, which a reader is intended to move through from one textual unit, a *node*, to another (Moulthrop and Salter 51). The term *node* has evolved through various eras of hypertext itself, being replaced by the term *lexia* by hypertext pioneer

George P. Landow, and later various labels such as tweet or post (Moulthrop and Salter 51). Twine names the *node* as a *passage*, and this is the language this project will use to refer to a textual unit of literary hypertext. To further complicate things, the passage as a textual unit may not always include text. A passage can house an image, video or sound cues and a reader can be brought to the next passage via a programmed timer. This, however, is not the typical way passages are designed. Twine's collectively designed instructional guide, the Twine Cookbook, refers to passages as "divisions of time, space, or combinations of the two. They can also be thought of as blocks of dialogue, sections of code, or simply ways to break up a complicated project into more easily understood parts." Most likely, a passage will include text and at least one hypertext link. A *link* is the final critical term that builds the foundation of a hypertext story. According to Moulthrop and Salter, the always-online nature of our lives has led us to become familiar with links as a word, or a phrase, distinguished by a unique colour and typically underlined, that signals the user to click or tap it. These visual traces, according to the authors, are only the top layer of a deeply complex process. A link may refer to a number of parts including the anchoring text, the housed string of code, the structural image of the connecting line in the Twine's interface, or an action. The final definition, according to Moulthrop and Salter, is the most significant for understanding literary hypertext (53). A link triggers an action that makes a change, in the context of a Twine story, typically a link will transition the reader to a new passage. This project will refer to Twine's links as *hypertext, hyperlink*, or *hypertext link* depending on the context. For example, *hypertext* is used when referring to text in a passage that houses a link, *hyperlink* refers to the link housed within the text or the action of linking as a verb, in the case of *hyperlinked*. *Hypertext link* is used in an attempt to refer to the text, link and action together.

In the past decade, Twine has cultivated a movement of support from marginalized game developers who are often excluded from masculinist, white spaces of game development (Anthropy 90; Harvey 96). Twine is a culture of free production and distribution. The tool is free to download, open-source, and can export stories as HTML files to be published online. It is also regarded as user-friendly as no coding knowledge is required by the author to build a basic hypertext story. Beyond technological and financial accessibility, literary hypertexts created in Twine have the potential to subvert assumed norms in traditional narrative mediums by promoting experimentation through multiple endings, branching plots, and interactive components (Harvey 101). Developed by interactive fiction author Chris Klimas in 2009 to reduce barriers to entry for storytellers of marginalized identities, Twine hypertext technology was selected for a study of this scope as the storytelling engine is free with an internet connection. Further, the interface and process to write a basic hypertext story is relatively intuitive. Instructions found in the opening passage of the interface advise the user to enclose text within double square brackets to create a hypertext to another passage. Although, critically, moving beyond the basics swiftly becomes inaccessible for the inexperienced and this is a barrier to entry for hypertext creation as a whole. For illness narratives, branching hypertext has the potential as a productive platform for authors to learn how power functions in their stories[8] as they build in narrative choices that yield consequences (Greco 85). Literary hypertext has been taken up in game studies as a platform that blows open access to game design for marginalized communities, and I began to wonder how this promise of access could translate for women and nonbinary people with hyperandrogenism to write and publish illness narratives.

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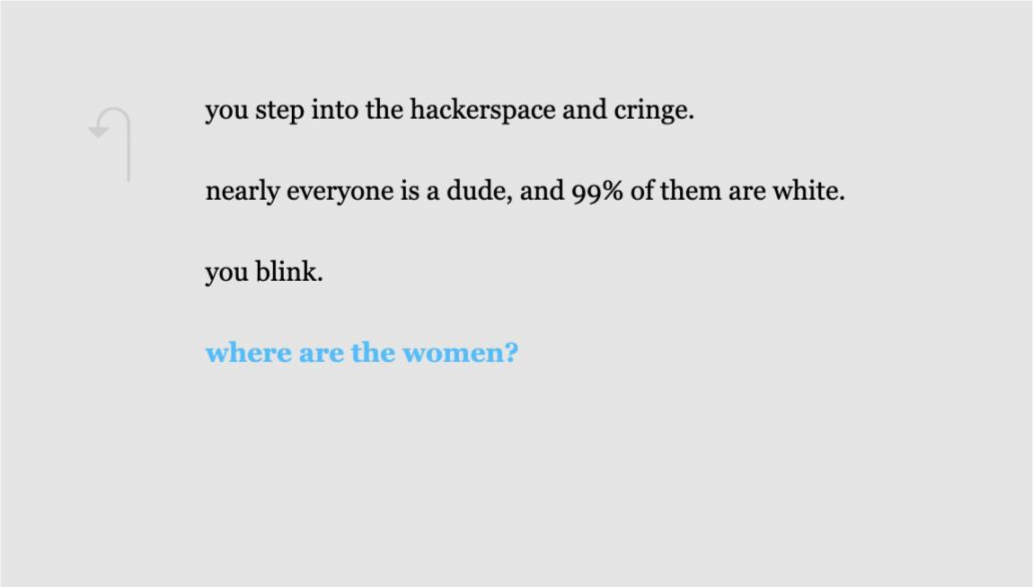
[8] The pedagogy aimed at narrative power and consequences is outlined in the "Module Design" section of the Method and Protocol chapter. Here, participants learned how power functions through the experience of hyperandrogenism as well as design principles of hypertext interactivity and multiple narrative paths, for example.

Twine has become a home for subjugated, queered, racialized, or gendered identities to occupy space in gaming and digital literary communities (Bernardi; Friedhoff). The platform has come to be described by scholars as a predominately “queer- and women-dominated” community that has facilitated the “democratization of hypertext” as a narrative form (Ensslin and Skains 10). The literary texts created using Twine are typically fiction or digital games, however, a smaller subset of Twines feature nonfiction narrative. For example, *Find the Woman of Colour at the Indie Game Jam* is a Twine narrative by Sui Sea “based on a true story” and ‘tagged’ by the author as a nonfiction piece. As the reader, you follow along with the author’s experience as a sole woman of colour at a “game jam” populated by men and white women who continually reassert the author’s identity as Other. In the story, you encounter the following scene: “you step into the hackerspace and cringe. nearly everyone is a dude, and 99% of them are white. you blink. where are the women?” The latter question is marked as hypertext that leads you further into the narrative. *Find the Woman of Colour* demonstrates how Twine is used to write nonfiction stories about the experience of marginalization – a sentiment critical to this project.



you step into the hackerspace and cringe.

nearly everyone is a dude, and 99% of them are white.

you blink.

where are the women?

Fig. 3. Screenshot from Sea, Sui. *Find the Woman of Colour at the Indie Game Jam.* Itch.io, 9 Jan. 2016, https://sui.itch.io/woc.

Game Creators at the Margins: #GamerGate and the Twine Revolution

The issues of sexism and exclusion have been at the heart of public game creation for decades, particularly in literary hypertext games. Because this project claims literary hypertext as a space of accessibility for marginalized individuals to tell their stories, it is vital to devote space, here, to large-scale movements of exclusion in the game-creation community. Sarah Einstein and Matthew Vetter discuss in their article "Women Writing in Digital Spaces: Engaging #Gamergate and Twine in the Gender Studies-Composition Course" the details surrounding a social media controversy and campaign known as #GamerGate. Einstein and Vetter argue "At the heart of this attack was a construction of 'gamer' as an essentialized identity; one that is male, socially conservative, and anti-feminist" (n.p.). In August of 2014, a sexist campaign of harassment began to proliferate in the online gaming community that targeted, specifically female game developers Zoë Quinn and Brianna Wu, as well as feminist journalist Anita Sarkeesian. The campaign was initiated by Quinn's ex-partner, Eron Gjoni, who penned a defaming blog post that accused Quinn of engaging in an unethical relationship with a gaming journalist named Nathan Grayson. Gjoni falsely argued that the massive success of Quinn's popular hypertext story-game, *Depression Quest,* was due to her taking advantage of a relationship with a journalist to cultivate a series of praising commentaries on her project. Proponents of #GamerGate also criticized Quinn's fundraising of *Depression Quest* via the platform Patreon. Massive support of Gjoni's blog post has been described as a right-wing backlash to increasing progressiveness or "wokeness" in the gaming community (O'Donnell 654; Dowling et al. 982; Mortensen and Sihvonen 1353). The response from Gjoni's supporters included doxing (publishing private or identifying information about an individual), threats of rape, and death threats against Quinn and other female game developers. Einstein and Vetter explore in their article ways to navigate the reality of sexism and exclusion in digital creation. They argue that “Women writing online face significantly more–and different kinds of–harassment than men writing online, and the emergence of this new sort of gendered violence is, unfortunately, key to understanding why women do, and do not, participate in digital discourses” (Einstein and Vetter). Conducting this research in the shadow of #GamerGate leads me to recognize not only the kind of oppression women and nonbinary folks experience in the normative medical system but also the kind of harassment and gatekeeping they experience when they attempt to tell their stories in the digital space.

The #GamerGate movement unfolded several years after prolific literary hypertext creator Ana Anthropy wrote her 2012 book *Rise of the Videogame Zinesters: How Freaks, Normals, Amateurs, Artists, Dreamers, Drop-outs, Queers, Housewives, and People Like You Are Taking Back an Art Form*. Anthropy’s book is the compass of my research. *Rise of the Videogame Zinesters* was one of the initial publications that identified a political movement in the DIY gaming industry spearheaded by marginalized writers. Her instructional manifesto became massively popular in the indie game creation community where identities who were typically silenced felt empowered by her call to action. In her book, Anthropy calls for the marginalized to organize and insert themselves into the gaming industry in ways that challenge traditionally normative methods of creation and dissemination of games. Specifically, she encourages the use of Twine. Anthropy summons her readers:

> There’s nothing to stop us from making our voices heard now. And there will be plenty of voices. Among those voices heard, there will be plenty of mediocrity, and plenty of

> games that have no meaning to anyone outside the author and maybe her friends. We'll find new ways to sort that shit. And imagine what we'll gain; real diversity, a plethora of voices and experiences, and a new avenue for human beings to tell their stories and connect with other human beings. Are you excited? (161)

Anthropy saw hope in the accessibility and DIY nature of literary hypertext technology for all to share their stories. Ultimately, she became a proponent of the "Twine Revolution" or the democratization of game design by using the affordances of the Twine software.

Cultural Take-up of Hyperandrogenism

From here, I began to wonder how literary hypertext may be a productive tool for individuals with hyperandrogenism to write their body-based stories. Hyperandrogenism and other sex disorders have been employed as a justification to call into question which bodily signifiers and hormonal nuances quantify biological sex. A relatively understudied and socially stigmatized disorder, hyperandrogenism has recently gained media attention as the focal point of the "gender testing" Olympic controversy. Following the public dispute over South African track runner Caster Semenya's 2016 Olympic gold medal in the women's 800-metre, she was mandated by the International Association of Athletics Federations (IAAF) to undergo a "sex-verification" test. The general secretary of the IAAF requested the verification of eligibility on the same day she had won the gold medal due to "ambiguity" regarding her biological sex (Cooky and Dwarkin 103). Media coverage speculated the sex inquiry was made specifically because of the deeper register of Semenya's voice, her muscular build, and her stark race time improvement (Cooky and Dwarkin 103). The test indicated Semenya had one of several conditions that cause differences in sex development, ultimately leading to elevated testosterone. Semenya was raised as a girl and has always identified as a woman. In an ongoing court trial, over more than a decade of her career, Semenya has been fighting the IAAF decision that she must pharmaceutically lower her natural testosterone through surgery, the hormonal contraceptive pill, or hormone-blocking injections, in order to compete in the women's category of her sport (The Associated Press). As of 2022, Semenya is challenging the ruling in the European Court of Human Rights (Compton).

Encapsulated within the Olympic "sex-verification" controversy are overtones of racism. As Magubane argues, the process of Semenya's formation as an intersex subject through institutional regulation "contains within it a racially exclusive impulse" (761). In court documents, the IAAF is quoted as saying: "There are some contexts where biology has to trump identity" (The Associated Press). IAAF's stance, however, according to Cooky and Dwarkin, is rooted in three grave misconceptions: biological sex is a dualistic binary, sports competitions are already level playing fields for those who compete, and elevated testosterone gives women a distinct athletic advantage (103). Beyond the results of the "sex-verification" test, Semenya has detailed her experiences over the years of being mandated to undergo intrusive, embarrassing, and dehumanizing examinations from the age of 18 (The Associated Press). Semenya's experience of hyperandrogenism, and many other women competing in professional and amateur sports, has included a public defence of gender identity.

The Pathologization of Hyperandrogenism

Hyperandrogenism is a prevalent expression of polycystic ovarian syndrome (PCOS), the most common endocrine disorder for women of childbearing age (Badawy and Elnashar 25). Hyperandrogenism is a complex diagnosis because it appears as a display of symptoms that could be tied to several underlining sex disorders including PCOS, Congenital Adrenal Hyperplasia, or Cushing's disease (Rachoń 205). Medical literature affirms that disordered causes of hyperandrogenism may be medically critical but choosing not to treat elevated testosterone for some women may pose “no health risk” (Sonksen et al. 826). In clinical practice, women diagnosed with hyperandrogenism are prescribed anti-androgens or else advised of cosmetic “solutions” including laser hair removal, medication for male-pattern hair loss, and bleaching cream to “restore” feminine embodiment (Cannon 15).

Medscape, a dominant online medical resource for educating physicians and healthcare practitioners on clinical guidelines, offers peer-reviewed scholarly guides on the presentation and treatment of diseases, including hormonal disorders. The description of the disorder’s presentation on *Medscape* produces a clear pathologizing of bodies that deviate from normative gender embodiment. PCOS clinical guidelines call for physicians to conduct a visual exam for increased testosterone. The modified Ferriman-Gallwey (mFG) score grades nine areas of the body from zero (no hair) to four, “including the upper lip, chin, chest, upper abdomen, lower abdomen, thighs, back, arm, and buttocks” (Lucidi). *Medscape* notes that “a total score of 8 or more is considered abnormal for an adult white woman”. The modified Ferriman-Gallwey (mFG) score, particularly in the way it is described here, is insufficient for various reasons. These guidelines fail to provide further context regarding the different criteria for white women versus non-white women and how this difference should be interpreted, direction on informed consent for the patient in regards to the visual examination, methods for uniform interpretation of the degree of “excess” hair, and how to screen for permanent or non-permanent hair removal practices that may have already been done on the body prior to the exam.

When visual cues for elevated testosterone are a diagnostic tool, the cause for medical concern would arise in the appearance of hirsutism where “hair is commonly seen on the upper lip, on the chin, around the nipples, and along the linea alba of the lower abdomen” (Lucidi). For physicians, visual symptoms of "abnormality" in diagnosing increased testosterone would also include signs of male-pattern baldness, clitoromegaly (enlarged clitoris), increased muscle mass, acne and deepening voice (Lucidi). Some women diagnosed with PCOS are given options of "medical treatment" for "excess" facial and body hair growth, suggesting, in conjunction with weight loss, "shaving and the use of chemical depilatories and/or bleaching cream" may be used (Lucidi). The clinical guidelines go on to explain that because plucking or waxing may cause ingrown hairs, "long-term, more permanent measures for unwanted hairs include electrolysis and laser treatment" (Lucidi). Within the framework of this diagnostic language, it is the display of gender deviation that is pathologized (such as "masculine" features, infertility, abnormal menstruation, etc.), rather than the underlying source of dysfunction (if one is present). The insufficiency of both PCOS diagnostic criteria and clinical procedures is two-fold. First, the centering of "androgen excess" which focuses on clinical signs of "increased" male hormones as a diagnostic criterion indicates a pathologizing of the bodies of women with PCOS that deviate from normative gender embodiment.

As I argue in "Sigmund Freud's *The Uncanny*, Hyperandrogenism and 'being-in-the-world'", the institutional treatment of hyperandrogenism is an act of medical and cultural pathologizing of deviant femininity. The pathology, in this sense, contributes to perceptions of abnormality in women with hyperandrogenism. Women with hyperandrogenism "because they fail by cultural standards to embody normative femininity—perceive themselves as reduced to a dysfunctional body, an abnormal body, and a body that must be treated medically" (Perram 3). This is a finding that is echoed in the literature on the experiences of women with PCOS (Ekback et al. 358; Himelein and Thatcher 613; Yoo et al. 3; Pfister and Rømer 167). According to some experiences, as told through illness narratives on the clinical encounter, hyperandrogenism becomes coded as a failing of hegemonic femininity. Here, an idea is born that once one is able to “achieve” a normative body, one will, in fact, be “cured” of the disease (Perram 3). This narrative not only ignores the potential concern of “root causes” of hyperandrogenism but also reinforces misconceptions of a biological sex binary (see Fausto-Sterling).

Recent literature suggests that women with PCOS are dissatisfied with the diagnostic process and therefore are seeking information through alternative sources (Hoyos et al.) In a study conducted by Gibson-Helm et al. it was found that in a sample size of 1385 women, only 35.2% were satisfied with their diagnosis experience. The main reasons for dissatisfaction, according to participants, were delayed diagnosis and inadequate information (Gibson-Helm et al. 604). The most critical area that women in the study believed required improvement was effective educational materials. Participants in the study identified forums, workshops, emails, and informational websites as potentially effective methods of education dissemination to patients during the diagnosis experience (608). Further, this study illuminates a distinct issue around access to a diagnosis. The authors note that, on average, women in their study encountered over three health professionals over the duration of one year in order to receive a diagnosis of PCOS (Gibson-Helm et al. 608).

This particular study did not focus on diverging experiences of diagnosis for Women of Colour. Women of Colour experience PCOS more intensely and frequently than white women (Basile). PCOS commonly has comorbidities or a high frequency of presenting itself with one or more other diseases and/or medical conditions. Most of these comorbidities, such as metabolic syndrome, also affect Women of Colour more dramatically. Black and Latinx communities have higher morbidity and mortality rates due to cardiovascular disease and diabetes and Black women and Mexican communities have higher rates of hyperinsulinemia and insulin resistance

(Basile). The emergence of health disparities that arise along racial lines is formed by social and environmental racism and oppression. For example, Black women with PCOS experience higher rates of hirsutism, obesity, and infertility compared to white women, yet have poorer access to fertility treatments (Galic et al. 109). PCOS and hyperandrogenism, like many diseases, are race and class issues. It is important for my project to consider the unique implications of when race and class disparity intersects with disease. This is a topic I discuss in-depth in the Literature Review chapter.

The Combined Oral Contraceptive Pill as First-Line Treatment for Hyperandrogenism

For a project that is exploring therapeutic responses to emotional issues related to a particular illness, it is significant to situate the sociohistorical context of how the disease is typically treated. The first-line treatment for hyperandrogenism related to PCOS is the combined oral contraceptive pill (COCP) (Peigné et al. 1487). COCP is widely administered across the globe and both its pharmacological impacts and cultural significance is extensively studied in multiple disciplines. Many individuals with PCOS and hyperandrogenism have found effective relief of their systems through the use of COCP, however, a “cure” narrative that dominates medical responses to hyperandrogenism erases nuanced experiences of the drug - both physiologically and historically.

COCP and its impacts on mood disorders is a highly debated scholarly topic with varying consensus. A prominent study by Keyes et al. found that women currently using hormonal contraception have better scores on the Center for Epidemiologic Studies Depression Scale. This finding, in conjunction with other similar studies, has contributed to some consensus amongst healthcare practitioners that COCP use aids in symptoms of depression. In contrast, Ellen Wiebe who conducts research on hormonal contraceptives and mood disorders in women, argues that hormonal contraceptives trigger the onset of mood issues that interfere with mental well-being in 25% of COCP users (Wiebe 2013). Wiebe interviewed 1311 women, of whom 51% reported experiencing at least one negative mood effect while using a hormonal contraceptive, which was either a new symptom or a heightened experience. Wiebe argues that one of the flaws of Keyes' original study was the ineffective measuring tool of the Epidemiologic Studies Depression Scale which does not measure mood effects such as crying more easily, irritability, or lability (Wiebe 2013). Notably, Wiebe discusses how the most common symptom reported by the women in her study was that "the pills are making me crazy" (Wiebe 2013). The use of subjective or embodied language to describe symptoms of negative mood effects is not recognized in Keyes' original study which contributes to the literature about COCP use and its positive effects. Depression, like all mood disorders, is a multifactorial disease impacted by complex environmental, genetic, social and unknown nuances. Taking a stance on COCP as a trigger or cure for mood disorders is less important in this project than understanding COCP as an agent of sociopolitical belief systems. These belief systems discursively shape all aspects of the experience of PCOS from institutional practices to individual patient-physician encounters.

The ongoing debate over the mood effects of COCP is situated within larger racial discourses as well. For example, Sevonna Brown, Human Rights Project Manager at the Black Women's Blueprint, argues that social prejudices regarding women as emotional and hormonal have become naturalized (Martis 2016). According to Brown, many physicians are failing to take complaints by women on COCP of mood effects such as anxiety and depression, seriously. Brown argues "The medical world—and society at large—often suggests that women are inherently emotional and irrational…This definitely impacts how we medicate and protect our bodies" (Martis 2016). Looking to nuanced experiences of the first-line treatment for PCOS is imperative for understanding some women's dissatisfaction with their treatment in the healthcare system and how these experiences may intersect with identity politics.

The introduction of COCP has been a monumental and effective crux of the feminist reproductive rights movement and it has afforded masses of women to find agency over the mechanisms of their bodies and allow them empowered approaches to make decisions about their future. In contrast, COCP has simultaneously been weaponized as a tool for the reproductive oppression of poor and racialized women and this context is vital to understand. In 1950, in the wake of the Second World War, a women's health activist named Margaret Sanger, founder of the Birth Control Federation (which eventually evolved into Planned Parenthood) became the leader of the American COCP movement and a central figure in its expansion (fig. 4). Rooted in a rich history of racism and fundamentally tied to the eugenics movement, Sanger's championing of the development of the COCP was contextualized by collective Western anxiety over the threat of an "excessive fertility" of "uncivilized" women (Marks 14). In Sanger's words: "the world and almost all our civilization for the next twenty-five years are going to depend on a simple, cheap, safe contraceptive to be used in poverty-stricken slums and jungles, and amongst the most ignorant people" (Marks 13). The sociopolitical landscape of early 20th century America—prior to the COCP legalization in 1960—was riddled with overpopulation panic. Hysterectomies were viewed as an appropriate "response" for postpartum Women of Color with multiple children. Dr. Richard Hauskenecht, in the PBS documentary *American Experience: The Pill* notes:

> We did them early after delivery. Six weeks, seven weeks postpartum…Doing a vaginal hysterectomy on somebody who's had three or four kids, six weeks postpartum, you got two choices: You either got to be faster than hell, or you'd better get the blood bank

> cranked up because the blood loss will be astonishing. It was prehistoric, absolutely prehistoric. (PBS 2003)

This systematic push towards a eugenics project, coupled with emerging medical technology, allowed space for the COCP to develop.

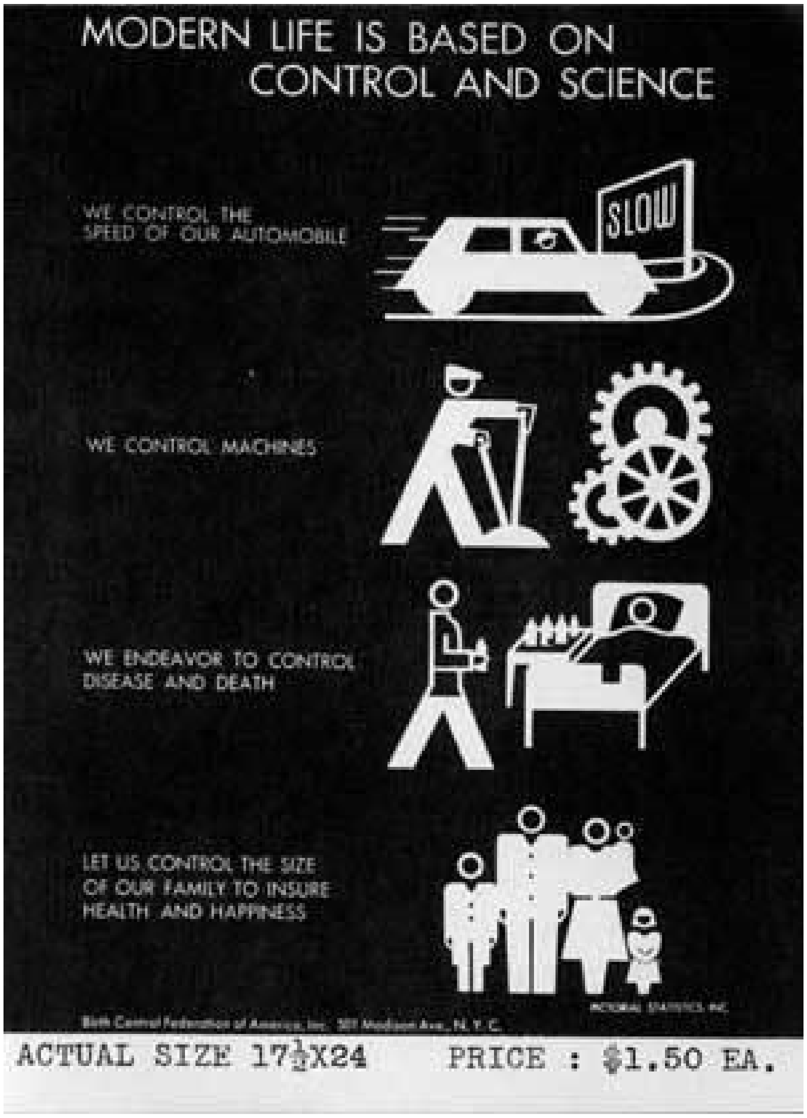


Fig. 4. Birth Control Federation of America, Inc. "Poster: Modern Life is Based on Control and Science, by Birth Control Federation of America, undated." *Smith Libraries Exhibits*, https://libex.smith.edu/omeka/items/show/485.

Accompanying Sanger's advocacy, the American COCP movement was pioneered by biologist Gregory Pincus, elite suffragist Kathrine McCormick, and Catholic gynecologist John Rock (Squires). By conducting experiments on female animals, Pincus discovered that hormonal progestin injections halted animal ovulation, and this led to the push for a human oral contraceptive pill. Rock attributed the deterioration and overpopulation of society to the recent progression of medical technology that worked to decrease infant mortality, and here, he saw the potential for the COCP as an advanced technological tool to facilitate a eugenics project. According to Rock, in 1954 "The union of Science and Humanitarianism is increasingly successful in the exemplary prevention of premature death which in the evil past restricted populations. Can this same union do nothing now to prevent [the] smothering of mankind by Man, before evils of the past inevitably again take over?" (Marks 15). According to a comprehensive 2012 historical review put forward by *The Official Publication of the College of Family Physicians of Canada*, initial COCP human trials held in Boston were conducted by Rock on participants who were told the study would evaluate their fertility capacity, though the project was, in fact, working to suppress their ovulation (Liao and Dollin). Due to the non-judicial nature of the trial, US regulations terminated the continuation of the study, leading Rock to look to continue the trial in Puerto Rico "with its perfect mix of overpopulation and no prohibitive laws" (Liao and Dollin 757). Throughout the 1950s and '60s, in line with an international eugenics project and in conjunction with a lack of judicial regulations, poor Puerto Rican women were being subjected to sterilization procedures without consent, colloquially known as *La Operacion* (Squires). The initial large-scale trial was conducted in a Puerto Rican housing project in 1954 and included over 200 women. Dr. Edris Rice-Wray, medical director of the Puerto Rico Family Planning Association who was working with Rock, facilitated a new project seemingly centred on transparency and consent in order to combat the detrimental participant drop-out rate. The program entailed door-to-door contact by social workers in San Juan housing projects, advocating for participation in a trial study that would prevent pregnancy. Despite Rice-Way's final report to Rock that the COCP did, in fact, yield a 100% pregnancy prevention rate but "too many side reactions to be generally acceptable" including three deaths of participants that were not medically investigated, the study allowed G.D. Searle & Co. to release the first version of the COCP in America, and later, internationally (Squires).

The widespread expansion of the COCP began to reflect the objectives of a nation-building eugenics project. In 1967, *TIME* reported:

> [The] latest reports show that illiterate women who can't count can still take their pills on schedule. In Pakistan, Denver's Dr. John C. Cobb got dozens of them to do it, simply by starting them on the night of the new moon. In semiliterate Taiwan, where IUDs have won wide acceptance, more and more women are switching to the pills. The number of users outside the U.S. is about 5,000,000, and the figure is rising. (Gibson)

Despite the significant expansion of the COCP, political push-back from targeted populations was proliferating as Black American leaders began to politically organize a resistance. At a Black Power Conference in Newark, New Jersey in 1969, members put forward an anti-contraception resolution arguing that the expansion of the COCP in Black communities was a government-facilitated "black genocide" assignment (*PBS* 2003). Despite ongoing resistance from African-American activists, the COCP did, in fact, prevail. As the Black liberation activist Tone Cade noted "I've been made aware of the national call to Sisters to abandon birth control... to picket family planning centers... to raise revolutionaries.... What plans do you have for the care of me and my child?" (*PBS* 2003). The ways in which the expansion of the COCP propelled the subjection of poor women and Women of Color were also met with an equally substantial desire to control fertility.

Enovid, the first brand of COCP released by G.D. Searle & Co, contained 10 times the amount of synthetic hormones required to halt ovulation (Squires). A lack of implemented clinical practices for informing women of Enovid's side effects led journalist Barbara Seaman to turn to the lived experiences of women. She wrote *The Doctors' Case Against the Pill*, a book that gave a platform to the testimonials of women on Enovid and which later was championed by Wisconsin Senator Gaylord Nelson. In 1970, known as The Nelson Pill Hearings, Nelson advocated for the "patient's right to know" in regards to the COCP and its side effects in a series of Senate hearings on Capitol Hill. Executive Director of the National Women's Health Network, Cindy Pearson, recalls the trials as an "entry point for making the medical industry more transparent to consumers" (Squires). Despite the impact outlined in the Nelson Pill Hearings, including the reduction of hormones in the COCP and mandated regulation to inform patients of side effects, there was a refusal to include women in the reform process. Notably, the D.C. Women's Liberation collective, led by Alice Wolfson, protested the lack of female influence at the trials, as Wolfson told reporters "It must be admitted that women make superb guinea pigs…They don't cost anything, they feed themselves, they clean their own cages, pay for their own pills, and remunerate the clinical observer. We will no longer tolerate intimidation by white-coated gods antiseptically directing our lives" (Squires). As *The Official Publication of the College of Family Physicians of Canada* notes, the history of the COCP "is marked by a lack of consent, a lack of full disclosure, a lack of truly informed choice, and a lack of clinically relevant research regarding risk" (Liao and Dollin 757). Understanding the history of COCP and eugenics is imperative for this project because it identifies a legacy of marginalized patients calling attention to unjust healthcare experiences. This history also shines a light on a complex legacy of COCP, where on one hand the drug has afforded masses of women control over their reproductive choices, and on the other, stifled that agency for others.

Soul Cysters Dot Net

In response to experiences of subjugation in the medical encounter and in social interaction, some women are turning to online illness narratives to write their "abject" bodies (Butler, *Bodies that Matter* 3) into a growing corporeal politic. My master's research examined the writing in an online women's PCOS health forum called Soul Cysters Dot Net as illness narrative and explored the types of discourses on gender and illness that were developing in this online space. When I began conceptualizing my master's research, I imagined that Soul Cysters Dot Net was wholly a site of resistance to normative ways of responding to illness, particularly through the healthcare system. However, I found that multiple, deviating dialogues were emerging: women were expressing empowerment and support in community, yet, at the same time, (re)producing discursive hegemonic femininity (Perram 2017; Schippers 85). Both the normative medical system and the Soul Cysters community are mandating a standard of femininity for women with PCOS. In the same way healthcare policies enable physicians to prescribe medications and perform procedures that combat "masculine" bodily expressions, the Soul Cysters community reinforces these same objectives. Physicians look to treat the bodies of women with PCOS through prescribing androgen blocker medications such as Spironolactone, oral and topical Minoxidil for male-pattern baldness, hair removal procedures such as laser and electrolysis or hair growth prevention cream like Vaniqa (Lucidi). Despite the community of the Soul Cysters forum working in transgressive ways which re-centre the subjectivity of these women, I found that the objective of discussions in this space was to discover new ways to attain normative femininity. Women in the Soul Cysters blog share alternative treatments used to lower androgen excess, to re-grow hair on their heads and diminish the hair on their bodies. These women share collective pain and mourning over their inability to become pregnant without a collective resistance to essentialist notions which inherently link womanhood to motherhood. The Soul Cysters rehearse false narratives to perform to physicians so that they may receive the diagnoses and accompanying prescriptions they desire. This subversion however is ultimately to obtain more efficient and accessible ways to combat the perceived masculinization of their bodies.

This is not to say that regulating gender is not imperative to the livelihoods of women and individuals with PCOS and hyperandrogenism, because it is. Nor is it to undermine the severe injustice women with PCOS face in the healthcare system or the lack of funding or mobilization PCOS draws for medical research. As the structures of oppression currently stand, these injustices for women with PCOS mean discrimination, alienation, and punishment of their bodily expressions insofar as they destabilize our societal understandings of gender. As I came to understand that the Soul Cysters blog replicates the gender regulations of the healthcare system and beyond, I also came to understand why. As Judith Butler argues, achieving gender normalcy is an effort of survival (*Undoing Gender* 100). Ultimately, our practices for reading a sexed body are socially constituted, but this does not mean that gender, as a process of becoming, is trivial. Gender affects us in deeply meaningful ways and there are serious implications when the sexed body is read “incorrectly” or when it is unreadable at all. These implications include both social persecution where performing gender “appropriately” becomes a mode of survival, and internal disarray when one’s process of becoming is stifled or halted. It is understandable, then, why the Soul Cysters reproduce standard femininity. Meeting this standard becomes either a process of survival or a “mode of becoming”[9] (Butler, *Undoing Gender* 217). From this place, I became interested in mapping the progress of novel and innovative tools for writing digital illness narratives for women and individuals with sex disorders.

Dissertation Overview

This Introduction provides a contextual overview of the major meta topics of my project, including illness narratives, electronic literature as foundational to literary hypertext, literary hypertext and nonfiction, the Twine Revolution, description of Twinery.org, analysis of the cultural take-up, clinical diagnosis, and treatment of hyperandrogenism, and a brief overview of my master’s work which will continue to inform this project. My intention for this research is to expand the current literature on illness narratives and the fast-growing field of medical/health humanities in Canada and abroad by extending critical significance to new modalities of nonlinear digital storytelling. Ultimately, I argue that the future of the illness narrative genre is not simply bending to a digital format, but, digital tools like hypertext have the capacity to reimagine illness narratives and to transform how people can reflect on their experiences and narrate their lives.

The Literature Review of this dissertation begins with an overview of the Twine database I built as a method for conducting literature reviews for qualitative research. This section will be published in a forthcoming article for *Interdisciplinary Digital Engagement in Arts & Humanities* called “Building Hypertext Literature Reviews for Qualitative Research.” The Literature Review then goes on to detail the scholarly field of topics related to this research, including hypertext theory, illness narratives, narrative therapy, research situated against

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[9] I refer to the process of embodying gender as a “mode of becoming” in a Butlerian sense where they question: “what happens to gender as a mode of becoming?” (*Undoing Gender* 81) when our norms for care work to cement bodies into fixed binaries?

narrative perspectives, phenomenology, critical approaches to discourse, norms, and intersex bodies in the linguistic turn, and crip theory in conversation with colonial medicine. Ultimately this trajectory of a literature review leads to this project's theoretical framework, detailed as feminist new materialism.

The Methodology chapter outlines the development of a novel methodology I designed for the corpus of this research, called critical discourse analysis for digital-born narratives (CDADN). This chapter unpacks the kinds of methodological approaches that have been taken before for similar data, and the reasons why a novel methodology was developed for this research. Then, an example Twine narrative called *You're Going to Make a Great Mother One Day* by Wally Ntagonistic is taken through CDADN's four-step analysis of Texts, Contexts, Actions and Interactions, and Ideology and Power. This example analysis outlines how the narratives in this project are analyzed using this methodology.

The Methods and Protocol chapter details this project's participant recruitment and research design. The module design process, as informed by political narrative therapy perspectives, is unpacked in detail. Much of this section will be published in a forthcoming chapter in the book *EnTwine: A Critical and Creative Companion to Teaching with Twine* edited by Anastasia Salter and Stuart Moulthrop and published by Amherst College Press. This chapter concludes with an analysis of the project's risk and accessibility assessment.

The Analysis and Discussion chapter is an amalgamation of a presentation of the findings with an analytical discussion of the relevance. This chapter is divided into five sections: Matter, Narrative Themes, Situating Narrative Themes, Technology, and Therapeutic Value of Literary Hypertext Illness Narratives. The first section on matter is an explicit connection to this project's theoretical framework of feminist new materialism through a grappling with materiality as well as researcher implication. The narrative themes section dives into the main thematic patterns identified within the participant narratives, while the situating narrative themes section positions these topics within a larger sociopolitical and technological context. The technology section analyzes the use of code and hypertext within the Twine software and the ways in which participants engaged (or not) in these features. The final section turns to participant Closing Interviews to analyze the therapeutic value of Twine illness narratives and explores a participant call to action regarding Twine as a teaching tool for healthcare providers.

The Conclusion of this project offers a summary of the key findings, an overview of the main contributions of this research, an analysis of research limitations and recommendations for future research. In essence, this chapter contextualizes the findings of this research: through the use of the Twine software, study participants were able to visually map out their experiences and organize them through hyperlinks, which proved to be beneficial for personal reflection. It is important to note that participants did not view writing a single illness narrative as a cure for their emotional or physical concerns. Instead, they found value in the reflective process of creating a Twine illness narrative. The study's findings align with the framework of narrative medicine, as participants believed that literary hypertext illness narratives must serve as tools for both personal reflection and educating the broader social and medical community on hyperandrogenism experiences.

Chapter II: Literature Review

Introduction

I conducted the following literature review using a methods approach that utilizes the novel capabilities of this project's subject: literary hypertext technology. In September of 2020, I facilitated a workshop at the Getting Started in Digital Humanities: Digital Humanities Initiative 2020 Workshop hosted out of the University of Illinois. The workshop was entitled "Twinery.org: Building Literary Hypertexts" and explored using Twine as a tool for multiple research and creative purposes. In this workshop, I discussed using the Twine software as a theoretical mind-mapping tool - a project I began while I was preparing for my comprehensive exams. The database that I created for my exam eventually became the "bones" of this literature review and will be discussed in detail below.

In the following literature review, I outline the various theoretical frameworks typically utilized by scholars to discuss illness narratives including phenomenology and its theoretical application to the health/medical humanities. Next, I discuss previous theoretical approaches to discourse, norms, and intersex bodies taken as a result of the linguistic turn in scholarship. I conclude this section by aligning myself with a feminist poststructuralist critique of phenomenology as a site of experience. I argue although illness narratives have typically been taken up through a phenomenological lens, my research requires a theoretical framework that considers discursive influences more thoroughly (not entirely). Next, I explore the scholarly field of poststructuralist discourse pioneered by Michel Foucault. This summary includes a discussion of the monumental work of Georges Canguilhem on norms and pathologization and maps the text's influence through to feminist poststructuralism and Judith Butler's work on intersex bodies.

Theories of crip and disability studies are later explored in relation to illness and pathologization. This is followed by an outline of the theoretical framework of hypertext and electronic literature. I discuss the historical take-up of hypertext and early grandiose claims regarding its emancipatory potential. Contemporary theory on hypertext shows that the medium has liberatory potential when designed as immersive, adaptable and user-friendly. Further, I consider a gap in hypertext literature as the field is typically looked at as hypertext readership. However, my research will focus on experiences of hypertext authorship for telling one's illness story. I then discuss the limitations of the discourse-heavy linguistic turn specific to this project. Finally, I discuss the theoretical framework taken in this research: feminist new materialism. I consider how a general theme in feminist theory is moving away from language-heavy poststructuralism to grappling with other forms of non-androcentric discourse with a centering of matter. I conclude a feminist new materialist framework will offer my research methods to grapple with the embodied narrative's emergence into the digital by emphasizing paths to consider both materiality and discourse.

Coming to Terms with the Literature Review

In the process of executing a comprehensive qualitative research project, one typically must conduct a thorough literature review of the topic. Literature reviews are expansively defined and may embody diverse purposes depending on the research goal. In qualitative projects, literature reviews behave as a structured and systemic critical outline of the state of the scholarly field related to the research topic. An effective literature review not only works to synthesize the trajectory of a scholarly field and/or topic through time and space (both in its historical evolution and sociopolitical context) but it should position the topic in conversation with the purpose of your research. In their 2019 guide *Writing the Literature Review: A Practical*

Guide, Sara Efrat Efron and Ruth Ravid argue that the objective of the literature review author is to "present a comprehensive, critical, and accurate understanding of the current state of knowledge; compare different research studies and theories; reveal gaps in current literature; and indicate what needs to be done to advance what is already known about the topic of choice" (2).

In this sense, literature reviews can be understood as methodological in that they *do* something. This something is an active production of connections that ultimately yields the rationale for a specific theoretical framework as well as a justification for the chosen methodological approach to the research project. The theoretical framework is a vital process that should assemble a relational network of the topic that comes to a crux at the core of the research question. Conventional methods for building such an intricate, systemic piece of research can be limiting for some authors who desire more interactive, dynamic engagement with their work. There is a deep need for novel, digital-born approaches to building literature reviews that can offer an alternative to maladaptive and siloed traditional writing practices.

This chapter details my experience preparing for both doctorial candidacy and writing my dissertation by building a digital literature review using the hypertext software, Twine. The informational database I developed was an invaluable resource during the course of my candidacy exam and throughout my dissertation research. The database stands as an evolving, affective network that houses the texts, theories and arguments relevant to my research, and the spaces where these entities come into contact with one another.

The Candidacy Exam

In my department, PhD students seeking candidacy must go through a process called the comprehensive exam. Over the course of six months or so, we spend time reading a list of seventy to one hundred integral texts in our field of study. Texts can include entire books, chapters from books, or scholarly articles. These are texts that shape our dissertation research and essentially become the foundation of our theoretical framework. During the comprehensive exam, our dissertation committee compiles a series of essay questions related to those readings. Over the course of seven days, we write seven short essays, each of which are three to five pages.

The relationship between students and the comprehensive exam is complex - we understand its significance in preparing us to write our dissertation proposals and to set us up for candidacy success. Nonetheless, it is a daunting event. A major stressor in this exam is coming to terms with a system to best prepare notes taken on over seventy texts, and specifically how to make these notes efficient and accessible during the exam week. In preparation for candidacy, I spent months reading texts and built a two-hundred-page Word document of compiled notes. I summarized each text's main points into a series of bullet points. I compiled a list of several significant quotes that I believed represented the overarching arguments of the piece. I also included pages of analysis, or contextualization of the text, sometimes written by me or other times a scholarly review. Finally, I wrote a list of keywords that represented that work.

Several months before my comprehensive exam I began to feel the weight of this inefficient two-hundred-page Word document that seemed like a time constraint to navigate at best and completely useless at worst. I began to understand that the problem with this note-taking method was that the connections between my texts were invisible. I could only engage with each work in isolation, and I was essentially missing that bigger-picture conceptualization of the theoretical frameworks that were threading throughout. I knew I was in trouble and that I needed a different, more inventive approach. At the time I was also beginning to develop a proposal for my dissertation project which was exploring how literary hypertext could be used as a tool for women and nonbinary individuals to write therapeutic illness narratives. As I was learning how to use literary hypertext tools to write creative-based narratives, I began to have discoveries about how literary hypertext could be used to make connections between theoretical works.

At the start of my graduate studies, I was hired onto the research team for Dr. Astrid Ensslin's "Writing New Bodies: Critical Co-design for 21st Century Digital-born Bibliotherapy" (WNB) which was funded by a Social Sciences and Humanities Research Council of Canada Insight Grant. We spent years, through this project, working with young women and nonbinary individuals as co-designers to inform the creation of a digital fiction body-image therapy application. One of my tasks on this research team was developing and facilitating a series of participant workshops across Canada. The workshops included a variety of activities designed to produce data for our application. We were interested in data that captured insight and perspectives of participants about body-image experiences. One method we used in these workshops was storyboarding participant narratives through the hypertext technology Twine. We spent time in the workshop offering a tutorial on the software and participants were invited to write and build their own literary hypertexts through the platform. This path into exploring literary hypertext planted the seed for Twine as an information management tool. This is when I decided to "translate" my two-hundred-page Word document into an interactive hypertext database. This became a self-pedagogical process to develop a novel method for building a large-scale study guide. I spent the next several months constructing connections between texts using hyperlinks and passages.

After successfully completing my comprehensive exam in the Fall of 2019 using my hypertext database, I knew I wanted to expand this project as a tool to write my dissertation. For the next several years, I continued to build this project, adding information from texts that I was engaging with for my dissertation research. With over one hundred critical texts, my hypertext database has now become the bones of the literature review chapter of my dissertation. I have created an interactive map that generates links between texts through concepts and ideas. Similar to, not just a Wikipedia page, but the Wikipedia interface as a whole, this small-scale database on the topics of my dissertation includes sections on medical/health humanities, gender theory, disability theory, digital humanities, hypertext theory, and feminist new materialist theory. Behind the scenes, in the software interface, you can see the database creates the visual of an intricate web or a network in which every line symbolizes a new connection between passages (fig. 5). The intricacy of the connections exposes what insight was left out when using a linear, stagnant Word document.

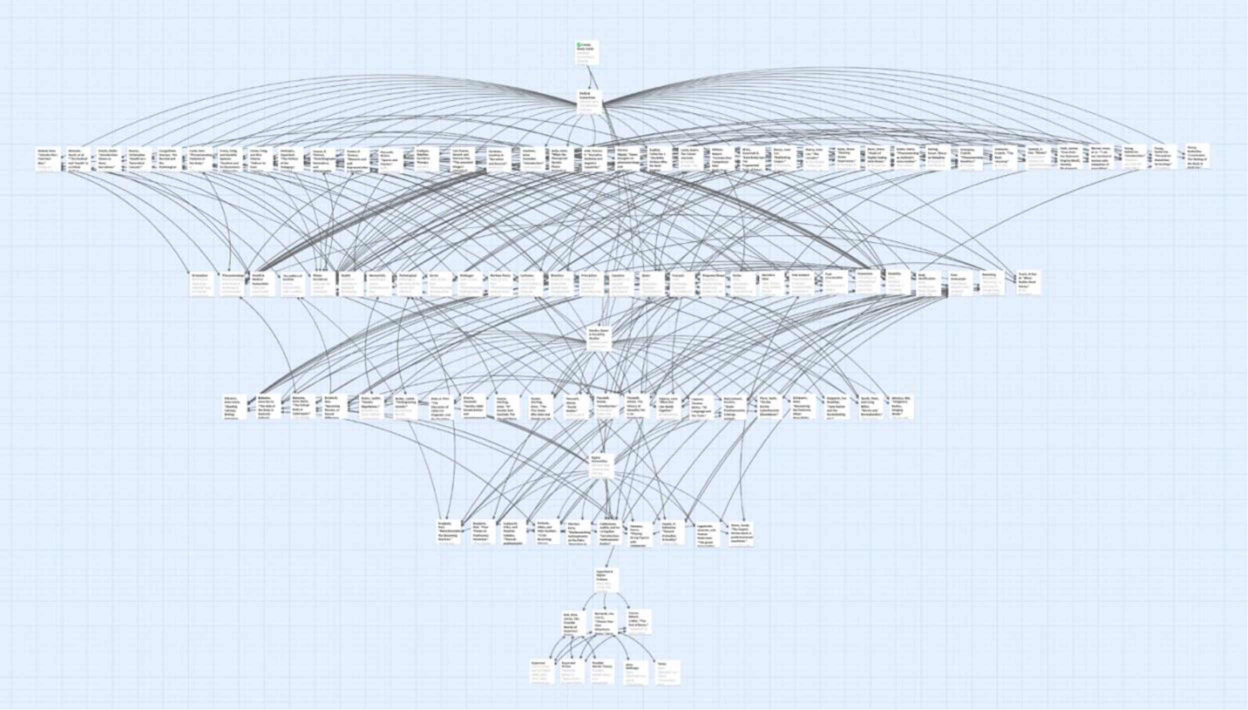


Fig. 5. Screenshot of Twine Literature Review

Twine for Information Management

Because of Twine's kinship with radical, nonnormative art production as well as its foregrounding of accessibility for beginners, it became the clear software choice to utilize in this project. Twine describes itself, on the website, as a tool for telling interactive, nonlinear stories. Although the engine has been strongly framed in both its cultural and scholarly take-up as a game creation tool, Twine has come to be embraced in interdisciplinary fields. Alongside Twine's role as a game and storytelling engine, the software has recently been positioned as a praxis method for pedagogy. Multiple, varying disciplines have published on the effectiveness of the Twine technology for building teaching-based and informational protocols, including for creating interactive patient or client case studies (Davis 2022; Kervyn et al. 2020), simulating the patient-physician encounter (Oje et al. 2018), trans-affirming research and pedagogy (Miles and Jenkins 2017), or experiential pandemic learning (Bolintineanu et al. 2022). Despite the reimaging of Twine as a method beyond, through and alongside traditional game design, there is little research on the technology as a tool for database design.

In an exploration of Twine as a mediation between narrative and database, Jon Heggestad argues that the organizational protocol of databases, as a site of struggle between dominant and counter-narratives, is often times erased. Heggestad brings into conversation the perspectives of database logic put forward by digital culture scholar Lev Manovich. Manovich argues that the inherent structure of databases is in opposition to that of narrative. Narrative, according to Manovich situates an order of plot events that follow a cause-and-effect logic (qtd. in Heggestad 4) whereas database logic democratizes information by uprooting assumptions of hierarchy. Heggestad, then, brings into focus the counterargument of N. Katherine Hayles who suggests that databases and narratives work through one another (*Writing Machines*). For Heggestad, "Databases, organized rhizomatically, provide users with a variety of narratives, rather than one solitary, static story. If narratives help us to organize events, databases can help us to organize narratives" (4). Heggestad goes on to suggest that the layering of narratives through multiplicity rather than hierarchy can respond to an enduring objective of the digital humanities that aims to intervene in traditional processes of canonicity. This objective is concerned with what narratives get told and what stories rise to the surface. In this sense, the storytelling tool of Twine appears perfectly primed for the moment. How does one visualize the contact between opposing schools of thought in scholarship, or represent academics building, challenging or subverting previously established theories and perspectives? This is the task of the literature review, and the hypertext database seems to be one way to tinker with the body of literature as a living, affective network of relations.

Overview of the Twine Database Structure

Table 1

Description of Classes in Twine Database Structure

Class A: Meta Disciplines			
Medical Humanities			
Gender	**Class B: Texts Within Meta Disciplines**		
Disability Theory	100+ Texts		
Digital Humanities			

Hypertext & Digital Fictions		**Class C: Individual Text Notes**	
Feminist New Materialist Theory			
Methods			**Class D: Themes**
			Orientation
			Phenomenology
			Health and Medical Humanities
			The Politics of Location
			Illness Narratives
			Health
			Normativity
			Pathological
			Jean-Paul Sartre
			Martin Heidegger
			Maurice Merleau-Ponty
			Cartesian
			Bioethics
			Principlism

			Casuistry
			Queer
			Michel Foucault
			Biopower/Biopolitics
			Judith Butler
			Narrative Ethics
			Post-Modern
			Post-Structuralist
			Humanism
			Body Modification
			Intersectionality
			Hypertext
			Digital Literature
			Possible Worlds Theory
			Anna Anthropy
			Twine
			Feminist New Materialism
			Assemblage Theory
			Matter

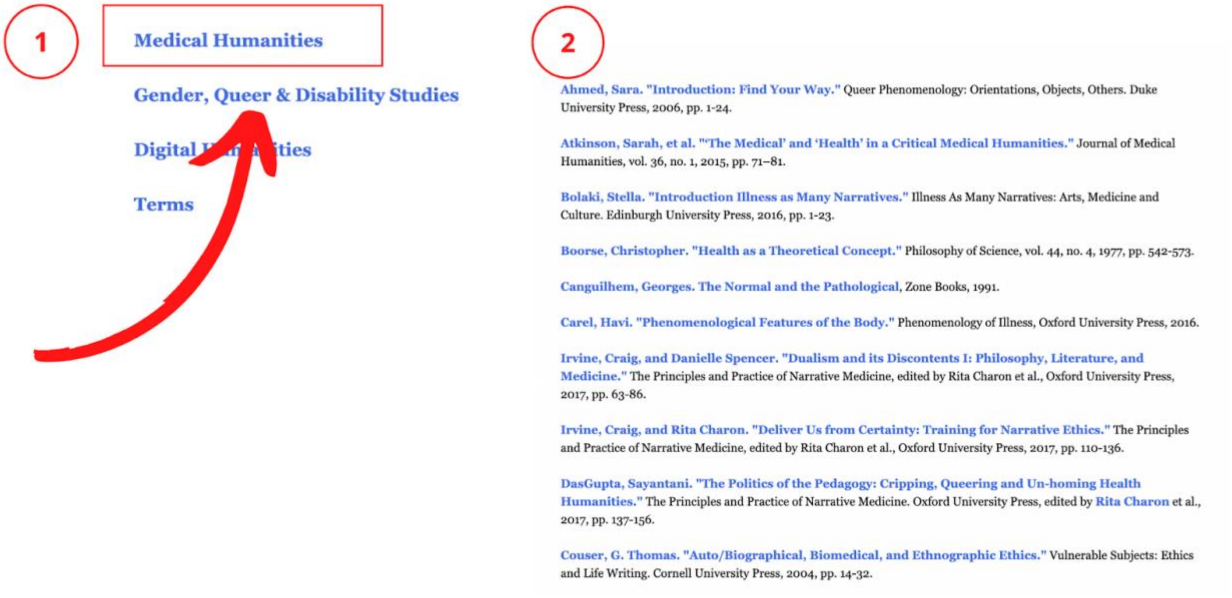
			Post-Humanism
			Becoming
			Disability

Twine Database Structure

Fig. 5 shows the interface of the literature review I built in Twine for my dissertation research. Although the intricate number of connections between passages depicts a notion of a chaotic network, the database is actually highly structured and conceptually it can be understood as resembling the layers of an onion. This section will detail a method for building a literature review in the Twine interface. The following section will describe how to use the database once it is completed. Table 1 is an outline of the various Class levels of the database.

To begin the task of building a literature review, I started with an opening passage that houses only eight parent hypertexts: [[Medical Humanities]], [[Gender, Disability Theory]], [[Digital Humanities]], [[Hypertext & Digital Fictions]], [[Feminist New Materialist Theory]], and [[Methods]]. These hypertext links are the encompassing, top-level disciplines that create the crux of my interdisciplinary research. I call these hyperlinks the Class A level. Class A can be understood as existing on the meta-level or the outermost layer of the database. Class A data is the access point that holds all the inner levels of data. Each subsequent level houses the data for the next level in the chain. Access to each subsequent level is granted through a hypertext.

Beginning in Class A, any hypertext can be selected, or clicked, to enter into a Class B passage. The second class, or Class B passages, house lists of texts that are included in the meta-disciplines. Fig. 6 shows, for example, that selecting the Class A hypertext of [[Medical Humanities]] takes the reader to a Class B passage. This second class passage includes a list of relevant scholarly texts related to the discipline of medical humanities.



Ahmed, Sara. "Introduction: Find Your Way." Queer Phenomenology: Orientations, Objects, Others. Duke University Press, 2006, pp. 1-24.

Atkinson, Sarah, et al. "'The Medical' and 'Health' in a Critical Medical Humanities." Journal of Medical Humanities, vol. 36, no. 1, 2015, pp. 71–81.

Bolaki, Stella. "Introduction Illness as Many Narratives." Illness As Many Narratives: Arts, Medicine and Culture. Edinburgh University Press, 2016, pp. 1-23.

Boorse, Christopher. "Health as a Theoretical Concept." Philosophy of Science, vol. 44, no. 4, 1977, pp. 542-573.

Canguilhem, Georges. The Normal and the Pathological, Zone Books, 1991.

Carel, Havi. "Phenomenological Features of the Body." Phenomenology of Illness, Oxford University Press, 2016.

Irvine, Craig, and Danielle Spencer. "Dualism and its Discontents I: Philosophy, Literature, and Medicine." The Principles and Practice of Narrative Medicine, edited by Rita Charon et al., Oxford University Press, 2017, pp. 63-86.

Irvine, Craig, and Rita Charon. "Deliver Us from Certainty: Training for Narrative Ethics." The Principles and Practice of Narrative Medicine, edited by Rita Charon et al., Oxford University Press, 2017, pp. 110-136.

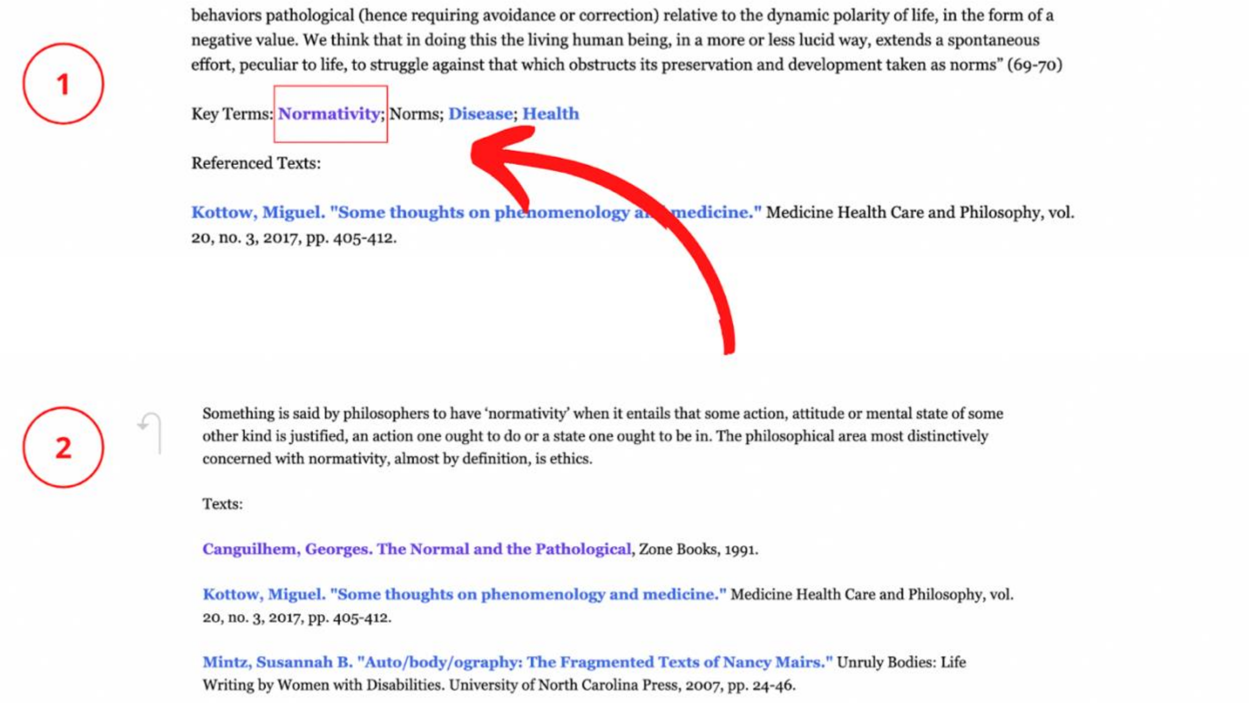
DasGupta, Sayantani. "The Politics of the Pedagogy: Cripping, Queering and Un-homing Health Humanities." The Principles and Practice of Narrative Medicine. Oxford University Press, edited by **Rita Charon** et al., 2017, pp. 137-156.

Couser, G. Thomas. "Auto/Biographical, Biomedical, and Ethnographic Ethics." Vulnerable Subjects: Ethics and Life Writing. Cornell University Press, 2004, pp. 14-32.

Fig. 6. Screenshot of "Medical Humanities" Passage in the Twine Literature Review

When one of the texts is selected, the reader is taken to the Class C level passages. This third passage level houses the most hypertexts and includes individual content passages on over one hundred scholarly texts. Each scholarly text is contained in its own passage. Class C level passages include a summary of the text, written by myself or a scholarly review, several quotes that I identified as representing the critical arguments of the text, key terms that are important to the piece, and sometimes, a list of related texts (typically directly referenced by the text). Within each of these Class C passages, which include notes on individual texts, important key terms are marked as hypertexts.

Selecting any of these terms brings the reader to the Class D level of the database, referred to as themes. Themes can include important scholars' names, theoretical frameworks, or concepts. For example, the database includes around 40 themes including [[Martin Heidegger]], [[Maurice Merleau-Ponty]], [[Cartesian]], [[Bioethics]], [[Principlism]], and [[Casuistry]]. When a theme is selected, a new passage will emerge that includes a definition of the theme, as well as a list of all the texts in the database that the theme is relevant to and housed as a hypertext within. For example, fig. 7 shows the term [[Normativity]] as a hyperlink. When that hyperlink is selected, a new passage emerges that includes an explanatory quote of normativity written by Stephen Darwall in the *Routledge Encyclopedia of Philosophy*, as well as a list of other texts in the database that explore the concept of normativity. From here, any Class hypertext may be selected as the database can be navigated fluidly through the Classes without going through the hierarchy. For example, hypertexts found in Class B may lead to a Class C passage, but they can also lead to a Class A, a Class D, or even another Class B passage. This is where the rhizomatic interactivity of Twine emerges.



behaviors pathological (hence requiring avoidance or correction) relative to the dynamic polarity of life, in the form of a negative value. We think that in doing this the living human being, in a more or less lucid way, extends a spontaneous effort, peculiar to life, to struggle against that which obstructs its preservation and development taken as norms" (69-70)

Key Terms: Normativity; Norms; Disease; Health

Referenced Texts:

Kottow, Miguel. "Some thoughts on phenomenology a medicine." Medicine Health Care and Philosophy, vol. 20, no. 3, 2017, pp. 405-412.

Something is said by philosophers to have 'normativity' when it entails that some action, attitude or mental state of some other kind is justified, an action one ought to do or a state one ought to be in. The philosophical area most distinctively concerned with normativity, almost by definition, is ethics.

Texts:

Canguilhem, Georges. The Normal and the Pathological, Zone Books, 1991.

Kottow, Miguel. "Some thoughts on phenomenology and medicine." Medicine Health Care and Philosophy, vol. 20, no. 3, 2017, pp. 405-412.

Mintz, Susannah B. "Auto/body/ography: The Fragmented Texts of Nancy Mairs." Unruly Bodies: Life Writing by Women with Disabilities. University of North Carolina Press, 2007, pp. 24-46.

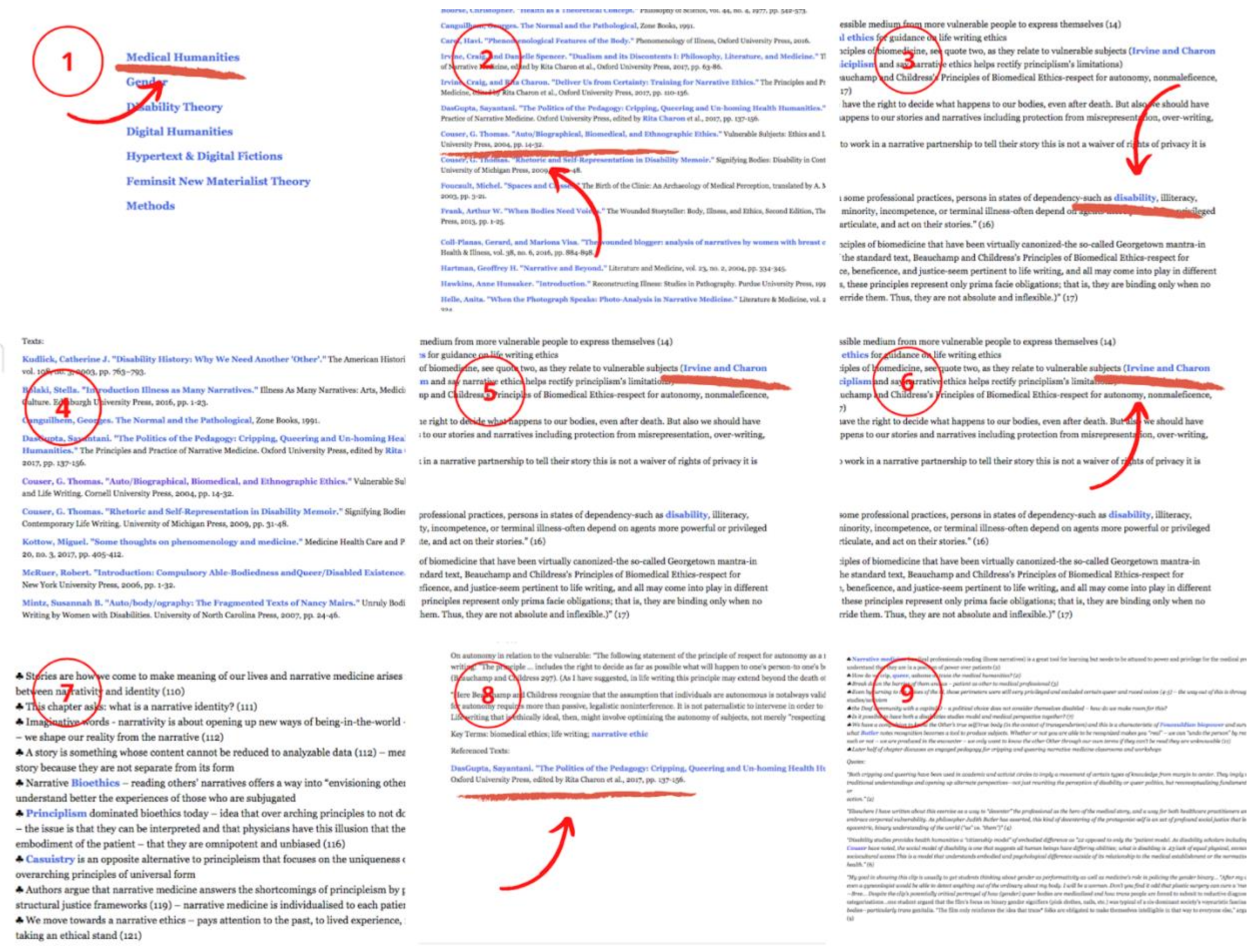
Fig. 7. Screenshot of "Normativity" Passage in the Twine Literature Review

Reading the Database

The intended function of the database is to illuminate the connections between texts, themes and disciplines to create the trajectory of a literature review. When reading my database, I can visually map, for example, the theoretical trajectory of the concept of phenomenology in my texts. Through the database I can identify that a significant thread running through the majority of the texts theorizing phenomenology is a distinct rejection of a Cartesian notion of the mind/body split (Frank 2013; Irvine and Spencer 2017; Mintz 2007; Young 1997), however, two distinct counter narratives emerge as an affinity with Spinoza's notion of a single, infinite, substance (Nancy 2009, 2015) or Sartre's distinction between the medicalized "body for others" and the lived body (Carel 2016; Kottow 2017). This dynamic reading method allows me a way into engaging with my research omnipotently by muting the boundaries between texts, to an extent.

The interface of the database is robust, but it is not useful for the purpose of reading, engaging or reflecting on the information within the database. The method for reading the database in an effective way comes from understanding the structure of the passages described in the previous section in conjunction with accessing the database when it is published online in HTML. In the published state, each passage of the database can be selected, or clicked, to reveal its content. Ideally, what the Twine database should do, for the purposes of this specific project, is generate the trajectory of a literature review.

Moving through the various classes of the database and engaging with the data that populates the passages of individual texts should eventually reveal theoretical themes that weave the texts into a web. The Class D layer generates the themes I identified from the information on each text. For example, when looking at fig. 8, clicking on the [[Medical Humanities]] hypertext in Class A will reveal a list of related texts (Step 1). From Class B, a chapter from *Vulnerable Subjects: Ethics and Life Writing* by G. Thomas Couser called "Auto/Biographical, Biomedical, and Ethnographic Ethics" might be selected (Step 2). This Class C passage contains the specific notes and information relating to this text including summaries of the key points, stand-out quotes that I found helpful, and keywords.



Medical Humanities
Gender
Disability Theory
Digital Humanities
Hypertext & Digital Fictions
Feminsit New Materialist Theory
Methods

Canguilhem, Georges. The Normal and the Pathological, Zone Books, 1991.
Carel, Havi. "Phenomenological Features of the Body." Phenomenology of Illness, Oxford University Press, 2016.
Irvine, Craig and Danielle Spencer. "Dualism and its Discontents I: Philosophy, Literature, and Medicine." Th
of Narrative Medicine, edited by Rita Charon et al., Oxford University Press, 2017, pp. 63-86.
Irvine, Craig, and Rita Charon. "Deliver Us from Certainty: Training for Narrative Ethics." The Principles and Pr
Medicine, edited by Rita Charon et al., Oxford University Press, 2017, pp. 110-136.
DasGupta, Sayantani. "The Politics of the Pedagogy: Cripping, Queering and Un-homing Health Humanities."
Practice of Narrative Medicine. Oxford University Press, edited by Rita Charon et al., 2017, pp. 137-156.
Couser, G. Thomas. "Auto/Biographical, Biomedical, and Ethnographic Ethics." Vulnerable Subjects: Ethics and L
University Press, 2004, pp. 14-32.
Couser, G. Thomas. "Rhetoric and Self-Representation in Disability Memoir." Signifying Bodies: Disability in Cont
University of Michigan Press, 2009, pp. 31-48.
Foucault, Michel. "Spaces and Classes." The Birth of the Clinic: An Archaeology of Medical Perception, translated by A. S
2003, pp. 3-21.
Frank, Arthur W. "When Bodies Need Voices." The Wounded Storyteller: Body, Illness, and Ethics, Second Edition, The
Press, 2013, pp. 1-25.
Coll-Planas, Gerard, and Mariona Visa. "The wounded blogger: analysis of narratives by women with breast c
Health & Illness, vol. 38, no. 6, 2016, pp. 884-898.
Hartman, Geoffrey H. "Narrative and Beyond." Literature and Medicine, vol. 23, no. 2, 2004, pp. 334-345.
Hawkins, Anne Hunsaker. "Introduction." Reconstructing Illness: Studies in Pathography. Purdue University Press, 199
Helle, Anita. "When the Photograph Speaks: Photo-Analysis in Narrative Medicine." Literature & Medicine, vol. 2

essible medium from more vulnerable people to express themselves (14)
l ethics for guidance on life writing ethics
nciples of biomedicine, see quote two, as they relate to vulnerable subjects (Irvine and Charon
iciplism and say narrative ethics helps rectify principlism's limitations)
eauchamp and Childress's Principles of Biomedical Ethics-respect for autonomy, nonmaleficence,
17)
have the right to decide what happens to our bodies, even after death. But also we should have
appens to our stories and narratives including protection from misrepresentation, over-writing,

to work in a narrative partnership to tell their story this is not a waiver of rights of privacy it is

n some professional practices, persons in states of dependency-such as disability, illiteracy,
minority, incompetence, or terminal illness-often depend on [illegible] privileged
articulate, and act on their stories." (16)

nciples of biomedicine that have been virtually canonized-the so-called Georgetown mantra-in
'the standard text, Beauchamp and Childress's Principles of Biomedical Ethics-respect for
ce, beneficence, and justice-seem pertinent to life writing, and all may come into play in different
s, these principles represent only prima facie obligations; that is, they are binding only when no
erride them. Thus, they are not absolute and inflexible.)" (17)

Texts:
Kudlick, Catherine J. "Disability History: Why We Need Another 'Other'." The American Histori
vol. 108, no. 3, 2003, pp. 763-793.
Bolaki, Stella. "Introduction Illness as Many Narratives." Illness As Many Narratives: Arts, Medici
Culture. Edinburgh University Press, 2016, pp. 1-23.
Canguilhem, Georges. The Normal and the Pathological, Zone Books, 1991.
DasGupta, Sayantani. "The Politics of the Pedagogy: Cripping, Queering and Un-homing Hea
Humanities." The Principles and Practice of Narrative Medicine. Oxford University Press, edited by Rita
2017, pp. 137-156.
Couser, G. Thomas. "Auto/Biographical, Biomedical, and Ethnographic Ethics." Vulnerable Su
and Life Writing. Cornell University Press, 2004, pp. 14-32.
Couser, G. Thomas. "Rhetoric and Self-Representation in Disability Memoir." Signifying Bodie
Contemporary Life Writing. University of Michigan Press, 2009, pp. 31-48.
Kottow, Miguel. "Some thoughts on phenomenology and medicine." Medicine Health Care and P
20, no. 3, 2017, pp. 405-412.
McRuer, Robert. "Introduction: Compulsory Able-Bodiedness andQueer/Disabled Existence.
New York University Press, 2006, pp. 1-32.
Mintz, Susannah B. "Auto/body/ography: The Fragmented Texts of Nancy Mairs." Unruly Bodi
Writing by Women with Disabilities. University of North Carolina Press, 2007, pp. 24-46.

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s for guidance on life writing ethics
of biomedicine, see quote two, as they relate to vulnerable subjects (Irvine and Charon
m and say narrative ethics helps rectify principlism's limitations)
up and Childress's Principles of Biomedical Ethics-respect for autonomy, nonmaleficence,

he right to decide what happens to our bodies, even after death. But also we should have
to our stories and narratives including protection from misrepresentation, over-writing,

in a narrative partnership to tell their story this is not a waiver of rights of privacy it is

professional practices, persons in states of dependency-such as disability, illiteracy,
ty, incompetence, or terminal illness-often depend on agents more powerful or privileged
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7)
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ppens to our stories and narratives including protection from misrepresentation, over-writing,

work in a narrative partnership to tell their story this is not a waiver of rights of privacy it is

some professional practices, persons in states of dependency-such as disability, illiteracy,
ninority, incompetence, or terminal illness-often depend on agents more powerful or privileged
rticulate, and act on their stories." (16)

iples of biomedicine that have been virtually canonized-the so-called Georgetown mantra-in
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, beneficence, and justice-seem pertinent to life writing, and all may come into play in different
these principles represent only prima facie obligations; that is, they are binding only when no
rride them. Thus, they are not absolute and inflexible.)" (17)

♣ Stories are how we come to make meaning of our lives and narrative medicine arises
between narrativity and identity (110)
♣ This chapter asks: what is a narrative identity? (111)
♣ Imaginative words - narrativity is about opening up new ways of being-in-the-world
– we shape our reality from the narrative (112)
♣ A story is something whose content cannot be reduced to analyzable data (112) – mea
story because they are not separate from its form
♣ Narrative Bioethics – reading others' narratives offers a way into "envisioning othe
understand better the experiences of those who are subjugated
♣ Principlism dominated bioethics today – idea that over arching principles to not d
– the issue is that they can be interpreted and that physicians have this illusion that the
embodiment of the patient – that they are omnipotent and unbiased (116)
♣ Casuistry is an opposite alternative to principleism that focuses on the uniqueness
overarching principles of universal form
♣ Authors argue that narrative medicine answers the shortcomings of principleism by
structural justice frameworks (119) – narrative medicine is individualised to each patie
♣ We move towards a narrative ethics – pays attention to the past, to lived experience,
taking an ethical stand (121)

On autonomy in relation to the vulnerable: "The following statement of the principle of respect for autonomy as a
writing: 'The principle ... includes the right to decide as far as possible what will happen to one's person-to one's b
(Beauchamp and Childress 297). (As I have suggested, in life writing this principle may extend beyond the death o
"Here Beauchamp and Childress recognize that the assumption that individuals are autonomous is notalways valid
for autonomy requires more than passive, legalistic noninterference. It is not paternalistic to intervene in order to
Life writing that is ethically ideal, then, might involve optimizing the autonomy of subjects, not merely "respecting
Key Terms: biomedical ethics; life writing; narrative ethic
Referenced Texts:
DasGupta, Sayantani. "The Politics of the Pedagogy: Cripping, Queering and Un-homing Health Hu
Oxford University Press, edited by Rita Charon et al., 2017, pp. 137-156.

Fig. 8. Screenshots of "Reading" the Twine Literature Review

Littered throughout the content of this passage are terms that I chose to hypertext because of their significance to this research. Specific terms are made into hypertext such as [[Illness Narratives]] and [[Disability]]. When those terms are selected, or clicked, Class D data is revealed, which is information on these terms. Looking at [[Disability]] specifically (Step 3) shows how this Class D passage links back to previous classes where reference to disability is made (Step 4). The Class C passage on this specific Couser chapter makes reference to the particular scholars Craig Irvine and Rita Charon (Step 5). When that hypertext is selected, or clicked (Step 6), it reveals another Class C passage specific to the chapter by these authors entitled "Deliver Us from Certainty: Training for Narrative Ethics" (Step 7). Finally, at the bottom of the Couser node, there is a reference to another text by Sayantani DasGupta entitled "The Politics of the Pedagogy: Cripping, Queering and Un-homing Health Humanities" which makes direct reference to this Couser chapter. When the DasGupta hypertext (Step 8) is selected, or clicked, the Class C node on this chapter (Step 9) is revealed.

Essentially, the Twine database becomes a cyclical web with no true ending to the database. A concept or author can be selected, and the program will repetitively tour the reader around the notes. Working with the Class D themes led me to an understanding of how I should organize my literature review. Explicitly, it consolidated the mass of information on each of my individual texts and reconfigured this information into a pattern that I could interpret. In this pattern, I began to see a trajectory of a theoretical progression from phenomenology to the discursive/linguistic turn to feminist new materialism. Both the practice of building this interface and reading through it led me to map out the larger theoretical frameworks that are underpinning my work.

Revisiting the work of Efron and Ravid on effective literature reviews situates this work at the entry point of a certain objective - to find a path forward beyond the research for future scholars of the topic. In this sense, I understand my research should navigate through, and pull threads from, an array of theories housed in multiple disciplines, including queer theory, phenomenology, feminist new materialism, disability theory, and poststructuralism. Ultimately, these theories must be situated in a feedback loop, rather than siloed, to locate the gap most effectively in the literature. As explored through the practice of reading the literature review, a distinct theoretical trajectory emerges. For my research, this looked like a trip through the clashing, competing and generative contact points between theories of phenomenology, poststructuralism, and posthumanism. Understanding this trajectory, built through the hypertext database, reveals a space at the crux of this theoretical trajectory for my research to live. Therefore, through this Twine database and the insight it has generated, I have written the following literature review.

Hypertext Theory

Hypertext – or digital data interconnected by a reader's click or finger tap - has come to embody the very inherent structure of the internet. Astrid Ensslin argues in her chapter in *The Oxford Encyclopedia of Literary Theory* entitled "Hypertext Theory" that the linguistic roots of the term hypertext paint a picture for the term's meaning related to the rhizomatic connection of networks. The term hypertext is rooted in the Greek *hypér* translating to "over" or "beyond" and the Latin term *texere*, meaning "to weave" (Ensslin, "Hypertext Theory" 2). Ensslin explains that hypertext networks online utilize the connective protocol of the digital, which is Hypertext Markup Language (HTML). Where the traditional method of hypertext navigation was limited to a mouse click, newer approaches incorporate "mouse-over, touch, controller buttons, voice recognition, or even head position and vision direction (as in the case of VR)" (Ensslin "Hypertext Theory" 2). Hypertext creates diverging paths between text segments, often referred to as *nodes*, and later relabeled as *lexias*, as outlined in the Introduction. As Ensslin argues "A typical hypertext lexia contains one or more hypertexts, which enable readers to choose different pathways for every reading, thus generating different mental images of the text, or indeed different textual manifestations" ("Hypertext Theory" 3). This interconnected data forms large masses of networked information online and it creates the very basic structures of digital tools we use every day including social media platforms, search engines, and email.

The genesis of hypertext theory can be marked at 1965 when information technology scholar Theodor Nelson coined the term hypertext in his lectures at Vassar College. He referred to hypertext as "non-sequential writing—text that branches and allows choices to the reader, best read at an interactive screen. As popularly conceived, this is a series of text chunks connected by links which offer the reader different pathways" (Ensslin "Hypertext Theory" 2). Nelson went on to argue that the capabilities of hypertext would stretch the margins of what was possible with information learning. He saw hypertext as a method that would define the future because it seemingly paralleled the branching ways in which humans form thought processes. Nelson argued that the boundless, interactive capability of hypertext would begin to infiltrate all structures of knowledge. Laura Okkema argues in her work entitled "Hearing the Voices of the Deserters: Activist Critical Making in Electronic Literature" that Nelson envisioned hypertext becoming the very foundation of learning where the hierarchies and divisions of disciplines would dissolve because "all those who can read would be able to read everything" (Okkema 29). For Nelson, a move toward information as hypertext was urgent as he believed the way in which society approached information processing was incongruent with the inherent rhizomatic nature of knowledge – and, in this sense, our progress as a culture was diminishing. Nelson's belief in the possibilities of hypertext is immortalized in Robert Coover's 1992 article for *The New York Times* entitled "The End of Books." Coover outlines the potentiality of learning with hypertext and describes the championing of its supporters: "You will often hear them proclaim, quite seriously, that there have been three great events in the history of literacy: the invention of writing, the invention of movable type and the invention of hypertext" (Coover). Coover hones in on the ways in which the scholarly value of hypertext, at the time, began to shift by framing the medium as a significant form of literature. From here, hypertext was not only appreciated as a tool to engage with information learning, but also a method for storytelling, particularly in a nonfiction sense.

Nelson's legacy of hypertext as a transformative, empowering structure went on to infiltrate belief systems around digital studies for decades. The field of hypertext literature has been categorized scholarly, similar to the feminist movement, in waves. Scholars in the first wave of digital humanities, such as George P. Landow and David J. Bolter, contributed to a sentiment that hypertext produces liberation because of its inherent capabilities. This sentiment was bolstered by Jane Yellowlees Douglas in her 1992 article "What Hypertexts Can Do That Print Narratives Cannot," which argues that hypertext shifts agency from the author to the reader of the text who now has the capability to choose the path of information. As Okkema claims, the scholarly sentiment around hypertext was that it inherently dissolved hierarchies of power through its democratic and at times anarchic disposition (29). These perspectives on hypertext were emerging alongside prominent scholarly affinities with poststructuralist and deconstructivist theoretical frameworks. As Ensslin and Skains suggest in their 2017 chapter "Hypertext: Storyspace to Twine" in *The Bloomsbury Handbook of Electronic Literature*, theories such as "anti-logo centrism, the writerly text, the death of the author, decentering and non-closure" all contributed to hypertext's image as a gatekeeper of reader empowerment (5). The scholarly take-up of hypertext literature in the late 1980s to 1990s, which was working through academia's strong affinity with poststructuralism, was the very essence of the *lexia* as a rhizome realized. As Ensslin argues, "ramifying, decentralized, horizontally organized root structures, which do not have a clear beginning or end. Rhizomes conveniently deviate from the arborescent, hierarchical structures associated with logocentrism" ("Hypertext Theory" 4). This sentiment of nonlinearity was paralleling academia's poststructuralist stride, where hypertext theories of this time sought to challenge textual hierarchies in favour of subversive, avant-garde, and individualized reading experiences (Ensslin, "Hypertext Theory" 4). Ultimately, hypertext was positioned as transcending a data information organizer to embody a tool for political change.

However, second-wave scholars of hypertext, emerging in the 2000s, have cautiously tempered the previous overenthusiastic views of the medium's capabilities. In fact, scholars such as Ensslin, Pope, Miall and Dobson, and Mangen and van der Weel have illuminated hypertext's potentially counter-liberating structure. In the same ways previous scholars highlighted the reader's agency in being able to choose where to "go" next, contemporary hypertext scholars note that the writer still creates boundaries of choice. The hypertext writer builds the structure of the text and is able to anticipate every possible reading path. As Ensslin and Skains suggest, hypertexts have even been shown "to have a delimiting rather than empowering function in hypertext readers, as they often lead to confusion, serendipity and cognitive overload in the readers not accustomed to hypertextual forms of creative writing" (5). It seems that previous claims of hypertext's liberatory potential were exaggerated. This liberatory potential is not lost, however, it merely requires careful methodological analysis. As Ensslin argues "Emphasizing that hypertext and other types of electronic, digital-born writing require unique and medium-specific hermeneutic frameworks, they embrace the fact that hypertexts are never read the same way twice and that their typically fluid and personalized meanings rely on multiple re-readings on the part of the reader-analyst" ("Hypertext Theory" 4). Scholars of the second wave of hypertext concluded that the emancipatory potential of hypertext is subtler than previously theorized, but nevertheless present and strengthened by writing that is informed by immersive, adaptable and user-friendly practices (Ensslin and Skains 8). This emancipatory potential becomes heightened through hypertexts that are able to adopt co-creation modalities where the reader becomes a participant in the text's creation (Ennslin and Skains 5). In these cases, subject boundaries break down between *reader* and *writer* where authorship is a collaborative process.

In 2010, Alice Bell published *The Possible Worlds of Hypertext Fiction* which details one of the most prominent methodological frameworks for analyzing hypertext literature. Bell applies Marie-Laure Ryan's 1991 model for possible worlds theory, as articulated in Ryan's book *Possible Worlds, Artificial Intelligence and Narrative Theory*, to a selection of Storyspace - a literary hypertext software - hypertext literatures in order to explore ontological self-consciousness (Bell 7). Bell suggests that when analyzing fictional texts, we must be attuned to how fictional stories actually work to produce alternate ontological networks. Bell argues that "ontological focus is particularly useful because it can be used to systematically map the ontological relationship between the reader and the hypertext in the real world and the fictional agents, such as characters and narrators, in the fictional world" ("Ontological Boundaries" 69). Ryan's theory suggests that our lives in relation to fictional texts can be organized by the categories of our *actual world* versus our *textual universe* (Bell and Ryan, *Possible Worlds* viii). These categorical spheres split further to incorporate alternate possible worlds where the character of the story (our self in the case of the actual world) projects their hopes, dreams, and wishes. Bell argues that her approach to possible worlds theory is not attempting to decipher between events of textual description that are ontologically illogical or not, but rather, she is interested in understanding how ontological structures are textually constructed (26). Applying

Bell’s possible worlds theory to my research is complex because the model explored in her book is contingent on fictional worlds created through text. This poses the question of how nonfictional writing, such as hypertext illness narratives, might be analyzed by paying attention to ontological construction. Although Bell draws a line between fiction and nonfiction, there is more to explore in the seeming construction of “truth” found in nonfiction accounts, particularly when considering the ways in which telling one’s story through experience can blur our understanding of informational reality. However, Bell’s contribution to the field of hypertext theory is most evidently a methodological approach and therefore will be discussed further in the Methodology chapter.

In 2004 N. Katherine Hayles published “Print is Flat, Code is Deep: The importance of media-specific analysis,” a vital work in the field of hypertext theory. Hayles calls on scholars to conceptualize text as an embodied entity of materiality. This materiality is a “dynamic quality that emerges from the interplay between the text as a physical artifact, its conceptual content, and the interpretive activities of readers and writers” (Hayles, “Print is Flat” 72). For Hayles, the materiality of hypertext is something that cannot be predetermined, but rather, is formed in its relationality to the reader. In later works, such as *My Mother was a Computer: Digital Subjects and Literary Texts*, Hayles sharpens her perspective on textual materiality as “an emergent property created through dynamic interactions between physical characteristics and signifying strategies” (*My Mother was a Computer* 3). In this sense, it becomes significant to distinguish between physicality and materiality, where the latter embodies the meaning-making processes produced through the former’s relationality with signification. In other words, materiality is about meaning. When the reader engages with the text, the materiality of the relationship is born through interactivity. Hayles argues that the materiality of hypertext is not the physicality of the text, but rather, more akin to “connective tissue” that bridges together the physical and the interpretive or “the artifact and the user” (“Print is Flat” 72). Hayles digs into the ramifications of hypertext theory being born from the poststructuralist movement by calling into question the linguistic turn’s framing of text as immaterial verbal construction. This ideology works to produce the Cartesian mind-body split by seemingly erasing the physicality of the text rather than viewing the material and the abstract as integrated. This Cartesian framing has real implications, according to Hayles, as it works to separate class and economic factors with the project of creation. This is how the politics of the production, publication and dissemination of texts can be separated from the textual creation of the author. As Hayles argues “We can no longer afford to pretend that texts are immaterial or that text on screen is the same as text in print. The immateriality of the text has ceased to be a useful or even a viable fiction” (“Print is Flat” 86-87). Hayles’ work is foundational for my project for two reasons: first, it opens up a path for feminist new materialism as a theoretical framework in relation to hypertext theory, and second, it highlights the complexities of the politics of text production. This is a topic I explore in-depth in the Introduction chapter where I discuss the Twine Revolution in relation to the accessibility of electronic literature for marginalized identities. Hayles’ work reinforces that the materiality of hypertext includes the meaning-making processes of interaction between the physical and the signification of language.

Finally, the third wave of hypertext scholarship, as described by Ensslin, actually precedes the second wave, yet has only recently been adopted more prolifically (“Hypertext Theory” 5). This third wave is turning more directly to the experiences of hypertext readers. This research is novel and ongoing, and it seeks to explore the multitude of ways readers process the rhizomatic, multimodal elements of digital-born literature. This scholarly turn to the experience of readers is promising, however, I wonder about ways to explore the experience of writers as well. Particularly, I am interested in the ways in which authors are experiencing the act of creating hypertext fictions in relation to their illness. The state of the literature on hypertext resides at an interesting crossroads, almost anticipating research that will look deeper into what it means to be a hypertext author. Where the current scholarly focus on hypertext centres readers and the experience of reading, navigating, and clicking hypertexts, I intend to shift the discussion toward the experience of writing hypertexts. The scholarly field of illness narratives has taken an approach to understanding the embodied practice of writing about one's experience of illness and questioning how this might be therapeutic for the author. This same sentiment seems to be missing from the literature on hypertexts, and therefore, I intend to steer the research into this new terrain.

Illness Narratives

Illness narrative is a relatively new genre that has migrated to the forefront of scholarly interest in the past thirty years, taken up in the fields of medicine, sociology, psychology, ethics, and later, medical/health humanities, narrative medicine, and narrative therapy. The emergence of illness narratives as a scholarly discipline can be understood as two-fold. The early development of the genre can be traced to an exploration of the role of personal narratives in medicine and healthcare (as will be discussed below through the works of scholars Arthur Kleinman, Anne Hunsaker Hawkins, Rita Charon, and Craig Irvine). In this context, illness narrative is emerging as a subsect of narrative medicine within the wider discipline of medicine. At the same time, literary scholars and cultural theorists were also beginning to explore the ways in which personal narratives about illness and disability could challenge dominant cultural narratives about health and the body (as will be discussed below in the narratives of Martha

Weinman Lear and Norman Cousin). In this second context, illness narrative is emerging as a genre of literature that goes on to intersect with development in gender and disability studies. This foundation becomes the precursor for a novel discipline referred to as health/medical humanities, an interdisciplinary field of study that explores the intersection of medicine, healthcare, and the humanities. It brings together scholars and practitioners from a range of disciplines, including literature, philosophy, history, anthropology, art, and ethics, to broaden understanding of health and illness beyond purely biological factors to include social, cultural, and political dimensions. Ultimately, the medical and literary roots of illness narrative collide to produce some aspects of health/medical humanities as shown through the more contemporary work of illness narrative scholars Arthur Frank, G. Thomas Couser and Stella Bolaki. Today, illness narratives is a rich and diverse field of inquiry that encompasses a wide range of perspectives and methodologies.

One of the introductory moments of the conceptualization of illness narratives as a scholarly genre was the publication of the momentous 1988 book, *The Illness Narratives: Suffering, Healing, and the Human Condition* by the medical anthropologist and psychiatrist, Arthur Kleinman. Kleinman became a pioneering proponent of the belief that illness holds social meaning for those who are affected and that this meaning should be analyzed and understood by the discipline of medicine. Five years later, Anne Hunsaker Hawkins wrote the innovative *Reconstructing Illness: Studies in Pathography*, the first account of the term pathography to describe the genre of illness narratives. Hawkins was a pioneer in the development of the nursing informatics field, which focuses on the use of information technology and data analysis in nursing practice and education. Hawkins' use of the term pathography was to describe a subgenre of autobiography that centres personal accounts of illness (3). Hawkins explains that the novel scholarship on pathography is a response to a lack of documented illness narratives as a historically popular genre. Before 1950, it was uncommon for publishers to support book projects that detailed nonfictional experiences of illness, and before the 1900s this genre was seemingly absent (Hawkins 3). As Hawkins describes, attempting to classify published pathographies was complex as most cataloging systems at that time organized works based on disease type. These methods, though, work to centre the illness over the author's experience, an outcome that the pathography genre tends to oppose. Therefore, Hawkins moves to classify pathographies by author intent which filters work into three defining categories: testimonial pathographies, angry pathographies, and pathographies advocating alternative modes of treatment (4). Concentrated in the 1960s and 1970s, testimonial pathographies, according to Hawkins, held strong religious overtones that attempted to share the experience of illness in relation to spiritual trial and conviction. Testimonial pathographies, according to Hawkins, aimed to strengthen the religious or spiritual faith of the reader, positioned formal medicine as authoritative, and maintained a positive tone in order to help readers dealing with similar illness experiences. Ultimately, the intention of these pathographies was didactic or altruistic (4).

Pathographies of anger, according to Hawkins, began to emerge in the 1980s. The authors of angry pathographies tend to express discontent towards their experiences in the healthcare system and their perceived subjugation in these encounters. Angry pathographies worked to ignite a "new cultural attitude" (Hawkins 6) that reveals the dualistic points of suffering that come with disease: first from the effects of the illness and second from the depersonalized encounter with the healthcare system. Hawkins notes that one of the first angry pathography accounts of prominence to surface in an American context was Martha Weinman Lear's 1980 *Heartsounds*. In her autobiographical book, Lear details the painful mishaps of her husband's experience with heart disease, including the progression of infection from an intern's dismissal of a needle-site inflammation, the story of a physician who places blame on a patient following his own incorrect advice, and doctors who will the death of a patient whose treatment has been exhausted (7). *Heartsounds*, according to Hawkins, paints a picture of patient victimhood in response to an irresponsible healthcare system that inflicts harm on the lives of those who encounter it. The third category of pathographies, those that advocate for alternative modes of treatment, surfaced in the late 1970s with Norman Cousin's *Anatomy of an Illness as Perceived by the Patient: Reflections on Healing and Regeneration*. Paralleling the sentiment of angry pathographies, this third category expresses deep dissatisfaction with normative practices of contemporary medicine (Hawkins 9), however, rather than expressing experience through anger, these pathographies seek out alternative treatment avenues. These avenues can include modalities that work to supplement traditional methods, as well as modalities that are intended to be a replacement for traditional methods. Themes of this third category of pathographies include limitless healing capabilities of the mind and attitude, belief in the results of holistic treatments, and coveting notions of an inner spirit (Hawkins 9). Similarly, these pathographies tend to reject the Cartesian notion of the mind-body split, and instead advocate for a deeper understanding of the interrelationship between the two. This sentiment of turning to self as a site of authority and as a partnership between the mind and body has become a prevalent theme in contemporary illness narrative scholarship today, as explored by illness narrative theorists such as Arthur Frank, Craig Irvine, Rita Charon and G. Thomas Couser.

One of the more accessible scholarly accounts of illness narratives came in 1995 with the publication of Arthur Frank's book on narrative theory entitled *The Wounded Storyteller.* Frank, a leader in the field of medical sociology and narrative medicine, explores the notion of the "remission society" where mass communities ritualistically weave in and out of the "sick" identity label leaving them "well but not cured" (8). Frank draws on illness accounts from authors such as Oliver Sacks, Anatole Broyard, Norman Cousins, and Audre Lorde to outline three main arguments. First, Frank expresses a need for the ill to reclaim their life stories, arguing that this reclamation is an act of forging new paths of agency for those who have been subjugated by their experiences. Second, Frank makes a stark condemnation of the Cartesian mind-body split to which Western healthcare seemingly subscribes (1). Instead, Frank argues for the patient's embodiment of their illness narrative, as these stories are "told not just about the body but through it" (3). His rejection of Cartesian dualism is reinforced by his third topic which explores the evolution of the body in relation to medicine from premodern to postmodern times.

Frank maps the dominant experience of illness beginning at premodernity through modernity to postmodernity[10] arguing that this evolution shows an expansion of the significance of the patient's voice (7). In the realm of premodernity, the sick would "go to bed and die, cared for by family members and neighbours with talent for healing" (Frank 5). In the transition to modernity, medical terminology and knowledge were gatekept by medical professionals who required the patient to forfeit not only their bodies but their life narratives to the medical institution. But there was also an influx of technological expertise, complex diagnostics, and medical progress through pharmacology and other treatments. Frank argues that this new experience of hope in relation to healing was perplexing for a society that understood illness as a mystery. Modernity brought recovery at the expense of chronic illness, relapse, and "watch-and-

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[10] Frank does not offer dates as a differentiation of these periods. He notes "I do not propose any strict periodization of the modern and the postmodern. I do believe that over a period of time, perhaps the last twenty years, how people think about themselves and their worlds has changed enough to deserve a label, and the most accepted label – increasingly diffused in journalism and popular culture – is postmodernism" (Frank 4).

wait" advice (where serious illness is identified in the early stages where no treatment is available until it progresses). Frank argues that modernity became a network of storytelling where patients share their narratives of experience with medical professionals who, in turn, translate those stories into data. Once this data is filtered through the medical pathways, the patient's reinterpreted narrative of the body is told back to them. However, the story no longer belongs to the patient but to the medical institution that claims their retelling as empirical truth. Frank argues that the experience of illness in the time of modernity involves the active colonization of the patient's body by the medical institution which ultimately views the mind as distinct from the experience of the body. The sick body in modernity is an empty vessel that becomes objectified in the illness experience rather than viewed as inseparable from the patient's sense of self. Postmodernity, for Frank, is a "postcolonial demand for voice" by the patient (13). Here, the illness becomes a reclaiming of agency where patients begin to observe that there is more meaning in the experience of illness outside the narrative capacity of the medical institution. Ultimately, postmodernity for Frank is "when the capacity for telling one's story is reclaimed" (7).

Similar to the work of Hawkins, Frank understands elements of illness narratives as classifiable and defined by one of three narrative typologies: restitution, quest, or chaos. Each narrative typology, for Frank, describes a different experience of being ill and illness narratives can incorporate multiple typologies. Unlike Hawkins' classifying system which seemingly uses a thematic categorization, Frank turns to the lived experience of the author. Restitution narratives centre around a collective goal of achieving health again. The role of those who encounter the patient, such as physicians, healthcare workers, and family, are like-minded agents of the patient's recovery. Frank argues, that in his own experience of illness, retribution narratives felt like a stripping of his agency. This typology tends to position the physician as the heroic protagonist in a narrative where the patient becomes the object to manipulate whose wily nature must be conquered (XIV). Chaos narratives, according to Frank, explore the unravelling of self that accompanies many experiences of illness. Chaos narratives sift through the complexities of diagnostic uncertainty when a patient's experience of pain or discomfort cannot be readily identified by the healthcare system (XIV). Chaos subsides once validation of experience is achieved by the patient, which may look like a diagnosis or recognition of pain and suffering. Finally, illness as quest emerges for Frank through narrative moments that work to resist sentiments of a diminished life, a feeling that tends to accompany the progression of a fatal disease. Quest narratives value the significance and meaning of a life in its entirety rather than a snapshot at its ending.

Following Frank's prolific work came an influx of scholarly inquiry into the illness narrative genre, particularly in the fields of medical/health humanities and narrative medicine in relation to ethics. In 1997, G. Thomas Couser wrote *Recovering Bodies: Illness Disability and Life Writing* which, for the field of illness narratives, has become a foundational work that intersects disability studies and autobiography. Couser has become known for his contributions to the field of disability studies and for his work on the intersections of literature, culture, and disability. In *Recovering Bodies*, Couser profiles the writing of individuals with disability or illness, including individuals with HIV/AIDS, breast cancer, deafness, and paralysis, and argues for both the resisting of stigma and the reclamation of the body from medicalized discourse through the telling of one's story. Couser went on to contribute to the foundations of illness narrative scholarship through his authoring of *Vulnerable Subjects: Ethics and Life Writing* (2004) and *Signifying Bodies: Disability in Contemporary Life Writing* (2009). In Couser's publication of *Signifying Bodies*, he continues his inquiry into the relationship between disability and narrative identity. Emerging at the heels of a legacy of institutionalized ableism that questions what a life worthy of living looks like, Couser turns to the autobiographical accounts of those living with disabilities. Couser argues that narratives of disability either reinforce or push back against “preferred rhetorics" of narrative. These preferred rhetorics typically see a normative trajectory of plot that may fall into one of several categories: triumphalist, gothic, spiritual compensation, and nostalgic. Triumph narratives of disability work to deny impairment by insisting on “overcoming” the confines of a “defective body” as seen through common stories of blind runners or deaf musicians, for example (Couser, *Signifying Bodies* 33). Couser notes that this “paradigm holds up the Supercrip, who is by definition atypical, as the model disabled person. These may be ‘true stories,’ but they are not truly representative lives. In any case this approach removes the stigma of disability from the author but leaves it in place for other individuals with the condition in question” (Couser, *Signifying Bodies* 33-34). Another common disability narrative that works to reinforce hegemonic discourse, according to Couser, is horror or gothic narratives that explore themes of disfigurement, dreadful conditions and shunning of the protagonist from their community (*Signifying Bodies* 33). Gothic narratives of disability work to evoke a sense of either pity or the prejudicial revulsion of the author. Narratives of spiritual compensation work through sentiments of “God’s plan” where stories typically begin with a “symbolic paradigm of disability, according to which an impairment is a mark of sin or God’s displeasure with an individual” (Couser, *Signifying Bodies* 36). Through a series of obstacles that have been overcome by the author, eventually, they come to believe that their disability is in fact a gift from God granting them either a mission or a higher purpose for their life. Finally, narratives of nostalgia evoke a yearning for the past before disability in order to grapple with a loss of hope in being able to return to this reality (Couser, *Signifying Bodies* 39). Each of these four hegemonic paradigms of disability narratives actively work, according to Couser, to both maintain and create a system of oppression against those living with disabilities. This is because narratives of triumph, horror, spiritual compensation and nostalgia always return to the disabled body as abject.

In response to hegemonic narratives of disability, Couser argues, there has emerged a novel category of a counterhegemonic and postcolonial challenging narrative style: the rhetoric of emancipation. This counterhegemonic narrative style is upheld by the pillars of subversion, self-creation, self-possession, and self-assertion. Most significantly, these narratives are inherently political in nature. The rhetoric of emancipation is attuned to the political struggle of identity for disabled people and ultimately calls for institutional recognition of the humanity and rights of those with disabilities (Couser, *Signifying Bodies* 47). Couser turns to the example of the 1989 autobiography *I Raise My Eyes to Say Yes* by Ruth Sienkiewicz-Mercer and Steven B. Kaplan. The book details the life story of Ruth, a woman born with a severe form of cerebral palsy that affected her ability to move freely, speak, or write. Ruth spent decades in rehabilitation and hospital institutions where she was misdiagnosed by physicians as lacking both intellectual and communicative capacity. In her story, Ruth discusses her discovery of communication through her gaze, and the new ways she was able to engage with the world after this breakthrough. However, unlike Frank's narratives of quest, or Couser's description of narratives of triumph, Ruth's story "decisively represents disability not as a flaw in her body but as the prejudicial construct of a normative culture" (*Signifying Bodies* 47). Ruth becomes political in a way that calls into inquiry the institutional treatment of disability and how it works to actively "other" the disabled experience. Further, Ruth's liberation is found not in approaching a state of "recovery" from her disability, but rather, from constituting her sense of identity in ways that challenge normative medicalized discourse. Couser notes:

> The role of her "gaze" in self-construction, then, is crucial. Whereas the disciplinary medical gaze had sized her up (or rather, down) as mentally deficient, through her own inquisitive and aggressive gaze she managed to challenge or defy her misdiagnosis—and, not incidentally, to have a social life. Once her consciousness and intelligence were recognized, she was able to expand on and refine this method of communication, but she could never abandon it. (*Signifying Bodies* 43)

Ultimately, Ruth's narrative of emancipation advocates for the political paradigm of disability that seeks to subvert traditional medicine's pathologization of "abject" bodies. This framework of the rhetoric of emancipation is valuable for this research when thinking about the pathologization of deviant femininity in relation to hyperandrogenism. Disability and hyperandrogenism parallel the experience of embodying the abject that ultimately must be "cured" in order to achieve a "healthy" state.

In 2004, Couser wrote *Vulnerable Subjects* which argues that illness narratives can be an accessible genre for vulnerable people to express themselves, however, there is a multitude of complexities when considering narrative agency in relation to illness (*Vulnerable Subjects* 14). Although illness narratives have the potential to be a liberating practice, traditional modes of publishing and writing narratives complicate consent. Certain illnesses or disabilities, Couser argues, can limit how a person is able to write or publish their story and this is where narrative partnerships may move to the forefront. Partnerships of publication, assisting authors, transcribers, translators and ghostwriters in relation to illness narratives must be attuned to a biomedical ethic to maintain the agency and voice of the author. Couser turns to the Four

Principles of Biomedical Ethics originally developed by Thomas Beauchamp and James Childress in their 1979 book *Principles of Biomedical Ethics* which are currently utilized in modern bioethical decision-making: respect for autonomy, nonmaleficence, beneficence, and justice. As Couser notes, these four principles "seem pertinent to life writing, and all may come into play in different ways. (And as in bioethics, these principles represent only prima facie obligations; that is, they are binding only when no conflicting obligations override them. Thus, they are not absolute and inflexible)" (*Vulnerable Subjects* 17).

With the emergence of the discipline of narrative medicine, as spearheaded by scholars such as Rita Charon and Craig Irvine, there has been a call to evaluate the shortcomings of biomedical principlism. Irvine and Charon argue in their 2017 chapter "Deliver Us from Certainty: Training for Narrative Ethics" in Charon et al.'s edited collection *The Principles and Practice of Narrative Medicine*, that reading the narratives of others offers a way into "envisioning otherness" (112). To envision otherness is to fortify a structure where readers can better understand the experiences of those who are marginalized through illness. However, as Irvine and Charon suggest, biomedical principlism argues that the oath to "do no harm" employed by physicians is, in fact, insufficient. This is because biomedical principlism insists on its universality when it has the potential to be interpreted differently by different physicians or pillars of medical discourse. The ability of physicians to contest and debate what they believe constitutes harm works to generate the illusion that they are omnipotent to the experiences and embodiment of the patient (Irvine and Charon 116). Irvine and Charon, then, put the notion of casuistry forward as a foil to principlism. Casuistry is a method of ethical reasoning that focuses on the analysis of particular cases or situations to inform an application of general principles or rules. The authors argue that this approach centres the unique, individualized experiences of the patient rather than attempting to fit this experience into a prototype. The authors note:

> What does this practice of narrative ethics look like? To exercise compassion in adjusting treatment to the particularities of this patient's life story, to remove the blindfold of a universalist principle of justice and attend to a patient's specific needs, indeed to exercise any of the virtues, which are never enacted universally but rather in unique situations with particular persons, requires narrative skill. (Irvine and Charon 120)

Casuistry parallels Frank's notion of *shading* as the act of analyzing a narrative in both its contextual wholeness and uniqueness. Ultimately, Irvine and Charon argue, casuistry has become the foundation of narrative medicine today, which foregrounds a narrative ethic attuned to lived experience, nuance, and feminist and structural justice frameworks (119).

In recent years, the trajectory of illness narrative scholarship has begun theorizing the proliferation of the genre in the digital space. In 2018, scholar Steve Rains wrote *Coping with Illness Digitally* which looks at the ways in which new media is being utilized to cope with illness, particularly responding to illness through the use of communication technologies like social media. Most notably, Rains reviews a series of studies that look at the potential of illness narratives online (see Anthony and Nagel; Tan; Graham et al.) and finds that engaging in this genre can be therapeutic and compared to more traditional forms of mental health therapy (69). Rains notes that illness blogging can be particularly beneficial as a therapeutic tool as it has been shown to be a generative agent where individuals can examine, reflect, and engage with their life stories (69). According to Rains, blogging about life stress factors in relation to illness holds "cathartic potential" and "may serve to make one feel empowered, relieved, and even exhilarated" (69). Significantly, Rains also concludes that the therapeutic benefits of expressive writing about illness online were amplified by the ability to receive digital comments from others who have read their story (70). This is particularly valuable insight for the research of this project because it speaks to the novel capabilities of online writing that cannot be fulfilled through traditional modalities of publication. The uniqueness of the digital space allows for the cultivation of the online network and digital community that can engage with each other in real time through comment, chat, or re-post functions.

According to the literature, illness narratives stand as a multifaceted practice for individuals to express and traverse their experiences with illness. For some who have endured institutionalized subjugation from the healthcare system and beyond, the practice of writing about one's illness subjectivity has served as a way to resist or undermine the authority of the medical establishment through self-representation (Couser, *Signifying Bodies* 31). Illness narrative, both as a research subject and as a personal practice, has a diversified, expansive scope. As Stella Bolaki, disability studies scholar and medical humanist, argues in her 2016 book *Illness as Many Narratives: Arts, Medicine and Culture,* approaches to illness narrative across time have been dynamic. Traditional perspectives have positioned the genre as a static, linear account of a relationship between biomedicine and the patient-physician encounter (Bolaki 1). This viewpoint benefits the authority of the medical establishment and fails to acknowledge illness narrative's history as a form of self-determination and resistance for marginalized identities (Couser, *Signifying Bodies* 31). Within the disciplines that engage with illness narrative, Bolaski calls for "critical interloping" which would invite interdisciplinary approaches to open up analysis for more nuanced research. This push for a more dynamic engagement with illness narrative recognizes the practice as manifold rather than one-dimensional and invites space for narrative complexities such as "formlessness" or "silence" (Bolaki 5). Bolaski exposes a new horizon for illness narratives beyond traditional practices of the linear written memoir to include the possibility of formlessness or narrative multiplicity present in the digital space.

Narrative Therapy

Illness narratives are deeply tied to the discipline of narrative therapy, in some contexts. Illness narratives can be one method of narrative therapy, however, writing about one's experience with illness for therapeutic benefit can also be an individualized practice unassociated with any formal stream of therapy. Natalia Panina-Beard et al. describe narrative therapy in the *Salem Press Encyclopedia* as a type of therapy that encourages the patient to construct stories about their lives as a method to generate meaning from experience. Stephen Madigan argues in *Narrative Therapy*:

> At the heart of narrative therapy is an unswerving commitment to a relational/contextual/anti-individualist therapeutic understanding of persons, problems, and relationships. This relational/contextual/anti-individualist practice was founded on a therapy designed to counter the prevailing dominant psychological ideas regarding the skin-bound individual self. (4)

Narrative therapy relies on nonjudgement from the practitioner, where the patient is guided to externalize unhelpful stories from their identity and contextualize values in a way that generates alternative, more productive life stories.

Narrative therapy was developed by Australian therapist Michael White in his 1990 book *Narrative Means to Therapeutic Ends*, coauthored by David Epston. White's analysis was influenced by the conceptualizations of power dynamics found in feminist, queer, and decolonial theory. White argues that the dominant and established methods and theoretical frameworks for psychology at the time included humanism and structuralism (Madigan 12), and narrative therapy grew in opposition to these methods. White's development of narrative therapy was rooted in the belief that the relational, textual self was influenced by poststructuralist foundational pillars concerned with the relationship between power, identity and knowledge in conjunction with "the origin and location of problems" (Madigan 9). Central to White's conceptualization of narrative therapy was the poststructuralist notion that people are "multistoried" and experience is nuanced. The therapist, here, acts as a guide to explore and/or challenge the patient's commonly accepted and culturally situated belief systems and how these factors influence thought processes. For narrative therapy, the ways that we come to understand ourselves in relation to the world are limitless and can be "rewritten" in multiple ways.

Parallel to the framework of illness narratives, narrative therapy emerged in response to the dominant discourse at the time that believed the medical/psychological institution housed experts on bodily and mental state, and their knowledge should be gatekept from patients. Narrative therapy, like illness narratives, challenges the process of story relinquishing that can occur in the patient-physician encounter, where the medical institution takes the story of the body and translates it into a highly specialized language, inaccessible to the patient. This story comes to inform a localized, bodily pathology in need of a treatment plan to aid in returning the body to a state of normalcy. For White, the medical institution works to locate and privatize problems as a material site in the body of the patient which upholds beliefs that the body is a docile, subjugated object (Madigan 16). Narrative therapy, in response, uses externalizing conversations to reposition issues "inside the relational and interactional context of culture and discourse, normativity, structural inequalities and so on, and removes the primary site of problems from being privatized inside the decontextualized client body" (Madigan 16). White was highly influenced by the poststructuralist theories of Michel Foucault in relation to cultural and discursive restraints (Madigan 17), mainly questioning how discourse works to propel "truth" into existence - particularly a patient's "truths" about their identity. In response, narrative therapy would challenge these truths and externalize them as historically-informed cultural constructions. Ultimately, meaning about our identities, experiences, and relationships is mediated through the process of how, and using what tools, we tell our stories. These stories hold real power over our relationality with the world. Narrative therapy suggests stories of the self can be told in multiple ways, which in turn, is a generative process for conflicting truths.

Considering this review of the scholarly history of the genre of illness narratives, it is apparent that the purpose of this research is less about filling an apparent gap in the literature and more about a continuation of the digital illness narrative story. I argue that the future of the illness narrative genre is not simply bending to a digital format, but, digital tools like hypertext have the capacity to reimagine illness narratives, to transform how people can reflect on their experiences and narrate their lives. There is so much more to understand about this genre than can be explored in this project, however, a small piece of the puzzle is examined by looking at the embodied narratives of women and individuals with hyperandrogenism and the ways in which they claim their identities in the digital space.

Against Narrativity

Along with the swift influx of a scholarly embrace of narrative medicine came pushback. Authors, patients and scholars began challenging the sweeping claims of the discipline, assumptions around cultivating empathy for physicians, and the role of the patient as a storyteller. In 2004 Galen Strawson published "Against Narrativity" which challenges two identified pillars of narrative medicine scholarship: first, that people inherently understand their lives as a story and second, that this narrativizing of the self is a good thing (428). He argues:

> There are deeply non-Narrative people and there are good ways to live that are deeply non-Narrative. I think the second and third views hinder human self-understanding, close down important avenues of thought, impoverish our grasp of ethical possibilities, needlessly and wrongly distress those who do not fit their model, and are potentially destructive in psychotherapeutic contexts. (Strawson 429)

In his analysis, Strawson develops a conceptual framework for two opposing embodiments of the self: diachronic and episodic. The former, according to Strawson tends to understand themselves as a temporal entity existing in the past and future, whereas the latter does not. This classification of the diachronic versus episodic sparked a series of scholarly reflections (see Battersby; Mackenzie and Poltera; Phelan; Schechtman; Tammi). Strawson began to open up space that is highly skeptical of strong claims made by narrative medicine and its proponents. What followed was a series of works extending this skepticism. Frank, as the symbol of the wounded storyteller, became the focus of a number of this criticism. Angela Woods, for example, published "Beyond the Wounded Storyteller: Rethinking Narrativity, Illness and Embodied Self-Experience" in the 2012 *Health, Illness and Disease: Philosophical Essays*. In this chapter, Woods uses Strawson's arguments to challenge narrative medicine's perceived belief that we are all narrative selves and therefore the most optimal and healthy way to respond to illness is through the practice of narrative. Woods makes important critiques of Frank's classification of illness narrative genres, in particular. She argues:

> It would seem that illness must be experienced as transformative; whether for better (as revealed in the quest narrative) or worse (as registered in the chaos narrative). Stories of restitution are on this view the preserve of those who are in denial, who are out of touch

> or remain beholden to the dominant narratives of the biomedical establishment. (Woods 122)

What Woods brings to the forefront is a need for a further nuancing of these categories that do not allow space for forms that appear incongruent with narrative, such as silence, meaninglessness and formlessness.

In 2013 Seamus O'Mahony published "Against Narrative Medicine," a counterargument to the claims that narrative medicine should be a dominant method of pedagogy for training physicians. O'Mahony argues that "postmodernist literary theory" wrongfully flattens the authority of institutionalized discourse by, for example, understanding a leading article in the *New England Journal of Medicine* and a poem as two equally weighted narratives (612). O'Mahony argues that the intention to teach physicians "empathy" is a task with no measurable outcome. According to the author, it not only risks the physician stepping into a role they are not trained for, such as "spiritual leader", but it also cultivates a culture of condemning physicians who cannot or do not desire to grieve with patients. This is an interesting entry point to understand how pushback against narrative medicine starts to grow along seemingly political lines. O'Mahony, for example, makes baffling, uncontextualized claims without citation in his paper such as: "Doctors should—and generally do—treat their patients with courtesy, dignity, and kindness", or "Older, more stoically inclined patients, in particular, may find this form of engagement [empathetic] with their doctor vulgar, embarrassing, and intrusive" (615). He mentions the "grand ambitions" of medical/health humanities as "the promotion of social justice; the teaching of empathy; the encouragement of sensitivity to ethnic, gender, and cultural issues; and an end to the old patriarchalism" (O'Mahony 612). There are overtones in these statements of undermining a perceived softness of social justice perspectives and reinstating the need for the removed, omnipotence of the authoritative institution.

Where some subsequent criticisms of narrative medicine unfold along similar lines, others take a different approach. Mad studies, in particular, has developed a series of criticism of narrative medicine's valorization of Frank's genre typologies and the ways in which mental illness is or is not accounted for. In 2021, Alise de Bie published a review of the literature that examined the outcomes of using autobiographical narratives of madness or mental illness as a pedagogical tool in postsecondary education to teach empathy. What the author concludes is that the typical approach to using these narratives is a method of colonizing the story of the patient in a way that is highly uncritical of the systems that uphold injustice for Mad communities. Ultimately de Bie finds that intentional engagement with the ethical and epistemological considerations she outlines in the paper can inform how narratives can act as pedagogical tools that may facilitate justice. These considerations include a commitment to foregrounding a critical understanding of how power comes to shape the experiences of Mad people.

Some patient authors have voiced strong criticism of the outcomes of an uncritical narrative medicine. In 2022, Brian Teare wrote an article for *The Boston Review* entitled "Neither Chaos Nor Quest: Toward a Nonnarrative Medicine." Teare calls into question the expectation of patients to earn treatment by relinquishing a redemptive narrative of the self. He writes:

> Though Frank's narrative medicine appears patient-centered, ultimately it underplays the fact that it's the medical–industrial complex and its caregiving archons who allow patients to speak and who decide whether to listen. Nothing ensures that they actually can listen, or will understand what they hear. Though narrative medicine encourages patient

> speech, trusting as it does that even the pain of serious illness can be transformed into language, when it listens it insists on hearing only a certain kind of narrative—even after acknowledging that the requisite authorial distance is often impossible for a patient with a 'chaotic body' whose only story 'is a non-self story'. (Teare)

Teare is speaking about a collision - a collision between what it means for him to be a queer man with seemingly undiagnosable symptoms in "a taxpayer-funded, city-run public health program for uninsured, low-income residents who made too much income to qualify for Medicare." This collision includes capitalism and his physician, "a butch colluding with patriarchy's classic strategy of gaslighting." A redemptive narrative, for Teare, is out of reach through all the ways in which the factors of his identity, experience, history, and pain are incongruent with the healthcare system's "structural inability to interpret non-narrative language as anything but chaos." Ultimately, Teare not only challenges an assumption of the narrative self but highlights how we have already placed value and meaning on how the story of the patient is understood.

What the collection of works challenging assumptions of narrative medicine can offer this project is two-fold. First, it is significant to separate the various practices and disciplines that are often conflated in the debates outlined in the medical/health humanities, and second, there needs to be a resisting of universal assumptions around the inherent narratology of the self. Medical humanities is a scholarly field that turns to the application of humanities, art and social sciences in medical education and practice. In more recent years a push has been made to rebrand, reimagine, or expand the medical humanities as the health humanities, a strategy to move the academic discipline into a more interdisciplinarity space inclusive of perspectives outside of medicine (Crawford et al. 4). Narrative medicine is a form of medical practice that centres the narrative of the patient, typically in medical education or the patient-physician encounter. Narrative therapy is an approach to counselling or mental-health therapy that uses specific techniques to develop a life story of the patient as a therapeutic technique. Finally, illness narrative is a genre that describes the presentation of an individual's illness experience. The illness narrative is typically taken-up either textually or verbally (in the case of a patient telling their story to a physician or therapist) but can embody various communicative forms including image and sound. Illness narratives are, at times, misattributed as always existing within, or considered synonymous with, narrative medicine, narrative therapy or medical/health humanities. This is a significant assumption to challenge.

Much of the criticism surrounding medical/health humanities' take-up of narrative medicine, for example, either calls into question the ways in which structural power dynamics found in the healthcare system come to exploit the patient's narrative or a sweeping assumption of the self as inherently narrative-bound. While illness narratives are a practice of narrative medicine, they also exist outside the normative healthcare system. This project pushes up against narrative medicine but does not fully intersect. No research is taking place within the walls of the healthcare system, the authors are not framed as patients telling their stories in order to receive better care, and there is no centering of illness narratives as an education tool for physicians (the participants reach this conclusion, though). This is similar to illness narratives as distinct from narrative therapy. As I argue in "The Possibilities of Illness Narratives in Virtual Reality for Bodies at the Margins"

> Where narrative therapy may require medical professionals to both facilitate the process and measure the outcomes of the therapy, the practice of illness narratives allows for approaches outside, within and parallel to the healthcare system. This is significant for

> pathologized bodies at the margins, many of whom have experienced subjugation in their healthcare encounters. (Perram, "The Possibilities of Illness Narratives" 138)

The foundations of this research dislodge the centring of the experience of the reader by removing this position from the study. This research is concerned with the experience of the author and the therapeutic value of the writing process, removed from the mediation of reading/hearing the narrative. Further, as an extension of reinforcing illness narratives as a practice independent of narrative medicine, this project must resist universal claims regarding the narrative-ness of the self. Illness narratives, specifically in the literary hypertext form, are understood in this project as one response to illness, among many.

Phenomenology

Through bioethical approaches, some phenomenologists, over time, have looked to illness narratives as a challenging of the ethical transgressions experienced by the subject in the medical institution (i.e., when patients are marginalized and treated unethically we must turn to their lived experience). A large subset of illness narrative scholars argue that authorship in the genre is a tool to return voice to the patient (Bolaki; Couser; Frank; Coll-Planas; Hartman; Hawkins; Rains; Young). These theorists suggest that when encounters with the medical institution become dehumanizing, illness narratives have the capacity to return agency to the patient. This is done through a phenomenological approach that centres the experiences of those who are ill. Phenomenology, over time, has become the theoretical framework that has most deeply saturated illness narrative scholarship.

Phenomenology as a methodological framework has established an expansive bond with the discipline of medical/health humanities. Applied widely across the discipline to advance research that centres the lived experience of the body in medicine, phenomenology's impact as a method has penetrated most subsets of medical/health humanities including bioethics, narrative medicine, narrative therapy, and patient-centred care. Despite phenomenology's complexities and nuanced variances as a philosophical theory, the concept is widely treated as a monolithic, one-size-fits-all application of method. Caution must be paid to carefully examine the ontological, epistemological, and methodological positioning of phenomenology in research as the concept's genesis greatly affects its application. In the field of medical/health humanities, methodological frameworks for phenomenology are widely drawn from two variances in ontological positioning: Edmund Husserl's transcendental approach and Martin Heidegger's hermeneutic approach (Lafont 14). While both approaches seek the absolute knowledge of embodied subjectivity, Husserl's method favours bias-free transcendence whereas Heidegger favours an interpretive relationality. The essence of the methodological variances in these two approaches to phenomenology is that for transcendental the observer must compartmentalize their own subjectivity in order to observe phenomena free of bias whereas hermeneutics understands that the observer can never escape their relationality (Neubauer et al. 92).

Medical Humanist Fredrik Svenaeus is an example of a theorist who has adopted portions of the transcendental model and methodologically applied it to his research on the uncanny experience of illness, particularly in his case study of anorexia nervosa. Svenaeus attempts to locate a neutral, close report of the essence of the patient's experience through qualitative description. He notes, "An attempt is made to better understand the ways in which the body becomes alien in anorexia nervosa by way of a phenomenological analysis […] The analysis is exemplified and supported by stories told by girls suffering from the illness" (Svenaeus, "Anorexia Nervosa" 81). In this analysis the researcher becomes an impartial, removed observer of the "truth" of the phenomenon, or the experience of the anorexia patient, through their stories.

Mapping the themes of participant stories and synthesizing a description of their experience allows Svenaeus to pinpoint what anorexia is – it is the experience of the patient. According to the transcendental model, the neutral observer who is not implicated in the phenomena is able to isolate the transcendent state and identify the universal essence.

In Anne Werner et al.'s research on illness stories of shame by women with chronic pain, the authors explicitly employ a transcendental phenomenological method. Werner et al. describe their methodology as mirroring the work of prominent transcendental phenomenologist Amedeo Giorgi by beginning analysis with a thematic categorization of the data (the participants' stories). Werner et al. then follow four stages:

> (a) reading all the material to obtain an overall impression, and bracketing previous preconceptions; (b) identifying units of meaning representing different aspects of the women's experiences, and coding for these; (c) condensing and abstracting the meaning within each of the coded groups; and (d) summarizing the contents of each code group to generalize descriptions and concepts reflecting the most important experiences from the voices of the women. (1038)

This prioritization of producing a descriptive structure of points of meaning through unbiased observation works to locate Husserl's universal essence of a phenomenon. Each experience is mapped onto the larger corpus of other experiences to find commonalities and target the reality of the phenomenon – its substance can be applied universally.

Hermeneutic phenomenology, on the other hand, adopts a more reflective approach where the narrative of the participant is situated within the context of their lifeworld. This is in order to illuminate how relationality with the world has shaped experience (Neubauer et al. 94). A significant characteristic of the hermeneutic phenomenological method is that the influence of the researcher's subjectivity and lifeworld is both inevitable and a valuable contribution to the analysis. In Jean-Luc Nancy's chapter "Rethinking Corpus" in Richard Kearney and Brian Treanor's 2015 edited volume *Carnal Hermeneutics* on the phenomenological philosophy of corporality, Nancy adopts a hermeneutic approach that engages with his own subjectivity. As he explores what it means to be a body in relationality with other flesh, he implicates his own experience in reflection. Nancy notes, "Touching sinks into the darkness. Beneath my fingers, the clarity of another's body transforms into the night that is created between our two skins. The night is what we have in common and what both joins and separates us" ("Rethinking Corpus" 81). Nancy echoes his experience of flesh. Rather than highly methodical, Nancy's hermeneutic approach is iterative in a cycle of reflection.

Medical Humanist Katherine Young's work on disembodiment and gynecology draws a hermeneutic methodological approach similar to that of Nancy. While examining the phenomenological experience of a gynecological exam, Young pulls from her own subjectivity. Young recalls, "Gynecological examinations return me to my body by encroaching on my viscera. Tugs, disturbances, intimations arrive intermittently from my remote interior. I am incapable of detachment" (52). In Young's analysis, she engages in a reflective process where she positions her own experience at the forefront. Although we are not privy to Young's writing practice, a "true" hermeneutic phenomenology would engage in a "hermeneutic circle" (Neubauer et al. 95) where the researcher engages in a cycle of reading data, reflective writing, and revising conclusions. As demonstrated by the works of Fredrik Svenaeus, Anne Werner et al., Jean-Luc Nancy and Katherine Young within the discipline of medical/health humanities, phenomenological methods are widely rooted in the diverging frameworks of Husserl's transcendental or Heidegger's hermeneutic approach. Both perspectives argue for the authority of lived experience, however, Husserl's framework favours a descriptive approach over Heidegger's reflective approach. Further research would consider the ways in which the transcendental and hermeneutic approaches may not be situated in an oppositional binary, but rather, in a dialectical series.

Feminist phenomenology is an expansive field that is built on the theoretical foundations of phenomenologists such as Edmund Husserl and Maurice Merleau-Ponty. Most notably, feminist phenomenology can be understood as born from the legacy of Simone de Beauvoir in her 1949 book The Second Sex. In The Second Sex, de Beauvoir contends with the lived experiences of women and how identity is formed through interactions between social, cultural, and political forces. One of de Beauvoir's critical contributions to feminist phenomenology is her focus on the embodied, subjective nature of women's experiences. De Beauvoir argues that women need to be recognized as active subjects in their embodied experience, rather than mere objects of the male gaze. At the core, de Beauvoir argues that women's bodies are not only material but also sociocultural meaning-making spaces. The way that language and discourse impact de Beauvoir's work is through her analysis of social construction. She argues that the ways in which discourse forms our understanding of womanhood render women as objects within a binary. She suggests that women's experiences are therefore not only formed by their embodied experiences but also by the cultural and discursive structures that frame those experiences. Ultimately, de Beauvoir's work on feminist phenomenology has contributed to a deeper understanding that social discursive phenomena impact bodily experience.

It is surprising that there is seemingly no scholarly work analyzing the experience of hyperandrogenism in relation to feminist phenomenology aside from my article "Illness of the Gendered Body, Freud's *The Uncanny*, and 'being-in-the-world'" published in *The Canadian*

Review of Comparative Literature. In this article, I argue that the phenomenological experience of gendered illness can be understood through a theoretical framework of both Sigmund Freud's *The Uncanny* as well as Heidegger's notion of an unhomelike being-in-the-world (Perram, "Illness of the Gendered Body" 592). This article turns to the work of phenomenologist Fredrik Svenaeus who has laid the theoretical foundation for connecting *The Uncanny* to the experience of illness, most notably in his case study of anorexia nervosa. I argue that the phenomenological experience of gendered illnesses such as hyperandrogenism mirrors the uncanny by distorting temporal reality by making alien both the past and future, rendering the body and therefore identity and selfhood abnormal, and finally working to trouble the notion of the everyday (Perram, "Illness of the Gendered Body" 592). First, a hyperandrogenous body poses the threat of "morphing" into the alien unfamiliar where suddenly one's understanding of their identity in relation to the past and future is challenged. I note "With hyperandrogenism, the destabilization of subjecthood is twofold. Supplementing the otherness of our human body, another layer - the gendered body - ties together sociocultural, historical, and political framing of biological sex, bodily appearance, and behaviour. We are not only bodies but gendered bodies" (Perram, "Illness of the Gendered Body" 594). Ultimately, when our understanding of health is tied to cultural notions of normative, binary sex expression, a distortion of the body across sexed lines forces one to relinquish their sense of identity. Further, temporally, hyperandrogenism disrupts our notion of the ordinary everyday, or our sense of 'being-in-the-world'. The illness reveals to you that you are no longer in the realm of normalcy but are, in fact, in a subversive reality where you now must try to escape and "return" to the everyday. From here, hyperandrogenism may disrupt first our sense of identity, and second our sense of temporality. Once illness has made our body alien to our self, "A crack splits through the temporal narrative of the self, igniting a need to rewrite the identity of the past in order to preserve the identity of the future" (Perram, "Illness of the Gendered Body" 598). In this sense, there becomes a need to reconstruct our story in ways that keep our identities and sense of temporality intact. Although phenomenology will not be my primary theoretical perspective for this project, it is an immensely generative framework to employ as a foundational understanding of the experience of embodied hyperandrogenism.

To date, the study of illness narratives has been tied to the theories of phenomenology. Phenomenology, however, has been challenged in the wake of feminist poststructuralism. A more notable critique comes from feminist poststructuralist theorist Joan Scott's chapter "Experience" in Judith Butler and Joan W. Scott's 1992 edited volume *Feminists Theorize the Political*, which challenges experience as the site of knowledge. Scott argues that when we render experience as the foundation of knowledge, we also name it as an essential, unchallenged predisposition. When experience is viewed as the "original" moment of truth, this excludes the possibility of additional, previous experiences or moments of influence. Scott argues that phenomenology, then, pulls focus from experience as highly historical and sociopolitical. In other words, our experiences are always already seeping in discourse and when we view them as truth we sidestep the ways subject positions are created through power. This criticism centres a challenging of experience as the site of authority. This feminist poststructuralist critique of phenomenology has become a crucial moment in my own exploration of a theoretical framework for my research. I understand that I must draw from theory that works to implicate discourse more strongly than phenomenology seems to do. The core of my decision rests in my case study of hyperandrogenism and how significant discursive practice becomes to the experience of being rendered "ill" when one is diagnosed with a biological sex disorder. This has led me away from continuing the practice of employing phenomenology as a theoretical framework for analyzing illness narratives in the digital space. Moving forward in my theoretical exploration, as the following sections reveal, I begin conceptualizing the linguistic turn in relation to feminist poststructuralism. However, as the introduction of this chapter notes, my theoretical journey for this project does not end in the linguistic turn, as I identify issues with the hyper-discursive forms of analysis and question their ability to account for aspects of my corpus that were central to meaning-making, including the materiality of the body. In the end, I align my theoretical framework with feminist new materialism, although, I find it crucial to my research to critically understand theoretical approaches to feminist poststructuralism as foundational tools to be built on. Therefore, the following sections of this chapter explore relevant theoretical understandings of critical approaches to discourse, norms and intersex bodies.

Critical Approaches to Discourse, Norms, and Intersex Bodies in the Linguistic Turn

When grappling with intersex identity through feminist theory, conceptualizations of norms, normalization, and pathologization are foundational. Georges Canguilhem's *The Normal and the Pathological* has endured as a seminal text tracing the historical lineage of biological notions of *normal* and deviance into *pathological*. Considered critical reading for disciplines from philosophy to medicine, *The Normal and the Pathological* examines the upsurge of disciplinary biology in the 1800s and maps its historical contingency. Canguilhem plots the early 19th-century conceptualizations of health and disease and demonstrates how the emergent epistemological bases of normal and pathological was politically, economically, and institutionally supported. Rather than biological, essentialist categories, Canguilhem shapes a radical philosophy that rejects a statistical certainty of the normal in favour of qualitative valuation. Canguilhem shows how pathology through bodily dysfunction is tied to a failure to adapt to the ever-evolving state of the normal and therefore cannot be separated from the experience or judgement of the individual. Canguilhem's work has gone on to influence the philosophies of many prominent theorists, shaping the ways in which they view the evolution of knowledge through history and the turbulent practice of establishing pillars of truth. Drawing from the work of Canguilhem, Judith Butler and Michel Foucault have formed the basis of their philosophies on a notion of *normal* as that which conforms to a norm and the *pathological* as a value description of the space outside the fluctuating boundary of the normal.

Critical to the research of my project is a theoretical grounding in poststructuralist theory and sexuality studies - particularly the ways in which these perspectives come to view intersex bodies as regulated through discourse. Decades of feminist theory on discursive (re)production of the body have been proceeded by the work of Michel Foucault. In 1975 Foucault published the landmark *Discipline and Punish: The Birth of the Prison*. In this work, Foucault discusses his concept of docile bodies where he argues that the subject is produced through normalized forms of surveillance and disciplinary power. The docility of the body is achieved through its regulation in a particular time and space. Foucault discusses the assemblages of subjects in space through the context of the institution. The societal institution takes many forms but includes the school, the prison, the military, and the hospital. Through combinations of series, subjects are placed in confined sequences (military ranks, students in a classroom, or prisoners in cells) and subjected to constant, elusive surveillance (i.e. the Panopticon). Docile bodies are also produced through the regulation of personal, economic, political and historical time in order to govern the way in which the subject experiences the passing of intervals. According to Foucault, the combined, coercive ownership of the subject's body in both time and space works to manipulate the subject as docile. Because the power of this organizational practice is productive and codified, these coercive measures are normalized and therefore indiscernible.

In 1976 Foucault laid the groundwork for contemporary feminist sexuality studies through the publication of *The History of Sexuality.* Foucault takes a sociohistorical approach to the production of sexuality as a concept arguing that it is through sex's discursive rendering as a site of power that the concept is born in the first place. As sexuality continued to infiltrate institutional discursive dynamics (through its perception as a cultural taboo, for example), it began to erect itself as an entity of subjecthood. Foucault concludes that when we are able to dissolve the discursive form of sexuality in our cultural, institutional and political assemblages we will truly become liberated from the oppression our ideas of sexuality place on identity. Foucault challenges the "repressive hypothesis" that argues power regulations have historically worked to repress the discussion of sexuality. Foucault suggests it is through historical regulation of sex, from the practice of Christian confession to tightening laws on "deviant" sex acts, that sexuality became a frequent topic in public discourse. Once sex became discursive, conceptions of a normal and pathological sexuality were produced. In this sense, Foucault argues that power is not, in fact repressive, but productive. Power produces subject positions, and in the case of the historical swelling of discursive sexuality, sexuality became an identity category and central to the ways in which we understood and spoke about ourselves and our communities. This productive form of power that has birthed discursive sexuality, according to Foucault, also generates a way to speak and know about deviant sexuality. We see this in the varying ways sexuality in relation to children, same-sex partners, multiple partners, labour and commodification, consent, and animals has been criminalized or pathologized throughout time. Foucault's work on discourse at the site of power and his poststructuralist theoretical approach have gone on to form the foundation of prominent streams of gender and queer studies to date as well as conceptualizations of illness subjectivities. Foucault's legacy intersects with this project through the ways in which I understand how medicalized discourse comes to shape illness and the process of pathologizing the abnormal body.

In 1980 Julia Kristeva wrote *Powers of Horror: An Essay on Abjection*, a poststructuralist and psychoanalytic exploration of the concept of the abject, building on the traditional theories of Sigmund Freud and Jacques Lacan. Kristeva argues that the abject is the feeling of subjective horror and disgust that is experienced by the confrontation of the *self* with the *other*. This recognition of distinct subject positions makes us aware of our own corporeal reality and creates a feeling of incongruence. The abject, then, is a subjective realization of the *other*, or that which is not a part of myself. Further, the abject is situated outside of the ways in which we organize categories, and therefore a confrontation with the abject jars our methods of conceptualization. For example, Kristeva turns to examples of garbage, filth, or a human corpse. These entities were once subjects in our cultural order but have now been "cast off" outside our realm of subjecthood. Yet, we can still recognize them in our environment, and this is what produces cognitive dissonance. This sense of incongruence triggers a desire to reproduce organizational boundaries to maintain our relationship with logical subjecthood. This desire is typically enacted through rituals that work to create a sense of separation from nature and society. Kristeva argues "It is thus not the lack of cleanliness or health that causes abjection but what disturbs identity, system, and order. What does not respect borders, positions, rules. The in-between, the ambiguous, the composite" (8). Kristeva's analysis of the abject has gone on to influence a host of disciplines, including gender studies.

Gender scholars such as Judith Butler have turned to the concept of the abject body to understand how bodies that challenge our normative binaries create a sense of cultural panic. Judith Butler discusses the concept of the abject body in her book 1996 *Bodies That Matter*.

According to Butler, the abject body refers to bodies that deviate from a cultural understanding of the sex binary and therefore become excluded from the normative standards of society. Butler uses the concept of the abject to describe how, through regulatory systems, bodies are filtered into a binary of normal and deviant. The abject body, then, becomes simultaneously a site of anxiety and fascination for the dominant culture because it takes hold of, and makes coherent, a space outside of normativity. The dominant culture processes the abject body as something both threatening and attractive as it exposes the limits of the constructed nature of gender. Butler's analysis of the abject body is significant because it challenges the dominant culture's assumptions about gender and sex and exposes the ways in which these categories are constructed and maintained through exclusion and marginalization. By deconstructing the norms of the gender and sex binary, Butler opens up the possibility for new forms of identity and community that are not based on these rigid categories. The concept of the abject body is critical to my analysis of hyperandrogenism and is a term that I rely on to explore the drive, from the self, from culture, and institutionally, to "cure" the hyperandrogenous body by pushing it back into the normative category of the feminine.

For intersex bodies, Canguilhem's legacy of norms and pathologization becomes significant when evaluating the concept of sex dimorphism and a sex binary in humans. A pivotal text in feminist science studies is Anne Fausto-Sterling's 1993 article "The Five Sexes: Why Male and Female Are Not Enough" where she argues that categories of male and female are not sufficient to capture the nuances of human sexual biology. Fausto-Sterling argues that in "nature" there is evidence for five distinct sexes. Feminist sex theory today has built on Fausto-Sterling's claims shining a light on the myriad of "naturally" produced intersex identities that may render variances in sex chromosomes, hormones, external genital, and internal organs. For my research on women and nonbinary individuals with hyperandrogenism, who are at times labelled as intersex (as seen in news coverage on the case of Caster Semenya), Canguilhem’s theory illuminates a connection between how hyperandrogenous bodies become pathologized through medicalized discourse. In 1993 Deborah Flndlay wrote the ground-breaking article “Discovering Sex: Medical Science, Feminism and Intersexuality” that reinforced Anne Fausto-Sterling’s argument of biological sex multiplicity in “The Five Sexes”. Flndlay maps the definitional categories of biological sex both employed and produced by obstetrician-gynecologists in 1950s Canada. Flndlay looks at how scientific practices of medicine are actually proponents of sociology in the way that they work to produce social concepts of biological sex. The field of medical science, according to Flndlay, then weaponizes these social concepts as naturalized “proof” of dichotomized sex. This in turn leads to a presumed distinction between social understandings of sex and gender and scientific understandings that allows for the pathologization of deviant sex (Flndlay 26). Instances of “natural” intersex bodies are then able to be framed as “abnormal” and a quest to “discover” the “true” sex of the body becomes the mission of medical care. Flndlay’s study looks at the decade of the 1950s as this was when the genetic test for the nuclear sex chromatin was discovered and became used as an instrument to “decipher” the “true” biological sex of ambiguously-sexed infants. The discovery of the genetic test superseded previous methods of sex verification in medicine, including gonadal and hormonal tests (36). This genetic test for the nuclear sex chromatin was a significant and timely discovery because it came at a time where an infant’s ambiguous external genitalia was viewed as a medical emergency. This is a sentiment still true today. Physicians felt institutionalized pressure to pronounce biological sex at birth via the birth certificate. Flnlay analyzed a sample of ten prominent obstetrician-gynecologist textbooks to examine not only the medicalized discourse on the pages, but the "metaphors, illustrations, and taken-for-granted assumptions about female biology" found on the pages that contributed to the fallacy of a sex binary (34). Flnlay concludes "Sex, then, was not 'biological material' waiting to be discovered in nature; rather, it was a representation, embodying specific assumptions about what biological sex should be like" (44). This is an important ontological starting point for my research to approach biological sex as produced through and enforced by ourselves in relationship with medicalized discourse. In this way, the pathologizing of deviant biological sex found in the experience of hyperandrogenism can easily be linked to other sex "disorders" such as intersexuality, congenital adrenal hyperplasia, testosterone biosynthetic defects, androgen insensitivity syndrome, gonadal dysgenesis, 5-alpha reductase deficiency, klinefelter syndrome, turner syndrome, or polycystic ovarian syndrome.

Returning to Foucault's legacy, we see that it is prominently woven throughout the major works of queer, disability and gender disciplines, and this is particularly true of Judith Butler's work on discourse and gender. Judith Butler's theories, built on but in conversation with Foucault's later works, have become the compass for contemporary feminist theory. In *Undoing Gender* Butler profiles the contentious debate surrounding a gender identity disorder (GID) diagnosis (later renamed in the Diagnostic and Statistical Manual of Mental Disorders as gender dysphoria). She outlines the implications of pathologizing GID and how a diagnosis could affect individual autonomy and access to healthcare resources (Butler, *Undoing Gender* 77). This turbulent distinction between normal and pathological comes at a high cost as Butler notes "autonomy is a socially conditioned way of living in the world" (Butler, *Undoing Gender* 77). These institutionalized distinctions are far from universally comprehensive as, Butler argues, a GID diagnosis could mean different things for individuals who will fall into these institutionalized categories. For some, the pathologizing of GID could legitimate their health status for access to surgeries, hormonal therapy, and insurance coverage. However, being pushed out of the classification of *normal* for other individuals could mean carrying a stigma that there is something deviant about their bodies or gender identity. The reality is that both experiences might be simultaneously true for most.

Butler's perspective on norms and normalization is useful in the work of mapping gender. Butler defines gender as "the apparatus by which the production and normalization of masculine and feminine take place along with the interstitial forms of hormonal, chromosomal, psychic, and performative that gender assumes" (Butler, *Undoing Gender* 42). Treatments for women with hyperandrogenism which aim to lower "male" hormones directly exemplify these hormonal and performative forms in which gender assumes. Social and medical pressures to present more "feminine" and combat symptoms that are read as "masculine" function as gender regulating as they both produce and normalize the gender binary. Butler suggests that when one exists outside the norm of gender, this is a contentious place to be as you are still only discernible in relation to the gender norm. They note, "To be not quite masculine or not quite feminine is still to be understood exclusively in terms of one's relationship to the 'quite masculine' and the 'quite feminine'" (Butler, *Undoing Gender* 42). This reproducing of the gender binary is evident for women and individuals with hyperandrogenism, and in particular the notion of being "not quite feminine" enough. Some individuals with the disease are held to a standard of femininity that they believe they are not meeting, and in response, some solutions offered by the medical community are to chemically and procedurally alter their bodies until the feminine standard is reached. This dilemma works to inform Butler's understanding of gender as socially produced. They argue that defining gender as existing exclusively on a binary plane of masculine and feminine misses the “critical point” that the ways in which our gender binary is produced are both conditional and come at a significant cost (Butler, *Undoing Gender* 42). I understand Butler’s theorizing of gender as an “opening up” of possibilities. They suggest that although there are clear and harmful hegemonic views of gender, variations of gender that are not recognized as normative are “as much a part of gender” as their normative counterparts (Butler, *Undoing Gender* 42). Further, they conclude that although gender is the site of production and normalization of the normative binary of masculine and feminine, gender can also be a place to dismantle and deconstruct these understandings.

From this place of understanding gender as an apparatus of production and normalization, Butler turns to Michel Foucault’s theorizing of how discourse works to produce a subject. They conclude that disciplinary discourse not only regulates the subject by making use of them but that it “actively constitutes” the subject (Butler, *Undoing Gender* 50). This process of constituting the subject through disciplinary discourse is evident in the way gender-variant individuals are punished and regulated through both the institutionalized state and through social encounters. Butler offers examples of this including surgical “correction” of intersexed individuals, the classification of gender dysphoria disorders including the resulting pathologization, and the state-inflicted regulations on same-sex parents or prospective parents (Butler, *Undoing Gender* 55). I would situate the social and medical response to women and individuals with hyperandrogenism within this gendered punishing and regulating as well. The social implications of leaving hyperandrogenous symptoms of excess testosterone “unregulated” are dire and the response from the medical system includes surgical, pharmaceutical and cosmetic interventions. Butler argues that these social and institutional regulations are producing results that remain effectively “unmarked”, yet nevertheless, are constituting the boundaries of personhood (Butler, *Undoing Gender* 56).

To reinforce their theorizing of gender regulation, Butler engages with the story of David Riemer who, following experiencing a section of his genitalia burning off as an infant due to a botched medical procedure was socially raised as a girl, re-named Brenda (Butler, *Undoing Gender* 64). The decision to raise David as Brenda was supported by a belief of complete social constructivism from his physician and parents. After discovering his past as he got older, David chose to return to living life as a male. What is most compelling in Butler’s analysis of David’s story is both the way David’s gender was socially and medically regulated and also the ways in which David came to understand and speak about his gender identity. First, Butler notes that the way one’s body looks to others constructs the body as gendered (Butler, *Undoing Gender* 64). From this place, we may scrutinize medical decisions to perform gender reassignment surgery or hormonal therapy for women and individuals with hyperandrogenism. Butler argues that these procedures are encouraged under the guise of “looking more normal,” yet they inflict scars and pain that do not align with this outcome. Butler concludes that gender-variant bodies such as David’s (and I would argue some individuals with hyperandrogenism), are “inconceivable” to many and therefore their bodies are regulated through invasive medical practices (Butler, *Undoing Gender* 64). Butler stresses that their purpose in employing David’s story is not because it proves or disproves either social constructivism or gender essentialism, but rather, they hope to highlight the disciplinary mechanisms used by David to understand and speak about his own gender identity. This process of self-reporting by David works to unveil the ways in which his gender identity is both affirmed and denied. Because David was subjected to constant unrelenting surveillance, scrutiny and abuse by medical professionals, who collectively dangled gender normalcy just out of reach, he began to understand that he was "failing" gender. The question of whether David was "feminine" enough, or meeting the standard of feminine normalcy, was constantly interrogated. Butler argues that David had come to understand that there was a label of who he should be, stable femininity, and he was not that (Butler, *Undoing Gender* 67). This unattainable norm, for David, ensues a certain logic: the norm was distinguishable from the way he felt—it was "other" and therefore he was "other" from stable femininity. Like David, some women and individuals with hyperandrogenism recognize that they too are "failing" femininity. When their bodies express signs of elevated androgens, they experience both external regulation as well as self-regulation in order to resolve this dissonance.

In Butler's chapter entitled, "Undiagnosing Gender," they explore the contentious debate surrounding a GID diagnosis and what this diagnosis means for both individual autonomy as well as access to resources (Butler, *Undoing Gender* 77). Butler does not attempt to establish an answer to the polarizing GID diagnosis debate but does suggest that "autonomy is a socially conditioned way of living in the world" (Butler, *Undoing Gender* 77). In this sense, mechanisms of autonomy, or the opposite such as a GID diagnosis or by extension a hyperandrogenism diagnosis, may be liberating for some and restrictive for others. As Butler points out, those opposing forces usually are occurring simultaneously (Butler, *Undoing Gender* 77). Exploring what autonomy might look like for women and individuals with hyperandrogenism seems to reflect Butler's analysis of a GID diagnosis. Some individuals with hyperandrogenism may believe that further reinforcing the condition as a medical illness will legitimize their diagnosis as valid and deserving of healthcare resources including medical research, insurance coverage for medications, and the development of pharmaceutical options.

Drawing from their understanding of gender as a site of possibility, Butler contemplates the repercussions of accepting a GID diagnosis as an avenue of autonomy. They wonder what happens to gender as “a mode of becoming” (Butler, *Undoing Gender* 217) when we play within the confines of a masculine/feminine dichotomy. Butler ponders: “Are we stopped in time, made more regular and coherent than we necessarily want to be, when we submit to the norms in order to achieve the entitlements one needs, and the status one desires?” (Butler, *Undoing Gender* 81). In conclusion, they rationalize that if a GID diagnosis is facilitating a way in which individuals can achieve their desired autonomy, we have a responsibility to locate a method which cultivates similar effects before we collectively reject a GID rationale (Butler, *Undoing Gender* 82). For women and individuals with hyperandrogenism, I wonder if writing about their illness experience can behave as this “method which cultivates similar effects” Butler is suggesting, these effects including a sense of autonomy.

Butler’s discussion of medical practices and the gender norm is particularly useful in understanding hyperandrogenism treatment. Medical procedures and practices that help preserve and foster primary and secondary sex characteristics can include breast augmentation surgery, Viagra, and, I would argue, hyperandrogenism treatment, including androgen blockers, laser hair removal and topical Rogaine (Butler, *Undoing Gender* 86). Butler questions why procedures and treatments that seek to move an individual further away from a gender norm require psychological counselling and interrogation yet practices that position individuals firmly within their gender norm are normalized. Sex becomes culturally understood or readable on the body through these sexed bodily traits. Ultimately, Butler argues that she does not “mean to suggest that purely cultural signs produce a material body, but only that the body does not become sexually readable without those signs, and that those signs are irreducibly cultural and material at once" (Butler, *Undoing Gender* 87). Butler is arguing that these processes of being hailed as gendered, or having one's body be sexually readable, function as socially constituted through cultural cues. However, although our understandings of gender are established through a combination of cultural and material signifiers, this does not delegitimize gender by rendering it fabricated. In fact, Butler argues, the significance of becoming a gender, and being recognized as such, is vital to one's sense of personhood, one's well-being, and one's ability to "flourish as a bodily being" (Butler, *Undoing Gender* 100). Ultimately, Butler calls on nourishing the movement to secure transgender people in positions of medical power as a short-term solution to the GID debate, but ultimately argues for an upheaval of our institutional and cultural understandings of gender norms. This call could reflect an avenue of progress for women and individuals with hyperandrogenism as well.

Through Butler's analysis on GID and intersex children, and Foucault's work on sexuality, it is evident that both thinkers have adopted Canguilhem perspective that the epistemological bases of *normal* and *pathological* are socio-politically constituted. Butler situates gender as a norm to which bodies become regulated. This includes the pathologization of queerness, disability, GID, and intersex identities which work to enforce compulsory able-bodiedness and cis-genderness, a perspective adopted by many gender and disability theorists including Robert McRuer, Susannah B. Mintz, and Anne Hunsaker Hawkins. Literature from feminist science studies, intersex theory, queer theory, and disability studies can help elucidate the ways that supposedly objective scientific research is in fact part of a larger discursive process that empowers some specific understandings of the body and disempowers others.

Dean Spade and Craig Willse in their 2015 chapter "Norms and Normalization" in *The Oxford Handbook of Feminist Theory*, outline further the legacy of Foucault's work on disciplinary norms for feminist poststructuralism. Spade and Willse argue that Foucault's theorizing of power as productive leaves room for us to consider the mechanisms that allow for the enforcement of norms. The authors suggest, "Bodies, subjectivities, and their relations in space come to be in relation to norms of embodiment, behavior, and thought" (Spade and Willse 553). Ultimately, this discursive conglomerate of power relations yields biopower. In *The History of Sexuality*, Foucault suggests biopower is "an explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations" (140). As Spade and Willse suggest, biopower is actually disciplinary where violent and coercive means of enforcing norms are soon replaced by internalized self-regulation so that "'soft' control replaces direct violence" (554). This understanding of disciplinary power is useful for my project which complicates and questions assumed biological sex norms. Where my research argues that hyperandrogenism unveils the fallacy of the sex binary, there emerges complexity around gender norms and embodiment. For example, in the Introduction, I discuss the findings of my master's research on Soul Cysters Dot Net and the seemingly collective goal of the community to "achieve" normative femininity. It is a convenient conclusion to render the impulse of the Soul Cysters Dot Net community as disciplinary biopower through self-regulation. However, this leaves "stuff" on the table that has not been engaged with, and that is the matter of the body and the affect of the physical morphing of visible sex characteristics.

It is also significant to note that in my project especially, processes of normalization through regulatory discourse do not suggest that norms are not "real" in the ways that have meaningful impacts on how we organize our sense of identity in relation to the world. This is not to suggest that proponents of regulatory discourse such as Foucault and Butler do not argue this, however. This conclusion, which will be theoretically supplemented in the feminist new materialism section of this chapter, leaves space for the political activism and sense of yearning for difference found in gender queerness. As Spade and Willse suggest, in conversation with Butler's work on GID, mental health diagnoses that centre distress around the failure of gender embodiment or the inability to meet gender norms, work to produce regulatory categories such as “healthy” and “sick” (555). These regulatory discourses have become increasingly insidious in the past several years as social and institutional understandings of trans identities, for example, have gone from a “sickness” in the brain to a “sickness” in the body. Where diagnosis was centred on attempting to interrogate and cure the mind of distress surrounding gender embodiment, has now shifted to fixing the “wrong” aspects of the sexed body. As Spade and Willse argue “The creation, maintenance, and enforcement of these norms is wrapped up in systems of scientific expertise and authorizes particular professionals as gatekeepers, and can include forced or denied medication and other healthcare treatments, including ‘reparative therapies’ and involuntary psychiatric imprisonment” (555). Understanding the complexities of gender and sex difference in relation to identity as well as the social and institutional oppression of queer identities has been the theoretical work of feminist and queer studies scholars to date.

The above navigation through the evolution of feminist poststructuralist theories, particularly a Butlerian/Foucauldian critique of norms and regulation, is coming to a head in contemporary scholarship. This crux is the feminist emancipatory project of the posthuman body (Braidotti; Irigaray; MacCormack; Plant; Cudworth and Hobden; Halberstam and Livingston; Haraway; Hayles; Balsamo). Collectively, feminist posthumanist authors argue for an emergent posthuman body contingent on the positivity of difference, multiplicity, and the concept of “not two nor one” (Irigaray). The emergence of posthumanism developed as a counter to poststructuralism’s heavy emphasis on language. As Karen Barad notes in her 2003 article

"Posthumanist Performativity: Toward an Understanding of How Matter Comes to Matter" how did "language become more trustworthy than matter?" (801). Poststructuralism centralizes the linguistic as a source of power. However, as N. Katherine Hayles argues, posthumanism emphasizes the influence of additional non-androcentric discourses, including code. She argues that code "becomes a powerful resource through which new communication channels can be opened between conscious, unconscious, and nonconscious human cognitions" (Hayles, "Traumas of Code" 140). A current scholarly trend in feminist work on the body is adopting a posthumanism framework that acknowledges new forms of discourse beyond traditional language. In later sections of this chapter, I will outline my theoretical framework for this project, feminist new materialism, which has grown out of the posthumanist critique of the linguistic turn. Although feminist poststructuralism offers invaluable methods for examining intersex bodies in relation to regulatory medicalized discourse, feminist new materialism provides the theoretical tools to account for the materiality of bodies intersecting with digital technology.

Crip Theory in Conversation with Colonial Medicine

Emerging from the activism of the disability rights movement of the 1970s was the social model of disability. This innovative model stood as a foil to the traditional medical model that positioned disability as a deficit in the patient's body that required treatment. By contrast, the social model of disability, spearheaded by community activists, argues that disability involves the experience of oppression that stems from the ways our social environment is inaccessible to bodily difference (Goering 134). Scholars such as British sociologist and activist Mike Oliver who wrote the ground-breaking 1990 book *The Politics of Disablement* which argued in favour of the social model of disability as well as a distinction between the terms of *impairment* and *disability*, have been vital pioneers of the social model of disability. Through the work of Oliver and other scholars, the academic field of disability studies was erected. Crip theory is a framework within disability studies that is concerned with both the historical and political oppression of those living with disabilities and the ways in which these experiences intersect with other forms of subjugation including sex and gender. Similarly, crip theory tends to hold a radical agenda that is deeply intertwined with queer theory and practices. As Robert McRuer argues in the 2006 *Crip Theory: Cultural Signs of Queerness and Disability*, crip theory has typically been "deployed to resist the contemporary spectacle of able-bodied heteronormativity" (3). McRuer's findings are immensely crucial for my project because they help to contextualize the history of the pathologization of biological sex deviation in relation to the pathologization of disability. Bodies that hold queerness, in this sense, continue to be subjugated because they are tied to the subjugation of disability. In turn, queerness and disability are upheld by the interdependent dominance of compulsory able-bodiedness and heteronormativity (McRuer 1). Neoliberal postmodernity, however, has seen a shift in the cultural tolerance of pathologized queer-disabled bodies. Where "heterosexuality and able-bodiedness were [once] wedded but invisible (and in need of embodied, visible, pathologized, and policed homosexualities and disabilities) eventually gave way to our own period, in which both dominant identities and nonpathological marginal identities are more visible and even at times spectacular" (McRuer 2). In fact, according to McRuer, neoliberalism insists upon a spectacular, visible able-bodied heteronormativity that validates queer-disabled embodiment. McRuer looks at many examples, including popular reality shows such as *Queer Eye for the Straight Guy*. The author notes that the neoliberal postmodernity that works to normalize media such as *Queer Eye* actually works by "identifying and disciplining disability" (McRuer 5) in order to contain it away from able-bodiedness. McRuer's understanding of crip theory is generative for the project of thinking about hyperandrogenism in relation to compulsory heteronormativity. It is evident that the pathologization of hyperandrogenism and the condition's rendering of the body as "abnormal" works in conjunction with cultural understandings of disability. But further, visible, postmodern instances of queerness depicted culturally, as McRuer argues, actually work to further pathologize hyperandrogenous bodies. When our media portrayals of queerness are visible and plentiful, yet carefully crafted as "other" to normativity, this reinforces first the recognition of an "abnormally" sexed body and second, the desire to "return" the body to its "natural" state.

In 2013, Alison Kafer wrote *Feminist, Queer, Crip*, which argues for the reimagining of new futures for disabled bodies. Kafer explores theories from climate justice, reproductive justice, cyborg theory, and gender theory to challenge disability studies' tendency to examine disability in isolation rather than within a feminist, queer, and crip coalition. In her book, Kafer foregrounds conceptualizing temporality in relation to disability and neoliberalism and puts forward the concept of crip time theory. Crip time is used to think critically about how disabled people and other marginalized groups are actively made invisible in our collective imaginings of past and future. Kafer argues that disability has been rendered as the space of "no future" (10). She argues, "The very absence of disability signals a better future. The presence of disability, then, signals something else: a future that bares too many traces of the ills of the present to be desirable. Disability is a future no one wants" (Kafer 2). The future that no one wants speaks to racist and ableist Darwinian notions of "evolving" the body of the human species into the "superhuman" that has no trace of bodily difference. Kafer suggests the desire for life longevity is wrapped up in racist, classist, and ableist notions of a utopian society that directly mirrors historical eugenics practices. Ultimately, Kafer makes a radical call to "fuck the future" as this appears to be "the only viable crip response" (31). From here, however, Kafer begins to explore the feminist posthumanist movement and particularly the ways in which Donna Haraway's feminist cyborg theory has been weaponized as a framework to eradicate disability in imaginings of feminist utopias. Kafer suggests "disability and disabled people are decontextualized, removed from the realm of the political, and presumed to play no active role in the category breakdowns that animate both the cyborg and the manifesto" (115). Kafer reveals important questions about the role bodily difference plays in feminist calls for institutional reform. For my research, this opens up questions about what role hyperandrogenism plays in our future. When thinking about the progression of medical science, will disabled and hyperandrogenous bodies be erased?

The current trajectory of scholarly crip theory has been guided by Jasbir K. Puar's acclaimed 2017 book *The Right to Maim: Debility, Capacity, Disability*. Puar builds an intricate landscape of the multifaceted relations between individualized disability and neoliberal systems of productivity and capacity enacted through state, economy, and labour practices. Puar argues that the terms *debility* and *disability* are distinct, but interlocked in the ways neoliberalism understands them in relation to the political economy of the body and the body's capacity to participate in labour. She suggests debility through imperialism, war, colonialism and labour is a pillar of neoliberal organizing structures found both in the global North and South. This is enforced in Puar's example of how the state insists upon upholding massive debt in order to maintain debility. Puar notes that the neoliberal order "promotes disability empowerment at the same time that it maintains the precarity of certain bodies and populations precisely through making them available for maiming" (*The Right to Maim* xvii). This availability for maiming is explored in depth throughout the book using various case studies. A poignant example is found in the second chapter of the book entitled “Crip Nationalism: From Narrative Prosthesis to Disaster Capitalism” where Puar argues that state economics of war and labour require bodies to be filtered through the process of injury and maiming (*The Right to Maim* 65). Because practices of war, labour, capitalism, migration and colonialism produce debility, the state must respond with seeming support, as seen through the Americans with Disabilities Act (ADA). The ADA, according to Puar, takes from flawed capitalist logic to position the disabled body as worthy of neoliberal production through labour or as an object of profit for the medical economy.

It is Puar’s first chapter of *The Right to Maim* entitled “Bodies with New Organs: Becoming Trans, Becoming Disabled” that I believe offers the richest insight for my project. This chapter maps the ways in which both neoliberal biopolitics and legislative policy work to reinforce both gender normativity and the practice of “passing” (the ability to appear and behave in ways that are culturally read as cis, straight, or able-bodied). These policies require trans and disabled subjects to understand their identities in relation to how their bodies can be productive for the state economy. The concern of “passing” is common rhetoric discussed by women with hyperandrogenism, as I discuss in the Introduction, who express a desire to be culturally “read” as feminine. Similar to her second chapter, Puar turns to the example of the ADA and notes that the act “reifies standards of bodily capacity and debility through the reproduction of gender normativity as integral to the productive potential of the disabled body” (*The Right to Maim* 38). Puar argues, further, that the production of white trans bodies into nationalistic intelligibility works through value extraction from different bodies of colour (*The Right to Maim* 34). Understanding the visibility of trans rights as a nationalistic project “highlights the impossibility of a rights platform that incorporates trans of color positions, since their inconceivability is a precondition to the emergence of the rights project, not to mention central to its deployment and successful integration into national legibility" (Puar, *The Right to Maim* 34-35). Puar's insight is critical when thinking about individuals with hyperandrogenism and their contact with the healthcare system.

One of the most socially meaningful symptoms of hyperandrogenism, and a symptom that causes significant distress for many women and individuals with the illness, is infertility. When thinking about historical notions of women's labour in relation to normative understandings of what a female body should be capable of, it is apparent that the ability to bear and care for children is fundamental to the economy of the state. Puar's work reminds me of the ways in which the feminist reproductive rights movement, hailed by chants of "My Body, My Choice", has been criticized by reproductive justice initiatives which argue that the former actively erases the violent history of Women of Colour's experiences with reproduction in relation to colonial medicine. This topic is explored in-depth in the work of INCITE!, a feminist grassroots activist organization committed to ending violence against Women of Colour, as well as the work of prison scholar Lisa Guenther in *The Gift of the Other: Levinas and the Politics of Reproduction*. Reproductive justice perspectives implicate the pro-choice movement in thriving as a white feminist coalition that works to promote a eugenics project for poor women and Women of Colour by advocating for the expansion of contraceptive resources into ghettos and prisons in order to combat the "over-breeding" of "less-desired" bodies. INCITE! released a report in 2014 entitled "Dangerous Contraceptives" outlining the systematic lack of disclosing side-effects of contraceptives for the purposes of population control of vulnerable women. The report looks at inadequate policy regulations for contraceptive consent, particularly for "women of color, indigenous women, women with disabilities, and women on federal assistance," and the potential side effects that are routinely concealed from patients (INCITE! 5).

Looking to the work of both Andrea Pitts in her article "White Supremacy, Mass Incarceration, and Clinical Medicine: A Critical Analysis of U.S. Correctional Healthcare" and Mary P. Sutphen and Bridie Andrews in their book entitled *Medicine and Colonial Identity*, colonial medicine may be understood as a nation-building project contingent on gendered and raced practices of conquering and pacifying particular bodies through healthcare resources. Sutphen and Andrews understand colonial medicine as the state ownership over medical knowledge production and knowledge dissemination for the purposes of maintaining hegemonic imperialism. Particularly, the authors argue Western colonial medicine functions as a "knowledge system which increasingly claimed unique access to truth about the body, health and disease" (Sutphen and Andrews 15). In this sense, colonial medicine normalizes medical knowledge as exclusively accessible to experts in the healthcare field.

Looking to a historical account of Frantz Fanon's 1959 experiential physician report practicing in French-occupied colonial Algeria, Pitts theorizes colonial medicine as functioning through state ownership over medical knowledge production, as well as the systemic rejection of the racialized patient's subjectivity—or a reducing of the racialized subject to merely a body through the hostile patient/physician encounter ("White Supremacy" 8). In Fanon's experiences as a healthcare provider in mid-century colonial Algeria, white physicians systemically dehumanized Black Algerian patients by giving authority only to what could be visibly seen on the patient's body by delegitimizing any testimonial of lived experience. According to Pitts, the body, then, is assumed to "speak for itself" ("White Supremacy" 8). Black patients' articulation of their subjectivity, including the experience of pain, was routinely positioned as unreliable, disingenuous, or having no grounding in reality by the white physician" (Pitts, "White Supremacy" 8). Further, Pitts contests, "the experience of illness—the pains, discomforts, longings, and sensations—of the patient are eclipsed…The colonized patient's own lived experience of her/his body becomes irrelevant to the process of forming a medical diagnosis" ("White Supremacy" 8). Pitts concludes by attributing colonial medicine as disinterested in the healthy well-being of the colonial subject, but rather, invested in colonial domination ("White Supremacy" 15). Andrea Pitts' discussion of "the politics of knowledge" reinforces this analysis, describing the legacy of colonial medicine as thriving through avenues of state and institutional ownership over knowledge production. Through these strategies, as she names "the politics of knowledge," hegemonic structures are able to maintain control over the production and dissemination of medical information, under the guise of "expertise," which leaves individuals vulnerable to medical coercion—particularly People of Colour (Pitts, "White Supremacy" 8).

In another article entitled "Cruel and Unusual Care and Punishment: Epistemic Injustices in Correctional Health Care," Pitts discusses the concept of hermeneutical injustice as occurring "when a collective gap in knowledge unfairly deprives an individual of an ability to make sense of her/his own experiences" ("Cruel and Unusual Care" 6). Within a general colonial backdrop, Pitts discusses the kinds of epistemological discourses that emerge as natural truth but are, in fact, rooted in the assimilation, conquering and annihilation of the colonized body. Pitts argues that the history of Indigenous colonization by white settlers has been a history of distorting collective memory where white colonizers have reconfigured Indigenous understanding to believe that they not only relied on the colonizer, but that their "guidance" was necessary for survival ("Cruel and Unusual Care" 8).

Pitts notes that the collective empirical research on race and healthcare exposes a severe gap in the quality of the healthcare experience for People of Colour. Implicating particularly the poor patient/physician encounter, Pitts notes:

> there are provider-level factors that may be linked to the high rates of health disparities among well-meaning whites who are not overtly biased and who do not believe that they are prejudiced… [these individuals] demonstrate unconscious stereotyping that can be attributed to certain meta-level attitudes about a subject's lack of certain beliefs or sets of distorted beliefs at the object level. ("Cruel and Unusual Care" 9)

These authors collectively argue that not only is there a deterioration of the patient/physician encounter that extends to the macro-level to indicate a widespread systematic dysfunction, but this institutional prejudice is born in the rejection of racial subjectivity. In other words, there exists a systemic reduction of the racialized patient to merely a body void of personal subjectivity. This systemic reduction is reinforced, for example, in cases of pain management. Studies in clinical medicine find that cases of identical symptoms are often prescribed varying treatments based on the visible racial difference of patients. Physicians systematically rate Black patients lower than white patients on factors such as "intelligence, educational level, level of compliance, likelihood to abuse drugs and alcohol, and likelihood of follow-up with occupational and rehabilitational therapy" (Pitts, "Cruel and Unusual Care" 9). Further, discussing conceptualizations of pain, Pitts offers an example of empirical research that finds male physicians prescribe twice the amount of painkillers to white patients for pain management than Black patients ("Cruel and Unusual Care" 8). Therefore, pain as an embodied experience is neglected in the racialized patient because symptoms of this nature cannot be visually located on the body. Pain of this nature can only be articulated through describing one's own subjective experience and articulations of embodied subjectivity are contingent on believing the patient.

The work of Pitts, INCITE!, and Sutphen and Andrews lay the foundation for an understanding of colonial medicine and its implications for Women of Colour today. Research on the experiences of Women of Colour with hyperandrogenism is relatively nonexistent. We know that women with PCOS are at a higher risk than the rest of the population for mental health disorders such as depression, anxiety, and body-image distress (Greenwood et al.; Alur-Gupta et al., "Body-Image Distress"). We also know that PCOS affects Women of Colour more frequently and severely than white women (Engmann et al. 493.e1). However, hyperandrogenism does not exist in a vacuum, and its higher prevalence in Women of Colour appears to be connected to the population's higher comorbidity rates. For example, some studies have shown a significantly higher prevalence of metabolic syndrome in Black compared to white women with PCOS (Engmann et al. 493.e1; Hillman et al. 530). Further, studies have shown that Black women score lower in several PCOS Quality of Life survey domains than white women indicating the lower quality of life (Alur-Gupta et al., "OR25-2 Racial Differences"). Most of the research on Indigenous women with hyperandrogenism is brief, does not refer to women's experiences, and typically discusses PCOS in relation to the higher relevance of diabetes in Indigenous populations. For example, Wilson et al. discuss in their article "First Nations, Inuit, and Métis Women's Sexual and Reproductive Health" that Indigenous women have "Higher rates of obesity—a result of the transition to a more sedentary lifestyle, along with the heightened food insecurity and limited access to recreational facilities experienced by many Aboriginal women—may result in more women suffering from PCOS/metabolic syndrome, and this may negatively impact their ability to get pregnant" (S31). There is a critical need to research the experiences of Women of Colour who have hyperandrogenism to better understand the effects of the disease on mental and physical health.

Approaching a Theoretical Framework: Feminist New Materialism

This chapter has outlined the scholarly trajectory of relevant topics to my research including intersex bodies, illness narratives, and hypertext literature. What has been revealed in this Literature Review is an evident theoretical progression of these topics over time. Scholars examining illness narratives have typically turned to phenomenology to examine the lived experience of the patient. Scholars exploring norms, pathologization and intersex bodies who have come out of the linguistic turn have taken up these topics through the theoretical lens of poststructuralism. This sentiment is true for the first wave of hypertext theories as well. Further, I have explored perspectives of crip theory that form at the intersection of queer theory and critical disability theory. The whole of these perspectives contributes to novel ways of viewing the world that value the materiality of the body in relation to technology. I understand that the literature is bending towards the posthuman, however, I want to think critically about what it is about posthumanism that is meaningful and vital for this project. Posthumanism is expansive and cannot be mistaken for a monolith. There are subsects, streams, and various frameworks that work to silo posthumanism into workable components. Here, I will turn to a framework put forward by Matthew E. Gladden for understanding the distinctions between analytic, synthetic, theoretical, and practical posthumanisms. Gladden's approach sees various streams of posthumanism fastened onto a grid of four quadrants: theoretical versus analytical and practical versus synthetic. From here, I understand that my posthumanist framework needs to embody both the analytical in that it views "posthumanity as a sociotechnological reality already existing in the contemporary world" and theoretical in that its "purpose is primarily to expand the knowledge possessed by humanity" (Gladden 40). According to Gladden, residing in the theory-analysis quadrant opens up possibilities for many posthumanist streams, including critical posthumanism, cultural posthumanism, or neohumanism. However, more precisely, I know I require a posthumanist framework that considers, through a feminist lens, how the materiality of the body comes to shape experience. This led me to feminist new materialism (FNM).

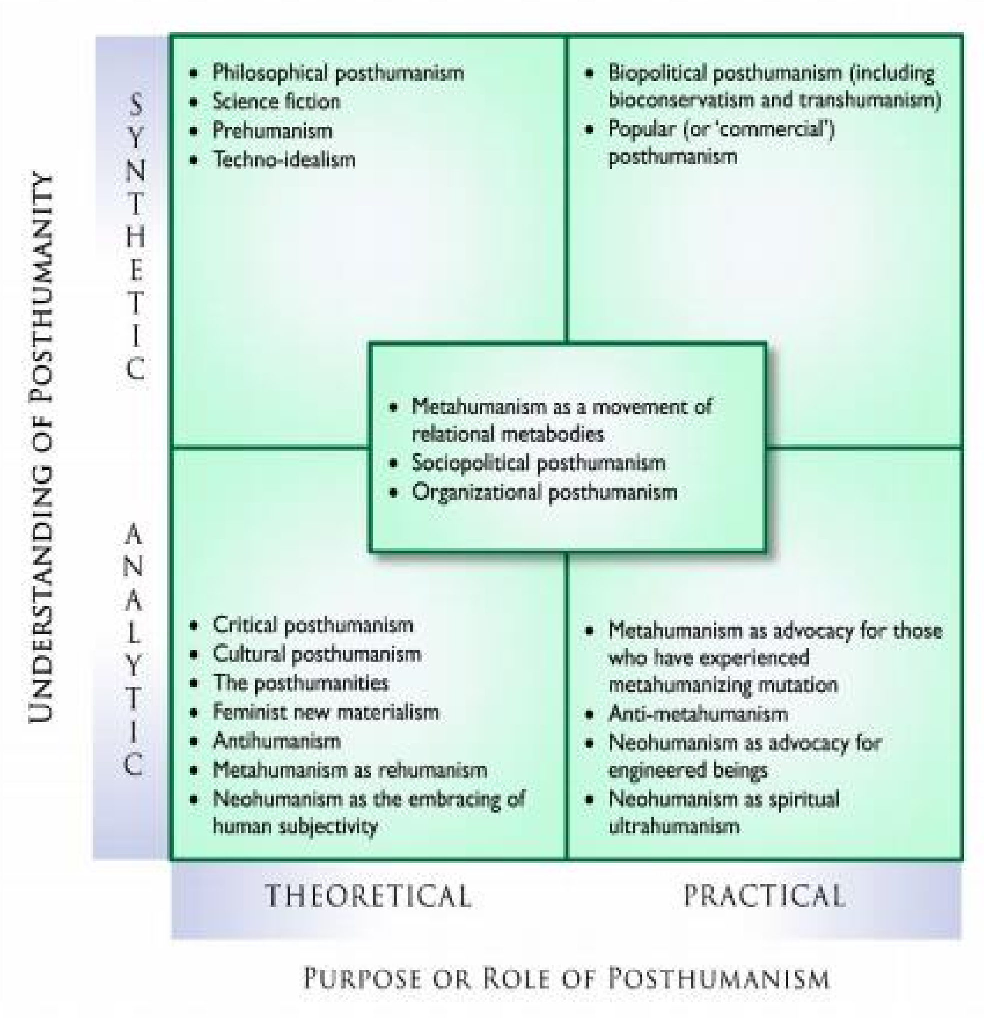


Fig. 1: Our proposed two-dimensional typology of posthumanism, which classifies a form of posthumanism based on whether it understands posthumanity as a sociotechnological reality already existing in the contemporary world ('analytic') or as a set of hypothetical future entities whose capacities differ from those of natural biological human beings ('synthetic') and whether its purpose is primarily to expand the knowledge possessed by humanity ('theoretical') or to produce some specific political, economic, social, cultural, or technological change within the world ('practical'). Classifications are suggested for numerous forms of posthumanism.

Fig. 9. Fig. 1 from Gladden, Matthew E. *Sapient Circuits and Digitalized Flesh: The Organization as Locus of Technological Posthumanization*, Defragmenter Media, 2018, pp. 40.

Feminist New Materialism is an expansive field of study that comes out of feminist science studies, environmental humanities, queer and affect theory, and the legacy of Gilles Deleuze and Félix Guattari's *A Thousand Plateaus*. FNM works with theories of the posthuman body in relation to ontology. According to Sarah E. Truman in "Feminist New Materialisms," FNM can be regarded as both a theoretical framework and a methodological approach, with the latter advocating for the direct implication of researchers in qualitative research, the challenging of positivism, and the recentring of non- and more-than-human agents (2). FNM challenges positivism, a philosophical system that regards truth as exclusively verified through natural phenomena, mathematics, and logic, by asserting that "thinking with" theoretical perspectives is a valid method of empirical research (Truman 2). Further, FNM is critical for my research and was chosen over similar methods of new materialism, for example, because of its centering of feminism. This kinship with feminism is a centering of the diverse experiences of marginalized identities. This is significant, as Truman argues, FNM engages in conversation with an array of fields including physics, science, and mathematics to explore the role of "more-than-human" agents (2). However, without foregrounding feminism in this work, there is a risk of reproducing a normative (white, male, cis, able-bodied, straight) subject.

FNM is a diverse discipline with contractions, inconsistencies, and divergence within the perspectives of its proponents. However, the foundational beliefs of FNM form a community of scholars that are attuned to exploring materiality and more-than-human subject formation. Notable scholars who have shaped the field of FNM include Karen Barad, Donna Haraway, Anne Marie Balsamo, Sadie Plant, Rosi Braidotti, Myra J. Hird, Jasbir Puar, Patricia Clough, and

Victoria Pitts-Taylor in their collective works in feminist science studies, cyborg theory, gender and cultural studies, and affect theory. FNM is in response to the "extra-discursive" perspectives on subject formation and calls for consideration of how matter comes to inform discursive experience. According to Kameron Sanzo in their 2018 article entitled "New Materialism(s)":

> The discourses catalogued under new materialism(s) share an agenda with posthumanism in that they seek a repositioning of the human among nonhuman actants, they question the stability of an individuated, liberal subject, and they advocate a critical materialist attention to the global, distributed influences of late capitalism and climate change. (para. 1)

What drew me to FNM theory is its turn to matter as a deeply vital reality. There is something important that the materiality of the body brings to our narratives and my project questions what that materiality means and how it goes on to shape both experience and discourse.

The field of FNM brings together a collective challenging of the seeming omnipotence of the linguistic turn that has dominated academia for decades and a call for both a decentering of humanism and a turn to affective materiality. FNM responds to humanistic perspectives of a Cartesian mind-body split and the ways in which this binary evokes similar binaries in response, including nature-culture, human-animal, and subject-object. This rejection of binary formations, for feminist new materialists, calls into question the ways in which the matter of "objects" has been taken up as passive. Vitality is a term employed heavily in the FNM theoretical movement, which speaks to matter's agency through its ability to enact relational affect on other forms of matter. As Truman notes, "These vitalist understandings of matter and the distributive nature of agency call up questions about causality, the nature of being, how phenomena interact and are produced, and responsibility: If agency and vitality are not restricted to humans but rather attributes of all matter, then the politics of collaboration and research ethics needs to be rethought" (4). The concept of the "new" inherent in FNM, according to Truman, is in response to a psychoanalytic form of Marxism that "views history, culture, and politics as ongoing material struggles rather than reified ideologies; these 'old' versions of materialism ground phenomena in human action and social construction" (2). FNM turns "back" to materialism in a novel way that does not start with a historical conceptualization, but rather, affective matter. Here is where the distinction between old and new materialism emerges. Truman notes, however, these frameworks should not be approached as in opposition to each other but working with both the "liveliness" of matter and the politics of subject formation.

FNM has emerged in response to the dominant philosophies of the linguistic turn, which was inclusive of both structuralism and poststructuralism. As shown through the trajectory of this Literature Review, my project draws heavily from theories that dominated poststructuralism, specifically the theory on intersex bodies. At first, these discourse-heavy theories appeared to be incongruent with FNM as a theoretical framework that emerged in response to the language-focused linguistic turn. Following further reading into FNM as an expansive movement, I now understand that although FNM is critical of poststructuralist dominance, I do not believe them to be mutually exclusive. In fact, the ways I employ FNM in this project about intersex bodies truly benefit from building off of poststructuralist beliefs rather than rejecting them outright. This is because poststructuralism offers ways to understand the discursively-constructed aspects of biological sex, whereas FNM centres the materiality of the body in relation to technology. Turman parallels this argument that the linguistic and material turns can work in relation to each other. Scholars of FNM have been misattributed to calling for an end to language as a significant entity of research, however, many proponents of FNM understand that language and discourse are material things. Feminist new materialists are critical of the ways in which poststructuralism has, at times, been taken up in scholarship in ways that reproduce binaries that they "purported to 'deconstruct,' such as nature and culture, language and materiality" (Truman 4). This is a significant insight because, as Truman argues, the seeming nature-culture binary generated through poststructuralism is actually a misreading of theorists such as Judith Butler, whose work has been incorrectly attributed to lacking a focus on materiality. In fact, FNM and poststructuralism similarly reject notions of the nature-culture binary as a proponent of representational logic. Truman argues:

> Epistemologically speaking, representationalism is the view that the only things people can know are representations of the world. Ontologically, this sets up a binary between distinct entities (that preexist and come to be known or experienced through representation) and the ontologically discreet knower. Furthermore, it sets up a binary between the representations of a thing, and whatever the thing is that's being represented. In representationalist logic separation is foundational. (4)

This is significant because it challenges a distinction between an ontological state of being and an epistemological state of knowing, arguing that to know and to be are relational.

Scholars such as Fausto-Sterling have adopted a FNM stance by emphasizing the deeply penetrable bodily difference of subjects, including the ways in which our cells react differently in varying environmental contexts (Sanzo). Identity and difference are as Sanzo suggests "products of complex interactions between matters inside and outside of bodies, and between the social and environmental conditions in which bodies exist." FNM looks to the affective turn to counter the seeming limitations of the linguistic turn's exclusive affinity to subject formation through discourse. Affect theory considers the relationality of bodies through unconscious means.

Through the work of Baruch Spinoza, affect has come to be understood by theorists as "the capacities of bodies to act or be acted upon by other bodies" (Truman 5). Affect theory holds roots in Deleuzian ontology and argues that, unlike emotion, affect is a prepersonal experience that lays the foundations for, but is independent of, signification, language, and representation. As Truman argues: "Affective capacities are coproduced through intensities, proximities, and viscosities circulating between, through, and transversal to individual bodies, but at the same time can also stick to particular bodies" (4). According to Turman, theories that incorporate affect tend to pay attention to how bodies relate and become rather than how bodies are. Some interpretations of affect theory that centre a prediscursive moment have, however, been challenged by queer, feminist, and critical disability scholars who argue that this perspective runs the risk of delegitimizing the affect of political forms of identity formation (Truman 4). Therefore, these scholars have prioritized finding ways to understand affect in relation to intersectionality. Assemblage theory emerged from this vantage point.

Through terms such as *assemblages* and *rhizomes*, FNM is concerned with the relationality between parts. In 2007 Karen Barad wrote *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning* where she put forward the concept of intra-action in response to interaction. Barad argues that intra-action is a signifier for mutually constituted agents that are in an entanglement with each other (*Meeting the Universe Halfway* 33). Truman notes that "rather than the term interaction (which suggests ontologically distinct individual agencies preceding interaction), phenomena are produced through intra-actions (specific material configurations of human, nonhuman, animal, material that do not preexist their relations)" (4). What is significant for my research in response to the concept of intra-action, is adopting Barad's claim that as a researcher, you are always already entangled in the process and outcomes of your research. Even through the act of observation you are actively intra-acting with and affecting other bodies of matter and this must be taken into account. Ultimately, for Barad, this means a way of "understanding the world from within and as part of it" (*Meeting the Universe Halfway* 88). This concept of intra-action of the researcher with the research is vital for my project which is applying a FNM theoretical framework. I am questioning the material realities of women and nonbinary individuals with hyperandrogenism, specifically how the body comes to interact with the digital-material, however, I understand it is critical to implicate myself in this analysis. Mainly, I wonder how I come to affect the data generated. How does my lived experience with hyperandrogenism come to shape the outcome of this research? Turning to a theoretical framework that pays attention to intra-action can open up understanding in this realm.

Assemblage Theory

In their book *A Thousand Plateaus*, Gilles Deleuze and Félix Guattari develop the ontological framework of assemblage theory. This theory argues that the "parts" that make up the whole of a body are not fixed, but rather, fluid, exchangeable, and entangled with "parts" of external bodies. Assemblage theory plays with assumptions of scale. For example, the theory challenges notions that "wholes" are singular, organic, or "pure" entities. Rather, "wholes" are made-up of individualized "parts" which intra-act with other, external "wholes". Assemblage theory came out of Deleuze and Guattari's work on dynamical systems theory which looks at how systems of material organize themselves. The scholars adapted this theory to include not only the material, but also linguistic, social and philosophical elements, to produce assemblage theory. Deleuze and Guattari use three intra-acting terms to work with the concept of assemblage: coding, stratification, and territorialization. These terms vary but are reliant on each other to function. As Daniel Smith and John Protevi explain in *The Stanford Encyclopedia of Philosophy*, "Coding is the process of ordering matter as it is drawn into a body; by contrast, stratification is the process of creating hierarchal bodies, while territorialization is the ordering of those bodies in 'assemblages,' that is to say, an emergent unity joining together heterogeneous bodies in a 'consistency.'" Deleuze and Guattari evoke the analogy of the constellation to explore these terms. A constellation is composed of an imaginative rendering that relies on the organization of matter in a particular order to create a body. This process of ordering to render the imaginative "reality" of the constellation is called coding. From here, Deleuze and Guattari argue that some "heavenly bodies" are included in our imagining of the constellation, and some are left out. This is dependent on where the stars are located, how close together they are, and how well they serve the larger project of rendering the constellation. This process of hierarchizing various bodies to form a territory is called stratification (Smith and Protevi). Territorialization, the final concept that completes the triad, is the process of organizing bodies in ways that create the larger assemblage. The process of territorialization can be of material bodies, such as humans and more-than-humans, or bodies of signification. Further, processes of deterritorialization and reterritorialization explore the ways in which parts become disconnected or reconnected to the larger body.

The conceptualization of Deleuze and Guattari's notion of assemblage theory is highly complex. It has been taken up in a myriad of disciplines including philosophy, political science, and, significant for this research, feminist new materialisms. In 2012, Jasbir K. Puar wrote the article "'I Would Rather be a Cyborg than a Goddess': Becoming-Intersectional in Assemblage Theory" which explores the use of assemblage theory through FNM and as a response to theories of intersectionality. For Puar, assemblages are important because:

> A. They de-privilege the human body as a discrete organic thing. As Haraway notes, the body does not end at the skin. We leave traces of our DNA everywhere we go, we live with other bodies within us, microbes and bacteria, we are enmeshed in forces, affects, energies, we are composites of information. B. Assemblages do not privilege bodies as human, nor as residing within a human/animal binary. Along with a de-exceptionalizing of human bodies, multiple forms of matter can be bodies – bodies of water, cities, institutions, and so on. Matter is an actor. ("'I Would Rather be a Cyborg than a Goddess'" 380)

This is a critical understanding of assemblages for my project on hyperandrogenism because it allows a shift in the conversation away from discussions of norms and performativity (which are important but dominant), to discussions about the biological mechanisms of the body. It allows me to ask questions such as: what is it like to feel hair growing on the surface of the face? What and how are bodily receptors *receiving* with the body's influx of pharmaceuticals? It also allows me to explore the ways in which the body intersects with hypertext technology in the process of narrative writing. These are methodological approaches that I explore further in the Methodology chapter.

Most significant for this project that assemblage theory offers is a way into a critical understanding of identity. As shown in the Screening Document of this project, the participant make-up is diverse and issues of race, sexuality, gender identity and ability must be accounted for. I spent a lot of time with the theory on FNM thinking about intersectionality - a framework I was originally intending to work with - and the ways in which it could offer tools to pay attention to identity politics in this work. The more research I was able to do, however, the more insight I found on employing assemblage theory over intersectionality. Puar argues that intersectionality has come to be understood as the first-line-approach for feminist theorizing of difference for the past thirty years. Intersectionality, spearheaded by Kimberlé Crenshaw in 1989, emerged from second-wave Black feminist thought that was challenging white-centric modes of approaching critical theory. Notably, Crenshaw used the analogy of the intersection of a traffic stop to explain how aspects of an individual's social and political identities, such as gender identity, class, sex, race, sexuality, and ability, intersect to create different modes of discrimination and privilege. Intersectionality, however, recently has been challenged by some scholars due to the framework's seeming reification of a standard, "neutral" identity in which all others become variants (Puar, "'I Would Rather be a Cyborg than a Goddess'" 371). Puar argues that as "transnational, postcolonial, and critical race theorists have pointed out, the centrality of the subject positioning of white women has been re-secured through the way in which intersectionality has been deployed" ("'I Would Rather be a Cyborg than a Goddess'" 373). Puar, then, calls for a queer assemblage framework to supplement the short-comings of intersectionality, as not oppositional but "frictional" to each other ("'I Would Rather be a Cyborg than a Goddess'" 372).

Feminist scholars of new materialism, such as Donna Haraway, Elizabeth Grosz, and Karan Barad, have argued that intersectionality is a "gridlock model" (Puar, "'I Would Rather be a Cyborg than a Goddess'" 56) that fails to embody the structures to account for nonrepresentational matter as unstable assemblages "that cannot be seamlessly disaggregated into identity formations" (Puar, "'I Would Rather be a Cyborg than a Goddess'" 56). In Donna Haraway's prolific 1985 essay "A Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late Twentieth Century," she concludes her analysis by proclaiming that she would rather be a cyborg than a goddess. This analogy, according to Puar, is Haraway's claiming of a postmodern more-than-human body by rejecting the historized and racialized body, which produces a distinction between assemblages and intersectionality ("'I Would Rather be a Cyborg than a Goddess'" 57). Many scholars have challenged Haraway's use of a racialized monarch to foil the posthuman body, suggesting that a declaration of desiring the posthuman body is an avoidance of theorizing race relations. Puar argues that this is a significant critique, however, it bypasses that linguistic performativity assumes that all meaning is confined to language ("'I Would Rather be a Cyborg than a Goddess'" 57-58). Ultimately, the distinctions between intersectionality and assemblage theory are rooted in a divergence in the conceptualization of identity. For intersectionality, experience is produced through the intersection of multiple identity parts in the subject. These identities can be "pulled out" and analyzed in how they relate to the sociopolitical experience. Assemblages, on the other hand, allow for the evolution, subtraction, and addition of identities. These identities cannot be "pulled out" to examine their relationships, nor do they hold individualized meaning. Unlike intersectionality, meaning is found in the assemblage. Ultimately, my choice for turning to assemblage theory over intersectionality is critical for this project because it affords a way to conceive of agency. Where intersectionality might view identity as a collection of predetermined parts that everyone is a combination of, assemblages account for "things" outside the body to compose identity.

Chapter Review

In this chapter, I have explored the relevant literature that shapes the theoretical progression of my project. This chapter begins by outlining my methodological process of the literature review by detailing the Twine database that I build for this purpose. I summarize the outcomes of a workshop I facilitated in September of 2020 called "Getting Started in Digital Humanities: Digital Humanities Initiative 2020 Workshop." The workshop was entitled

“Twinery.org: Building Literary Hypertexts” and detailed the novel capabilities of literary hypertext technology including as a theoretical mind mapping tool. I outline the ways in which I mapped my theoretical texts in relation to a set of thematic terms. Finally, I detail how this database revealed the theoretical trajectory of my project.

I begin the exploration of theory related to my project by looking at the history of hypertext theory over the years, paying attention to the ways in which scholars have positioned hypertext’s potentiality as a liberating medium of narrativity. Particularly, the newest wave of hypertext theory claims the emancipatory potential of hypertext is subtler than previously theorized, but nevertheless present and strengthened by writing that is informed by immersive, adaptable and user-friendly practices. Ultimately, the third wave is turning towards the experiences of hypertext readers. Here is where I conclude the need for scholarship that is interested in exploring the experiences of hypertext writers.

I then detail the field of literature on illness narratives. I explore the typical ways in which illness narratives have been classified by scholars such as Hawkins, Couser and Frank. Next, I turn to phenomenology and look at how this theoretical framework has come to shape decades of perspectives on the discipline of illness narratives. I discuss the field of medical humanities and the methodological frameworks for phenomenology that are widely drawn from two variances in ontological positioning: Edmund Husserl’s transcendental approach versus Martin Heidegger’s hermeneutic approach. Finally, I detail how phenomenology’s affinity with experience as the site of knowledge has been challenged by proponents of feminist poststructuralism.

Next, I turn to integral theory from the linguistic turn in relation to critical approaches to discourse, norms, and intersex bodies. I begin by outlining Georges Canguilhem’s distinctions between the notion of the *normal* and the *pathological*. Then, I explore notions of the pathological in relation to Foucault's work on docile bodies and deviant sexuality. Finally, I put pathologization in conversation with intersex bodies by turning to the work of Judith Butler in relation to abject bodies. I end this section by noting the recent scholarly turn to the posthuman as a counter to poststructuralism's heavy emphasis on language.

I explore, in the next section, relevant scholarship on crip theory in conversation with colonial medicine. The history of disability is deeply tied to the experience of hyperandrogenism as an "abject" body. For my research, crip theory opens up questions about what role hyperandrogenism plays in our future. When thinking about the progression of medical science, disability and hyperandrogenism are tied together as bodies at risk of being erased. I end this section by outlining Andrea Pitts' work on colonial medicine and its relevance to this project, particularly when considering the high rates of PCOS for Women of Colour as well as the eugenic history of the oral contraceptive pill (the first line of treatment for PCOS).

In my last section, I outline my theoretical framework of feminist new materialism. I understand that my project draws heavily from theories of poststructuralism, specifically theory on intersex bodies. Theories of the language-focused linguistic turn appeared at first to be incongruent with FNM as a theoretical framework. However, following further reading on the different ways FNM has been taken up, I now understand that although FNM is critical of poststructuralist dominance, I do not believe them to be mutually exclusive. I employ FNM in this project in ways that benefit from poststructuralist beliefs, particularly when thinking about abject and intersex bodies. Poststructuralism informs a FNM framework by offering ways to understand the discursively-constructed aspects of biological sex, where FNM centres the materiality of the body in relation to technology. I end this section by turning to assemblage theory instead of intersectionality by exploring how the former offers ways to discuss the biological mechanisms of the body in relation to technological narrativity.

Chapter III: Methodology

Introduction

When thinking about my research and the possibilities of approaching a distinct methodology, I am consistently drawn back to a 1988 quote from Michel Foucault that he gave in an interview with a graduate student named Michael Bess. The quote is as follows:

> What I am trying to do is to approach this extremely important and tangled phenomenon in our society, the exercise of power, with the most reflective, and I would say prudent attitude. Prudent in my analysis, in the moral and theoretical postulates, I use: I try to figure out what's at stake. But to question the relations of power in the most scrupulous and attentive manner possible, looking into all the domains of its exercise, that's not the same thing as constructing a mythology of power as the beast of the apocalypse. ("Power, Moral Values, and the Intellectual" 11)

As I began the task of building a methodological framework for my project, I found it helpful to turn to guidance from these two sentiments: first, to approach the workings of power in my own research with prudence, rather than hastily assembling the narrative of the "beast of the apocalypse," and secondly, I want to continue to question what is at stake. It has been too easy in this project to build a clean narrative of power where an abstract caricature of the medical institution becomes a top-down, oppressive force that steals agency from the patient effectively rendering them an object. When Foucault discusses the "mythology of power as the beast of the apocalypse," however, I think he is referring to the ways in which analysis of power relations can easily slip into value judgments enclosed within structuralist categories. When we tell a story that the medical institution is a sovereign, oppressive force that has a singular desire to "cure" bodies at the expense of patient agency, it becomes a generative form of discursive knowledge production. This knowledge argues particular truths such as the medical institution is a monolith with a singular purpose or the patient with hyperandrogenism had agency before the medical encounter. When Foucault questions what is at stake, it invites space to question what is lost in a narrative framing such as this one.

Through a top-down power method of analysis, there is no language to understand the medical institution in relation to pockets of resistance or understand ourselves as actors that can uphold pillars of knowledge. In contrast, when power is understood as pervasive and dispersed amongst many forces rather than wielded by a uniform structure, there is better positioning to see the mechanisms that pull truth into existence. This is important because, in a top-down power narrative, the reformation of the medical institution would produce pure equity on all fronts. This reformation, though, fails to address our collectively accepted models of truth that produce knowledge on pathology. In Foucault's understanding of power, the medical institution is a participatory agent in a network of discourse rather than the sole impetus.

Foucault's framework of discourse is imperative for this project as it allows space for a more generative analysis of how hyperandrogenism is discursively produced as an identity category. Further, this understanding does not take away from the majority of the theoretical underpinnings of illness narratives, narrative therapy, and medical/health humanities discussed in previous chapters, or the experiences of individuals with hyperandrogenism in this study who share stories of harmful and dehumanizing subjugation in the medical encounter. Generative discourse actually works to legitimize these perspectives because it highlights subjugation as a method of our collective understanding of what illness is and how we should respond to it as a community.

Critical Discourse Analysis for Digital-Born Narratives

Foucault's approach to discourse analysis is difficult to grasp as he resists providing a clear guide for application. However, he does flesh out how this methodological approach can be conducted through a plethora of his own analyses, and this has become the foundation of a formal critical discourse analysis (CDA). As I worked to apply a CDA methodology to my own research, it became clear that this framework is robust but, at the same time, lacking in *something*. That *something* is related to the corpus of my research, which by nature is discursive, however, it zeros in on nuances that seem to evade capture from a typical CDA. These discursive nuances include narrativity, how discourse becomes materialized or embodied, and elements of the digital practice including code. From here, I wondered what the scholarly field had to offer that might incorporate a CDA approach with narrativity in the digital space.

In this pursuit, I have become aware of a distinct gap in the literature on a CDA methodology that would be appropriate for my research. The data that I will be working with for my research requires a CDA methodology that can examine how narrativity creates meaning through digital technology. Therefore, in this chapter, I detail the development of my own critical discourse analysis for digital-born narrative (CDADN). CDADN amalgamates important aspects of CDA with some aspects of narrative analysis, digital discourse analysis, critical code studies, and feminist new materialist theory, to produce a methodology that examines the discursive power dynamics and materiality of narratives online. This CDADN adopts a macro-social meaning of 'narrative' defined by Ruth Page in her 2018 book *Narratives Online* as "not specific, verbal accounts of a particular set of events, but rather a general way of describing events or patterns of social-cultural behavior" (5-6). This is an important distinction as Page's definition allows for a honing of the concept of digital narratives as a network that includes all variations of my research data. My research data includes not only the Twine narratives participants have submitted, but interview transcripts, screenshots of the visual interface of the Twines, code, images included in the Twines, and hypertexts. These differing forms of data fail to be comprehensively captured in Page's definition of narrative, however, they become extensions or components of digital narrative and therefore, I argue, can be captured in a methodological analysis of digital-born narratives, in this way. In other words, CDADN is a methodology that centres digital-born narratives at the root of the corpus but invites differing forms of data that may emerge to be analyzed in relation to the narrative.

In order to establish the foundation of a CDADN methodology, I turn to Carla Willig's work on applying six stages of a Foucauldian CDA in *Introducing Qualitative Research in Psychology*. To supplement this approach, I adopt aspects of Mariana Souto-Manning's work developing critical narrative analysis, Crispin Thurlow's research on computer-mediated communication, Mark C. Marino's foundational work on critical code studies, and Sarah E. Truman's feminist new materialist approach to qualitative research. I pull in useful aspects of each of these frameworks to extend Rodney H. Jones, Alice Chik, and Christoph A. Hafner's four-step methodology for discourse analysis in *Discourse and Digital Practices* to create a framework that has the capacity, through extended parameters, to analyze discursive power relations and materiality in specific data: digital-born narratives.

Jones et al. in *Discourse and Digital Practices* offer four distinct levels of analysis for a working digital discourse analysis. The authors call the first stage of discourse analysis *Texts* in which analysts must pay attention to the nuance of "texture" (8). The texture of the digital text may include looking at intertextuality through hypertexts and references, multimodality including the use of emojis or pictures, or dialogic referring to the dialectical nature of online content. For example, in examining online blogs we must consider how the original post is being commented on, linked to, or re-posted. The second stage considers *Context*, not only in a sociohistorical sense but also in the ways in which digital technologies allow for, what Jones et al. call, the “layering” of offline and online spaces (14). In this sense, the relevance of the discourse in a certain temporal and spatial moment expands to include ideologies, events, and technologies circulating the discourse both online and in the “real” world. *Actions and Interactions*, the third stage, looks at how digital technology is used to ignite social action. Authors can utilize and adapt digital tools for various purposes and intentions. Therefore, it becomes important to consider how technology is adapted and for what purpose. The final stage of Jones et al.’s approach to digital discourse analysis questions the workings of *Ideology and Power* in the digital space. This four-step approach to digital discourse analysis was chosen as a framework to build on for CDADN because it centers the ways in which digital practices shape and are shaped in their relationality with power, a critical perspective of this research project. However, Jones et al.’s framework is lacking in a distinct foregrounding of novel aspects of this research including the impact of code, materiality, and narratology. Therefore, helpful aspects of the methodological work of the scholars mentioned above have been moulded into Jones et al.’s four-step framework for digital discourse analysis to form CDADN.

Carla Willig in *Introducing Qualitative Research in Psychology* describes a six-stage approach to conducting a Foucauldian discourse analysis (FDA). According to Willig, FDA is “concerned with language and its role in the constitution of social and psychological life” (130). Employing a Foucauldian approach to discourse analysis, according to Willig, means broadening the parameters in which the immediate context of communicative language may be defined to include meaning as a whole. Discourse, in this sense, encapsulates the process of knowledge production while FDA questions how the boundaries of what can be known are established. Willig suggests a six-stage guideline for conducting FDA that centres discursive formation, actors/action, and subjectivity. Willig's process was chosen to inform the development of CDADN because it offers a concrete way into conducting a Foucauldian-influenced discourse analysis which is a pillar of my theoretical framework on gender and identity.

Mariana Souto-Manning in her article "Critical narrative analysis: the interplay of critical discourse and narrative analyses" argues that there is a distinct lacking in CDA to consider the unique influence of personal narratives to both shape and be shaped by our sociocultural reality. A critical narrative analysis (CNA) deconstructs how "everyday narratives as a genre offer institutional discourses an effective way to assert themselves as power discourses. Therefore, "CNA allows us to learn how people create their selves in constant social interactions" (Souto-Manning 162). What CNA does, that narrative analysis and CDA cannot do alone, according to Souto-Manning, is enact praxis. CNA opens space for individuals to challenge and problematize how larger institutional discourses come to shape their stories, and ultimately take action. As Souto-Manning argues: "Praxically, the goal of CNA is to foster critically meta-aware individuals who question institutional discourses as opposed to uncritically embracing and being colonized by such discourses. Thus, in terms of praxis, CNA offers immediate lifeworld implications" (177). Exploring the impact of narrativity through CNA pays particular attention to abstractness and intertextuality that is inherent to story worlds. Intertextuality, Souto-Manning explains, is the tendency for narrative to imbed other stories, contexts, events, and references within its story world. The significance of a methodology to consider narrative intertextuality supports the nature of literary hypertext as well. Souto-Manning's focus on centering narrativity in relation to discourse analysis will supplement CDADN as a method to understand digital stories.

Digital discourse studies is a scholarly discipline that has experienced tremendous growth in the past decade. Described by Crispin Thurlow as a "world of research that attends primarily to linguistic, sociolinguistic and discursive phenomena in new/social media" ("Digital Discourse" 2), digital discourse studies is situated within the wider field referred to as computer mediated communication (CMC). Pioneered by scholars such as Susan Herring and Naomi S. Baron, CMC was grounded in a linguistics approach to analyzing new media language through structure, meaning, interaction, and social function (Thurlow "Digital Discourse" 2). Later, the field of CMC expanded to include critical analysis beyond linguistic functions such as sociopolitical context, the relationship between online and offline factors, and social meanings of technology. As Thurlow argues, there was a "need to move beyond an undue emphasis on the linguistic and orthographic features of digital media language, shifting towards more ethnographically-grounded user-related approaches" ("Digital Discourse" 2-3). Striving towards expansion, scholars of CMC moved beyond an isolated analysis of the "formal" features of new media language, to consider more critically situated practice ("Digital Discourse" 3). CMC experienced a paradigm shift from a closed analysis of what the media looks like, to considering how the media is used, what meanings it creates, and what contextual circumstances it exists within.

The shift in CMC from a distinctly linguistic approach to a framework bolstered by heavily contextual, discursive, and communicative analysis set the scene for the development of digital discourse analysis. Today, digital discourse studies is a highly interdisciplinary field situated in the legacy of CMC and therefore holds an affinity with CMC's new discursive approach. The development of a CDADN methodology is directly informed by the practices of digital discourse analysis described above. Due to the nature of this project's corpus (digital-born illness narratives), it is critical for a methodology to not only utilize the analytical approaches put forward by a digital discourse analysis framework but also consider how this framework can benefit from both narrative analysis and CDA influences.

Relying mainly on discourse analysis to analyze the data of this project leaves out a small, but critical, section of my corpus: the code choices of participants in their Twine stories. Rather than a fully-fledged programming language, Twine is a type of straightforward mark-up that can be enhanced with variables, conditional logic, images, CSS, and JavaScript. Twine aspects that this project considers as code include terms participants choose to hypertext and how they alter the appearance of their Twines with font, colour and alignment choices. These were the basic programming elements introduced in the Twine module for participants to explore. I am turning towards a basic understanding of critical code studies to inform my discourse analysis to account for these code choices.

Critical code studies, an emerging field pioneered by scholars and practitioners Mark C. Marino, Rita Raley, Nick Montfort and John Cayley, is the interpretation of the significance of computer source code beyond its functionality. It is a call to read code critically for insight into not only how it functions, but what it means in a cultural sense. Marino argues "We had to get past the understanding of code as meaningless math (also, as it turns out, a false conception) and instead approach it as a culturally situated sign system full of denotations and connotations, rendered meaningful by its many and diverse readers, both human and machinic" (19). When we read lines of code, we have to approach the analysis with an understanding that this language is not value-neutral, but in fact, mediated culturally, socially, and politically. Marino described his path into thinking about computer source code through a critical lens when he was attempting to analyze conversation agents, or chatbots, through media-specific analysis. He soon realized something was not clicking and wondered "What made analyzing them different from analyzing other digital or print objects? Soon it became obvious: the code" (Marino 18). There was something about what the computer code signified, that was unable to be captured through his media-specific analysis, and here he began developing a methodology to analyze this data appropriately.

Mark C. Marino's guiding questions for qualitative research in his 2020 book *Critical Code Studies* are an imperative addition to CDADN because they offer a way into analyzing both the underlying code of the Twine software and the code choices participants may have embedded into their stories. Although the coding languages and commands incorporated by my participants were relatively rudimentary (mainly in the CSS language and used to alter the aesthetic appearance of the Twine), these code choices made by the authors altered the narrative meaning and nuance of the stories but failed to be captured by a standard discourse analysis methodology. By incorporating Marino's guiding principles that consider the critical aspects of code into my own methodology, I have found a path to analyze the contextual undercurrents that code choices produce in relation to digital narratives.

When I began conceptualizing my theoretical framework for this project and settled on feminist new materialisms, I had some trouble attempting to reconcile the theory's seemingly capricious relationship with discourse. Feminist new materialism, as both a methodological and theoretical framework, challenges the centering of humanism and recognizes agency in matter. As described in the Literature Review, I came to a place of understanding that feminist new materialism, or the facet that I employ in this project, builds on work done in the linguistic turn while it works with discursive phenomena. This became important because I knew I would have to employ a form of discourse analysis methodology to analyze my corpus because of the narrative component of this research. However, I wondered how to incorporate feminist new materialist theory into a discourse analysis.

Here, I turn to Sarah E. Truman's 2019 article "Feminist New Materialisms" in *The SAGE Encyclopedia of Research Methods* to engage a feminist new materialist informed discourse analysis. Truman turns to an understanding of feminist new materialism as an approach to qualitative research. This framework has enriched the methodology of this project by bringing to the forefront consideration of matter, more-than-human agents, and the fallacy of research neutrality. Incorporating Truman's guiding questions offers this research space to think with theory, while also centering the research process in analysis. Other methodologies that I am drawing from hone in more rigorously on content analysis of the corpus, however, a feminist new materialist approach offers a method to think about my position as the researcher, the ethical considerations of working with marginalized participants, and a responsibility to the networks and affects created in the process of this research. Taken together, CDADN is a medley of a methodological approach that is tailored to digital-born narratives and a customized framework for this project.

What Approaches Have Been Taken Before CDADN?

There are existent methodologies that have laid the groundwork for digital-born narratives already. Bronwen Thomas' *Literature and Social Media*, for example, looks at how participatory practices of social media can work to produce and disseminate radically new forms of literature. Ruth Page's pivotal mediated narrative analysis is designed for analyzing shared stories online. Methodological approaches such as these are effective for some forms of digital-born narratives, however, they are not perfect matches for my corpus and this led me to develop my own specialized approach. These past methodological approaches intend to capture the nuances of collaborative authorship and user intervention through online public networks (Page 12). Page, for example, questions what it means to share our stories on social media and considers how stories shift, grow, or morph once they become publicly consumed. Page argues, "interpretation of sharing as a social practice cannot be approached without recourse to the first two: the narrative representation and its multilayered, mediated, interactional contexts" (28). Thomas, similarly, discusses the emergence of electronic literature in the context of "fans, participatory cultures and transmedia storytelling," (32) placing a strong emphasis on the idea that the meaning-making processes of digital-born narratives are created in community consumption. Although narrative representation and some aspects of mediation are critical for my research, the literary hypertext narratives in this study exist in relative isolation from online engagement. For ethical considerations, stories were not uploaded to an online space to be engaged with by the public. Participants did contribute their stories to a secure folder for other participants to read, however, this community-building practice was not a formal aspect of the study. Additionally, there were no opportunities for participants to post comments about other stories or engage in other social media practices. The participant's Twine stories are digital-born, but they do not live in a public online space where they can be shared, read, and interacted with in the ways mediated narrative analysis requires. Therefore, this research will build on the foundation of pioneering forms of narrative analysis yet will hone in on the unique characteristics present in my corpus.

A body of methodological tools exists in the field of hypertext fiction, including Marie-Laure Ryan's 1991 model of possible worlds theory (PWT). Alice Bell argues, that an "ontological focus is particularly useful because it can be used to systematically map the ontological relationship between the reader and the hypertext in the real world and the fictional agents, such as characters and narrators, in the fictional world" ("Ontological Boundaries" 69). In her chapter "Digital Fictionality: Possible Worlds Theory, Ontology, and hypertexts," Bell uses PWT to create a methodological approach to analyzing the "ontological function" of hypertexts in digital fictions (*Possible Worlds Theory and Contemporary Narratology* 249). She argues that rather than thinking about fiction as abstract or purely philosophical, she intends to frame possible worlds theory "as a transmedial approach to fiction, fictionality, individual fictional texts, and, in this case, digital fiction" (*Possible Worlds Theory and Contemporary Narratology* 249). Although PWT could offer a valuable interpretation of various narrative paths written by the participants in this project, Bell's methodology is grounded in fictional narrativity found in canonical hypertext fictions like Joyce's *afternoon*, Moulthrop's *Victory Garden* and Jackson's *Patchwork Girl.* Illness narratives, in turn, may take on fictional aspects, however, they are generally described as autobiographical nonfiction of the author's experience with illness. The CDA for digital-born narrative methodology I employ must be able to adapt to fluid genre categories with a particular focus on autobiographical nonfiction narrative. I do extend PWT to fit as a framework to explore nonfiction illness narratives in a 2022 article for *Digital Creativity* called "The Possibilities of Illness Narratives in Virtual Reality for Bodies at the Margins." However, this approach engages with possible worlds created through storytelling in the virtual environment. Further, I require a methodological approach that can adapt beyond the narrative to analyze other forms of data in the study, mainly participant interviews.

What is Discourse in CDADN?

Despite an abundance of work on the systemic workings of discourse, Foucault seems to resist providing a conclusive definition of the term. In the *Archaeology of Knowledge*, for example, he describes discourse as "the general domain of all statements, sometimes as an individualizable group of statements, and sometimes as a regulated practice that accounts for a number of statements" (80). Sara Mills in her book *Michel Foucault* clarifies that this general domain includes all articulated expressions and statements of meaning which create an effect. Discourse, here, for example, would include illness narratives in the digital space in accordance with the ways in which these utterances are meaningful and impactful. Foucault at times has classified discourse as groupings of statements as well-meaning an assemblage of rhetoric in thematic ways. Finally, Foucault has identified discourse to encompass the implicit rules of social order which produce certain statements and perspectives.

These implied, presuppositional operating systems allow for the domination of institutional taxonomies of power through collective compliance. For example, we understand that we are ill when our bodies are displaying signifiers that destabilize that which has been accepted as normal: feeling pain, the emergence of lesions, or the experience of changes in our secondary sex characteristics. We may then visit a healthcare facility when we believe we are ill and submit our bodies to various exams or procedures. Then our bodies either return to a state of "normalcy," or we perhaps may take on a new identity of "ill person" – to reside in the "kingdom of the sick" (Sontag 3). A key question driving this research is what kind of processes of normalization are at play in this illness experience. To examine this question, I turn to Mills' consolidation of Foucault's continuum of definitions for discourse as "a regulated set of statements which combine with others in predictable ways. Discourse is regulated by a set of rules which lead to the distribution and circulation of certain utterances and statements" (54). For Foucault, a discourse is mediated through constant contact with forces of permittance/hindrance. Mills uses the example of the Bible as a discourse to explain how other, diverging discourses become stifled (54). As a widely distributed, printed, cited, and studied religious text, the contents of the Bible have prevailed over time to become the foundations of many pillars of truth in various cultures.

The Bible's proliferation has occurred parallel to the stifling of other, diverging and unknown religious texts. The reasons for and methods of the Bible's ideological impact and widespread institutional authorization are active structurings of a discursive field. If we identify as an Atheist and behave in accordance with a set of values that we understand to be non-religious - these values are, in fact, shaped in relation to how we know religion. Our individual, cultural and institutional understandings of truth - how we understand ourselves, our bodies, our relationships with others, nature, etc. - are formed in response both to the embrace or rejection of the Bible's theology. What is significant when dealing with the notion of Foucault's discourse is the rooting of the term in its contingency to power. As Foucault discusses in "The Order of Discourse" we must question the mechanisms that facilitate the upholding and circulation of certain discourses over others. Whose ideas and utterances are propelled in the societal "meaning-making" machine and whose are cast away into the void? How do institutional hegemonies produce and reproduce these same perspectives? How do we all participate in this cyclical dissemination?

Foucault calls on us to consider discourse as distinct from duplication of reality. Discourse is not an avenue through which reality becomes visible and knowable to us, but rather an apparatus that works to organize a reality as it appears (Mills 55). Foucault argues:

> We must not imagine that the world turns towards us a legible face which we would only have to decipher; the world is not the accomplice of our knowledge; there is no prediscursive providence which disposes the world in our favour…we must conceive of discourse as a violence which we do to things, or in any case as a practice which we impose on them; and it is in this practice that the events of discourse find the principle of their regularity. ("The Order of Discourse" 67)

This "violence which we do to things" is complex. For example, hyperandrogenism is actually one of many disorders that affect the hormonal nuances of the human body. Beyond endocrinological, there are also many distinct classifications for "diseases" which mark the human sex chromosomes – all of which work to call into question the biological sex of a patient. Klinefelter Syndrome is a disorder which causes an extra X chromosome in males (XXY), Trisomy X causes an additional X chromosome in females (XXX), and XYY Syndrome embodies its namesake. Disorders such as these (which include recorded instances that reach as high as an assortment of five X and Y chromosomes) are not wholly unheard of and many times go undiagnosed due to the absence of symptoms (Nussbaum 76; 107). A central framing of this research is grappling with how discourses of institutional medical regimes and social positioning work to manifest a dichotomy of biological sex, and further, how this becomes part of an agenda of normalization to pathologize instances of deviation. In this sense, we work as an efficient and effective collective to generate the reality which we know: the existence of trans, female and male bodies. Foucault acknowledges that it is difficult, perhaps even undoable, to think outside of the discourses in which we enact.

Clarifying a Stream of Critical Discourse Analysis for CDADN

In 1989 CDA was first developed by sociolinguist Norman Fairclough, informed by Foucault’s work on discourse, society, and power. In *Language and Power*, Fairclough argues that a comprehensive CDA will examine the use of language as a site of both social power and ideology. It is significant, here, because of my heavy reliance on the perspectives of Foucault, to distinguish between CDA and Foucauldian discourse analysis (FDA). CDA appears to encompass more broadly methodological approaches to examining discourse and power, whereas FDA is a form of CDA that more systematically and theoretically looks to the perspectives of Foucault rather than a heavy linguistic analysis. CDA has various subdivisions, including the discourse historical approach of Ruth Wodak, the sociocognitive approach of Teun van Dijk, and the textually oriented discourse analysis of Norman Fairclough (Lennon). My approach to CDA will amalgamate portions of most of these streams, yet, most significantly, be guided by the distinctive perspectives of Foucault (examining how discourse works to pathologize deviant identities, how disease is not ahistorical but contingent on our sociopolitical landscape, and how institutional discourse works to organize bodies into relations of power). Therefore, throughout this chapter and beyond, my use of the term Foucauldian CDA encapsulates a refined stream of CDA.

Turning to an example, Reisa Klein shows in her article “Networked Scars: Tattooed Bodies after Breast Cancer” how Foucauldian CDA can be operationalized as a mode to evaluate the ways in which “biopolitics” (Foucault, “A Birth of a Biopolitics”) shapes the writing and bodies of women with breast cancer. Klein skillfully plays with the notion of competing discourses: the stigmatization of disfigured bodies, the masculinization of tattoo culture, notions of self-care, community and empowerment, and the masking of surgery scars in accordance with normative femininity (3). Her research pulls writing from a corpus of women's health websites and groups the rhetoric in thematic ways, paying particular attention to what types of assemblages are constituted amongst these discourses. In practice, she identifies the following quote from the Canadian Breast Cancer Foundation website:

> Once your breasts have been reconstructed, it is possible to undergo a procedure to reconstruct a nipple. A new nipple can be formed from a bit of skin from the breast or another part of the body. A tattoo procedure can be used to darken the reconstructed nipple and areola. The new nipple(s) will not have the sensation of a natural nipple. (qtd. in Klein 15)

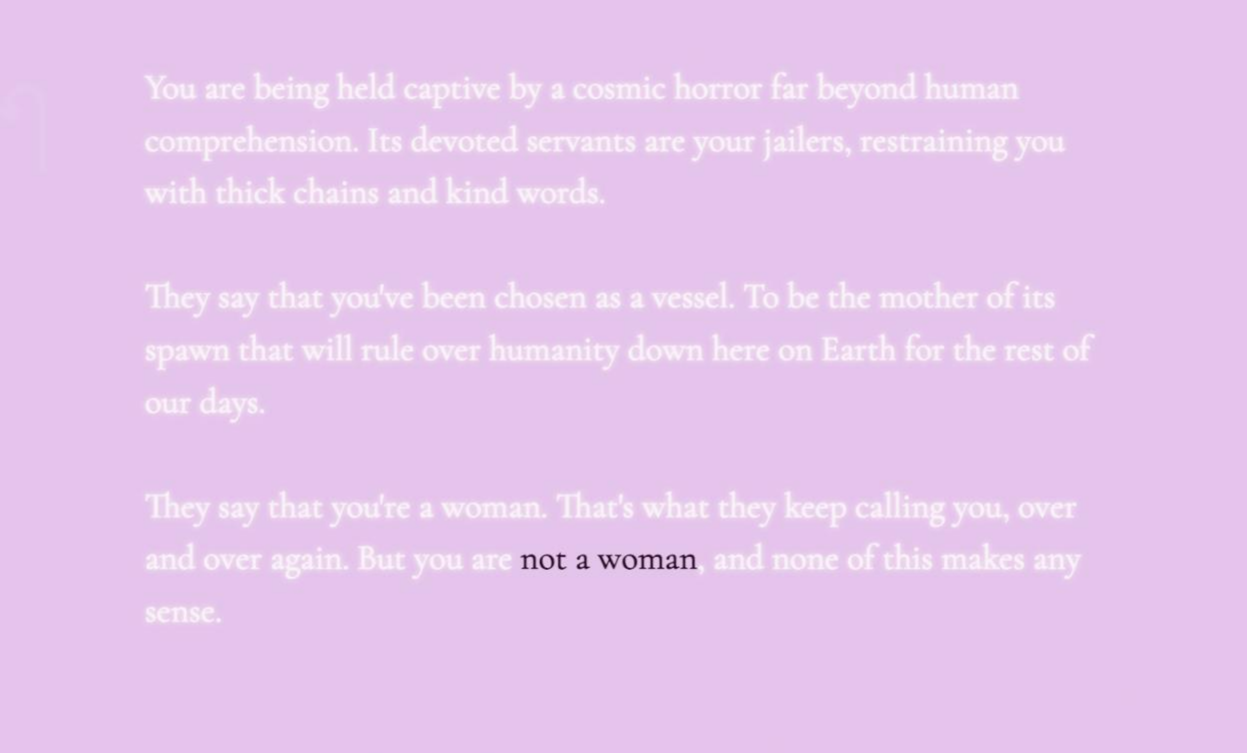
In the process of pulling apart the discursive arrangements in this statement, Klein concludes that the intent of information is to frame reconstructive surgery as the only viable option following a mastectomy (16). From here, Klein identifies that this sentiment, asserted by a media source that holds relative authoritative prestige is indeed mirroring larger, institutional discourses of the medical institution. These discourses, in this case, abide by a heteronormative and sexist "normalization" agenda of the female body (16). The "power-knowledge nexus" (Given 3), here, conceives of and mandates the reality of the breast cancer experience. We understand that in order to return to the "kingdom of the well" (Sontag 3), we must not only rid our bodies of cancerous cells but also expel any bodily signifiers of abnormality.

In order to establish a workable way to conduct a Foucauldian CDA beyond abstract theorizing, I turn to Lisa Given in the 2008 *SAGE Encyclopedia of Qualitative Research Methods*. According to Given, what is imperative in the process of making a Foucauldian CDA operational is attending to the "power-knowledge nexus" (Given 3). For Foucault, power is an entanglement of forces that function to actively constitute knowledge in productive ways. The sociohistorical contingencies of power make it so that discourse becomes a productive machine, continuously positioning and repositioning certain discursive framings as valid and others as unintelligible. The intent of Foucauldian CDA analysis, then, is to offer the "possibility of illuminating the effects of power Foucault posited as being exercised from innumerable points within a given context, and this possibility is one of the attractions of the approach in qualitative research" (Given 3). In practice, Foucauldian CDA allows space for the implementation of various conventional qualitative data (textual or other discursive forms) producing methods including interviews, transcripts, observational media analysis, or artistic artifacts. As a Foucauldian critical discourse analyst, one's job would be to challenge and identify ways the discursive forms of data are participating in and/or resisting collectively agreed-upon rules which govern a contextualized reality (Given 3).

CDADN Application

CDADN involves a four-step process for analyzing data: *Texts, Contexts, Actions and Interactions,* and *Ideology and Power.* Each step uses a set of questions to prompt critical analysis surrounding a particular guiding theme. For example, the third step, with a guiding theme of *Actions and Interactions*, poses the question: how have the digital features, including code, been impacted by and respond to larger social factors? This question is informed by Thurlow's digital discourse studies in particular and leads the researcher to think beyond established boundaries of text analysis to consider how digital elements interact with larger sociopolitical contexts to create meaning. Each step's guiding theme and corresponding set of questions are directly informed by the work of Willig, Souto-Manning, Jones et al., Thurlow, Marino and Truman. This chapter will unpack the CDADN four-step framework by engaging with excerpts from an example text: a popular Twine game by Wally Ntagonistic called *You're*

Going to Make a Great Mother One Day. Described as a “reproductive horror Twine story,” in Ntagonistic’s interactive fiction the reader/player is taken prisoner by an unknown cult who mutilates their body in order to bear an otherworldly child. The captors repeat on a loop that: “you're going to make a great mother one day” despite the fact that “you are not a woman.” Ntagonistic’s work reflects on performative gender, identity, bodily autonomy, and reproductive freedom and questions what it truly means to be a woman. This interactive fiction was chosen as an example text to demonstrate CDADN as it explores concepts of gender identity and performative femininity in ways that are reflected in this project as a whole.



You are being held captive by a cosmic horror far beyond human comprehension. Its devoted servants are your jailers, restraining you with thick chains and kind words.

They say that you've been chosen as a vessel. To be the mother of its spawn that will rule over humanity down here on Earth for the rest of our days.

They say that you're a woman. That's what they keep calling you, over and over again. But you are not a woman, and none of this makes any sense.

Fig. 10. Screenshot from Ntagonistic, Wally. *You’re Going to Make a Great Mother One Day*. itch.io, 13 May 2018, https://ntagonistic.itch.io/mother.

CDADN Step 1: Texts

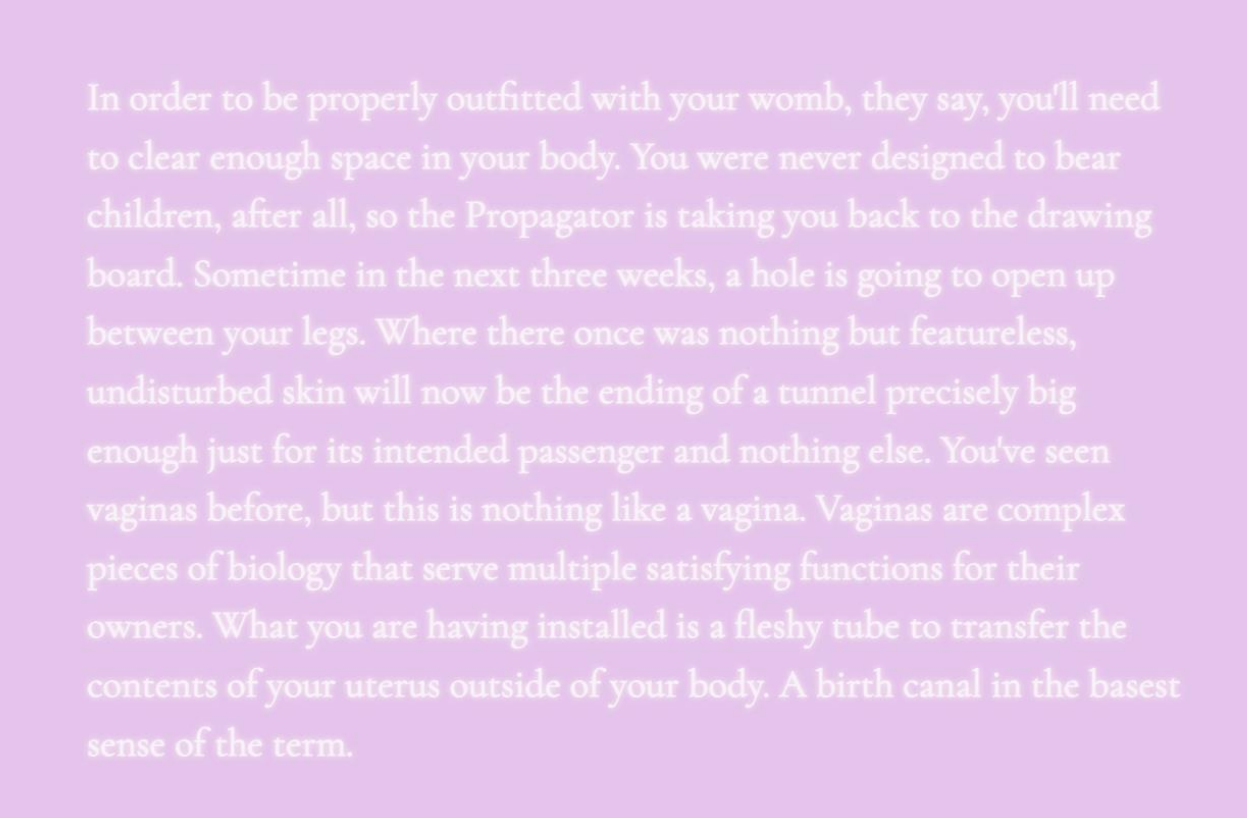
a). How does the narrative build the discursive object?

b). In what ways does multimodality shape the narrative?

c). In what ways is meaning altered through the narrative's interaction with other agents (texts, readers, authors, etc.)?

The first stage of the CDADN methodology is grappling with the construction of the text in its relationality as well as discursive framing. Fig. 10 is a passage from *Great Mother* that describes the process of bodily mutilation the reader/player is subjected to in order to build a "woman's" body conducive to growing the cult's child. A womb must be inserted into the abdomen and a utilitarian single-purpose vagina for birthing a fetus will be fastened. The first step of CDADN offers several questions that may act as tools for analysis. The first question prompts a consideration of the construction of the discursive object and is directly informed by Carla Willig's first stage of a Foucauldian CDA detailed in *Introducing Qualitative Research in Psychology* as well as Souto-Manning's work on CNA and how we construct ourselves through the telling of our stories. Souto-Manning argues "CNA allows us to learn how people create their selves in constant social interactions (Forgas 2002) at both personal and institutional levels, and how institutional discourses influence and are influenced by personal everyday narratives" (162-163). The first question prompts the analyst to think about how the subject is created through narrativity, specifically.

For example, the discursive object, in *Great Mother,* may be interpreted as the reader/player's body and is being framed as a gendered, productive machine-object. The body as machine-object is described using language that positions the body as a mechanism of labour in order to produce a commodity. In fig. 11, the author describes the need to clear space in the body for the production of the fetus, the body's failure to produce will result in it being taken back to the "drawing board" for design, and a fleshy tube will be "installed" for the purposes of transporting a "passenger." This language frames the reader/player's body as an object in an economy of production and consumption of resources for profit, rather than an actor with agency and subjectivity. However, this framing of the discursive body in conjunction with language of gore/horror/pain codes the protagonist's experience, and by extension the point-of-view of the reader/player, as undesirable. In other words, we are led to understand that what is happening to the protagonist is unjust.



In order to be properly outfitted with your womb, they say, you'll need to clear enough space in your body. You were never designed to bear children, after all, so the Propagator is taking you back to the drawing board. Sometime in the next three weeks, a hole is going to open up between your legs. Where there once was nothing but featureless, undisturbed skin will now be the ending of a tunnel precisely big enough just for its intended passenger and nothing else. You've seen vaginas before, but this is nothing like a vagina. Vaginas are complex pieces of biology that serve multiple satisfying functions for their owners. What you are having installed is a fleshy tube to transfer the contents of your uterus outside of your body. A birth canal in the basest sense of the term.

Fig. 11. Screenshot from Ntagonistic, Wally. *You're Going to Make a Great Mother One Day*. itch.io, 13 May 2018, https://ntagonistic.itch.io/mother.

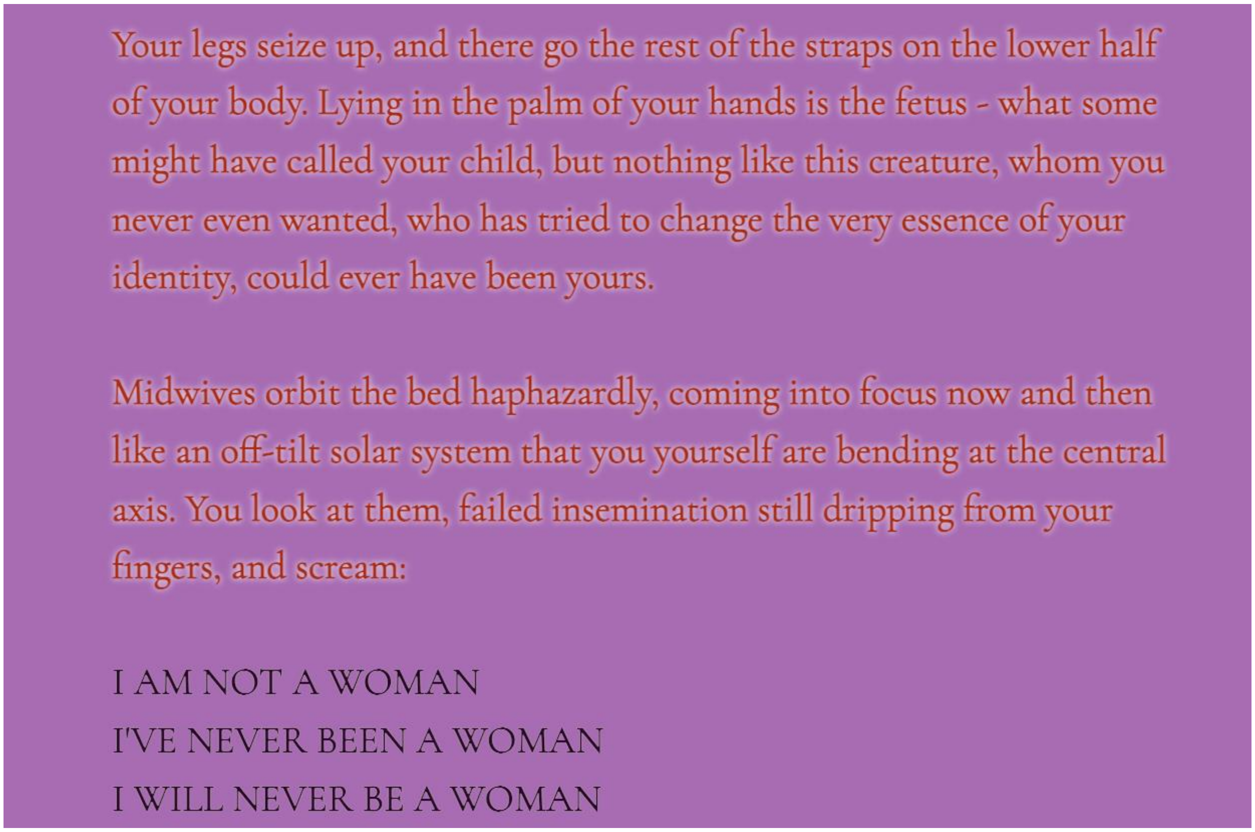
The second prompting question asks the analyst to consider how multimodality comes to shape the text and create meaning. This prompt is directly informed by Thurlow's work in digital discourse studies and centres the factors through which print and digital texts may be different. Thurlow argues that new media scholarship is contained by three broad, interrelated organizing principles: discourse, multimodality, and ideology. Discourse is concerned with the ways in which language and communication practices come to shape our sociohistorical and political identities, communities, and institutions. This is moving beyond the "abstract, grammatical language of linguistics" to consider the function of language as a cultural tool (Thurlow, "Digital Discourse" 3). Multimodality illuminates how language makes meaning through its interactions with other systems of semiotic organization. Thurlow argues that these interactions are created through the "layering" of media practices, the "convergence" of old and new media, and understanding the "spatialized" experience of the digital user ("Digital Discourse" 4). The Foucauldian sediment of discursive ideology seeks "to understand how our uses of language feed ideological systems, just as we want to know how ideologies shape the way we use language" (Thurlow, "Digital Discourse" 4). Here, digital discourse analysis aims to question how ideology becomes not only a driving force in discursive media but also how digital systems are produced within ideology.

Digital multimodality is expansive and may include variations of linguistic, textual, special, visual, temporal, and auditory elements through differing platforms, software, and/or code that may be realized in a single artifact. For Twine, multimodal practices can include images, sounds, movement, and most notably, hypertexts. The ways in which hypertexts are employed to generate meaning are pivotal data for this project because it is reflective of what is unique about the literary hypertext medium. For a Twine story to continue, or not continue, there typically must be a hypertext for a reader/player to select (not in every case as timers can be set up to bring the reader/player to the next passage). These hypertext options become pivotal moments in the narrative where distinct choices must be made by the author including what text to hypertext, what passage to link to, and aesthetic appearance. Further, the spatial and descriptive characteristics of the hypertexts in a passage can be categorized in different ways.

Anastasia Salter and Stuart Moulthrop in their 2021 book *Twining* offer three different terms to describe the linking strategies of an author. *Navigational* linking identifies the movement of a character or point of view through a story world space, *procedural* linking uses described action as an anchor, and *conversational* linking relies on responsive speech as the anchor of the hypertext (Salter and Moulthrop 69). In terms of the spatial organization of hypertexts, the authors argue that these three linking strategies tend to replicate similar features of composition: they might divide the passage text into two parts called *bifold construction*, or keep text in a single block known as *unified construction* (Salter and Moulthrop 69). In a *bifold construction*, the upper section of text tends to be a diegetic report of plot events while the bottom section tends to be "hypothetical, consisting of language still in play" (Salter and Moulthrop 69) in the form of hypertexts that advance the story to the next passage(s). This bottom section might have a linear, single hypertext or forked path with multiple options. A *unified construction*, in contrast, pulls the hypertexts into the diegetic block of text. In a broad and nonabsolute sense, Salter and Moulthrop argue that a *bifold construction* is more representative of a game-like Twine structure where *unified construction* mirrors traditional literary conventions (70).

An analyst might engage with the prompting question in *Great Mother*, for example, by examining how hypertexts function in the story and what kinds of patterns emerge. The hypertext choices made in *Great Mother* could be understood as dualistic. The first section of the narrative maintains a *unified construction* with a single, identical hypertext link that reads "not a woman" in reference to the protagonist's identity. Every "not a woman" hypertext is the only option for the reader/player to be brought to the next passage, creating a linear story path in this first section of the Twine. This choice by Ntagonistic is impactful for several reasons. First, a single hypertext option ensures that every reader/player will experience the same narrative structure where each passage will be read in a uniform order. Second, a single hypertext option for the reader/player actually removes the concept of choice in a forward path. An author may intend for this strategy to lead the reader/player to identify with that option, or perhaps resent the lack of choice. Third, Ntagonistic's use of the "not a woman" hypertext goes further as its repetition acts as a throughline in the narrative plot. The reader/player is consistently brought back to the declaration that they are not a woman as a stark contrast to the violent construction of womanhood that is being enacted on them. The first section's reliance on a *unified construction* plays to, what Salter and Moulthrop suggest, a literary interest.

In the second part of *Great Mother,* Ntagonistic moves away from single hypertext link options to include passages with multiple path choices in a *bifold construction* with typically *conversational* linking. Fig. 12 describes distress in the moment of birthing the fetus followed by three hypertext options: "I AM NOT A WOMAN," "I'VE NEVER BEEN A WOMAN," and "I WILL NEVER BE A WOMAN." Ntagonistic's intent to move the narrative into a rhizomatic story structure creates a sense of dissonance as all the hypertext options are reproductions of each other converging in the same sentiment. There is an illusion of choice through three hypertext options to split the plot, however, each option yields a similar narrative experience where the protagonist continues to resist the violent construction of womanhood being enacted on their body. The effect of artificial choice in the narrative for the reader/player mirrors the lack of agency in the plot of the story for the protagonist.



Your legs seize up, and there go the rest of the straps on the lower half of your body. Lying in the palm of your hands is the fetus - what some might have called your child, but nothing like this creature, whom you never even wanted, who has tried to change the very essence of your identity, could ever have been yours.

Midwives orbit the bed haphazardly, coming into focus now and then like an off-tilt solar system that you yourself are bending at the central axis. You look at them, failed insemination still dripping from your fingers, and scream:

I AM NOT A WOMAN
I'VE NEVER BEEN A WOMAN
I WILL NEVER BE A WOMAN

Fig. 12. Screenshot from Ntagonistic, Wally. *You're Going to Make a Great Mother One Day*. itch.io, 13 May 2018, https://ntagonistic.itch.io/mother.

The final prompting question for the first stage of CDADN asks the analyst to consider how narrative meaning becomes altered through the text's dialectic with other agents, including texts, authors and readers. Understanding the ways in which intended meaning in literary hypertext may shift, fracture, mushroom, or expand in each unique reader experience, is complex. For illness narratives in this project, for example, the therapeutic practice of writing is concerned less with the experience of the reader. In fact, if the author chooses not to publish their Twine online, there may not be a reader of the story. This, however, does not diminish the therapeutic aspects of the narrative process. At the root of the illness narrative practice, though, is the process of community building and creating solidarity in the wake of illness. As discussed in other chapters, akin to the community-building tradition of illness narratives, the research process of this project concluded with participants being invited to share their Twine stories in a private digital space for other participants to read. The narrative about a singular illness journey expands, for the reader, to a kindred, mirrored experience. The community-building portal will be discussed in depth in the Methods and Protocol chapter.

Great Mother is a compelling narrative to filter through the third prompt of the first stage of CDADN, because it grapples with complex issues of identification which can produce differing responses from readers. The anchoring line “But you are not a woman” acts as a rhetorical device of repetition in order to pull the reader through the text - both in a literary sense and a literal sense through hypertext. *Great Mother* requires the reader to select the hypertext that declares “not a woman” to move through the plot which may produce differing interpretations and responses from readers of differing gender embodiments and identities. The impact of selecting the hypertext that reads “But you are not a woman” may have opposing effects on different women, as well. For example, will a cisgender woman whose gender identity has never been pathologized experience the act of selecting this hypertext differently from others? How would this action alter the meaning for this reader? Some woman-identified reader/players may interpret *Great Mother* as a narrative that is challenging the limiting, social construction of womanhood where the protagonist’s refusal to identify as a woman is a rejection of the accompanying sexism. However, an individual who has experienced the pathologization of their gender identity may understand *Great Mother* as an exploration of medicalized responses to non-cisgender identities in relation to body parts. Like all literature, the reader/player of literary hypertext illness narratives makes new narrative meaning within each encounter.

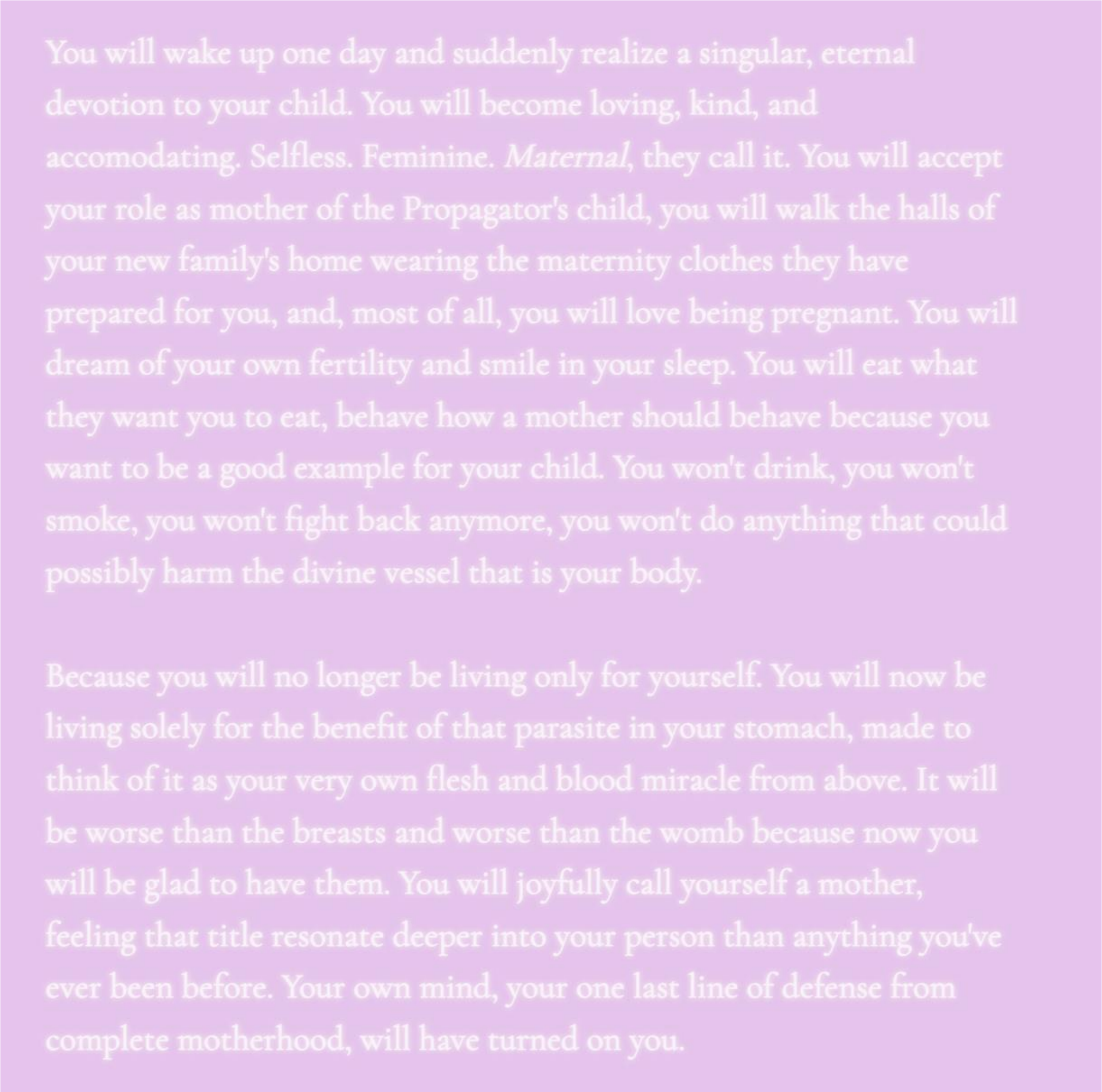
CDADN Step 2: Contexts

a). How do larger discourses come to shape and layer onto the narrative?

b). What is the context of the software development including ownership, coding language, and intended function?

The second step of CDADN methodology asks the analyst to think about the nuance of context and the ways in which larger contextual discourses interact with the text. This step is informed by Jones et al.'s understanding of *Contexts* as the "social and material situations in which texts are constructed, consumed, exchanged and appropriated" (4). The first prompting question for the second stage of CDADN asks how larger discourses come to impact and layer onto the text. This question is directly informed by Willig's second stage of conducting Foucauldian CDA as well as Souto-Manning's methodology on CNA. Souto-Manning argues that "CNA proposes that when individuals make sense of their experiences through narratives, they bring together the micro (personal) and the macro (social or institutional) situations in place. Thus, discourse-analytic approaches that ignore the larger (macro) context purport an incomplete analysis" (163). This notion of bringing together the micro and the macro, for CNA and by extension CDADN, challenges some discursive-analytic approaches that view the personal and the institutional as separate entities. Engaging with the ways in which larger contextual discourses layer onto the text repositions the text as an institutional agent, an actor of the macro rather than in mediation with it.

Turning to *Great Mother,* the first prompting question reveals that the narrative uses the genre of horror/fantasy as a tool to make a political commentary on issues of sex and gender in relation to society. In fig. 13, the protagonist confronts their immediate fate that will see their mind and body absorbed into traditional maternal performativity. Maternal, in the world of *Great Mother*, is synonymous with femininity, devotion to the child, and complete selflessness. The protagonist fears that following their body's mutilation into womanhood, their mind, as the last factor in their resistance, will also betray them as the identity of mother will “resonate deeper into your person than anything you’ve ever been before.” *Great Mother*, as a textual artifact, is converging in a dialectic with larger political contexts around gender identity in ways that challenge normative ways of understanding how motherhood should be both realized and enacted. Employing the first prompting question of CDADN in the second stage enables the researcher to look beyond the boundaries of the textual narrative for a richer understanding of context. For example, *Great Mother* is currently published on itch.io, an online and free platform to host indie games. This platform enables a tagging feature for games where the author can link their project to an array of descriptors. The tags for *Great Mother* include Horror, LGBT, Surreal, Transgender, Twine, and Weird. The descriptors of LGBT and Transgender offer insight into the larger political contexts to which the narrative responds and may lead the reader/player to filter their experience of the story through their relationship with those descriptors, in differing ways.



You will wake up one day and suddenly realize a singular, eternal devotion to your child. You will become loving, kind, and accomodating. Selfless. Feminine. *Maternal*, they call it. You will accept your role as mother of the Propagator's child, you will walk the halls of your new family's home wearing the maternity clothes they have prepared for you, and, most of all, you will love being pregnant. You will dream of your own fertility and smile in your sleep. You will eat what they want you to eat, behave how a mother should behave because you want to be a good example for your child. You won't drink, you won't smoke, you won't fight back anymore, you won't do anything that could possibly harm the divine vessel that is your body.

Because you will no longer be living only for yourself. You will now be living solely for the benefit of that parasite in your stomach, made to think of it as your very own flesh and blood miracle from above. It will be worse than the breasts and worse than the womb because now you will be glad to have them. You will joyfully call yourself a mother, feeling that title resonate deeper into your person than anything you've ever been before. Your own mind, your one last line of defense from complete motherhood, will have turned on you.

Fig. 13. Screenshot from Ntagonistic, Wally. *You're Going to Make a Great Mother One Day*. itch.io, 13 May 2018, https://ntagonistic.itch.io/mother.

The second prompting question for the second stage of CDADN grapples with the contextual factors around the software used to create the text in relation to ownership, coding language, and intended function. Software to analyze at this stage can include not only the tool to write but host, edit, distribute, map and storyboard, the text. This second question is informed by

Marino's work in critical code studies that argues against an "understanding of code as meaningless math (also, as it turns out, a false conception) and instead approach it as a culturally situated sign system full of denotations and connotations, rendered meaningful by its many and diverse readers, both human and machinic" (19). When conducting critical code analysis, Marino calls for researchers to anchor their analysis around a common effort to explore the extra-functional significance of computer code, looking at how code creates meaning beyond its function, or in other words, the purpose of the code for the task it completes in the computer program (34). To engage with code in this way, Marino suggests a methodological approach that first considers the context and functionality of the code, followed by an examination of symbols, structures, evolution (changes over time), and processes through a critical theory lens (23). Marino's analysis is open, however, he offers a series of questions for guiding researchers in navigating their analysis. His questions can be summarized in three stages: context, software and language choice, and relationality. For CDADN, the second prompting question of the *Context* stage is informed by Marino's second point regarding software and language choice. Analyzing the software choice through this lens, according to Marino, considers the historical, archaeological, and sociological contexts of the software by asking who developed the tool, when, for what purpose, and where? Understanding the contextual factors that have supported the development of Twine in this project, for example, is critical. Twine, as the chosen software to write literary hypertext illness narratives, has become an embodied agent of relationality with this research. Twine has a story and evolution of its own that is at the core of this research, and understanding this context as deeply meaningful to the outcomes of the analysis is imperative.

Great Mother was also written using the Twine software, as indicated by the additional information section of the story on itch.io. The choice to use Twine by Ntagonistic to write this story is not discussed in the additional information, however, understanding the sociohistorical context of the software offers rich insight into a relationship between a narrative about compulsory womanhood and a tool intended to diminish barriers to entry for storytellers of marginalized identities. At this stage of the CDADN methodology, the analyst could consider the history of the Twine Revolution and #GamerGate, the publishing of and response to Anna Anthropy's 2012 book *Rise of the Videogame Zinesters*, and Chris Klimas' journey to create a platform founded on a culture of free production of interactive stories. These topics - covered in depth in the Introduction chapter - are generative factors of the analysis offering differing ways of understanding *Great Mother*. For this example, we might consider Twine as a catalyst enabling works of fiction that challenge normative ideas about both gameplay and gendered themes, such as *Great Mother*, to be written and distributed. Or, more accurately, games like *Great Mother* that push back against traditional practices of masculinist game development have always grown parallel to mainstream creation, however, the legacy and intention of Twine may offer a trusting relationship for development and distribution.

CDADN Step 3: Actions and Interactions

a). What are the narrative subject positions formed and how do these positions enact or restrict moments for action?

c). How have the digital features, including code, been impacted by and respond to larger social factors?

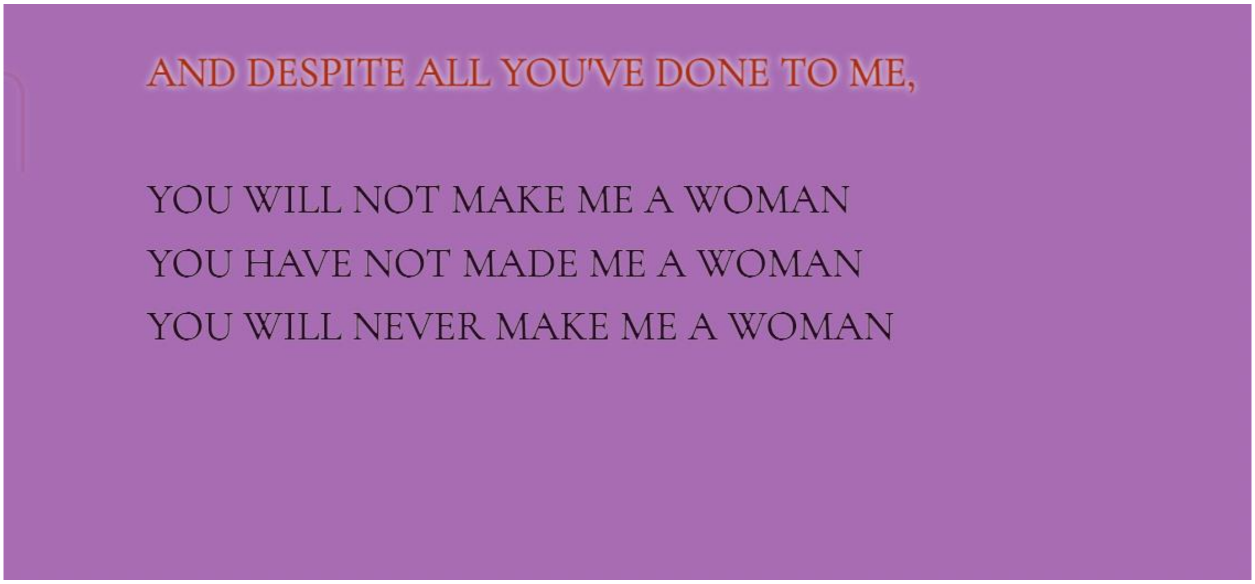
e). How have you acted as a responsible researcher? How does your research benefit marginalized humans and more-than-humans in its affect (generated networks, relations, and worlds)?

The third step of CDADN looks to explore the relationships formed around *Actions and Interactions* involving subject positions, digital features of the narrative, and the researcher's impact on networks formed in the wake of the research. This turning to dialectic action, according to Jones et al. is about understanding "what people do with texts, especially what they do with and to each other" (4). This moment in a CDADN methodological analysis is significant because it is when the researcher begins to map the paths of impact generated by the text, beyond the boundaries of the discursive context around the narrative. The first prompting question of the third step of CDADN calls the analyst to identify both the subject positions formed in the narrative and the ways in which these positions enact or restrict moments for action. This question is informed by the fourth and fifth stage of Willig's framework for a Foucauldian CDA. Willig argues that "discourses construct subjects as well as objects and, as a result, make available positions within networks of meaning that speakers can take up (as well as place others within)" (132). In *Great Mother*, there emerge several varying subject positions within the narrative, including the protagonist, the Other, and the narrator. Each of these subject positions work to either enact or restrict moments for action which is the latter half of the first prompting question of step three, informed by Willig's fifth stage of Foucauldian CDA. Willig argues "By constructing particular versions of the world, and by positioning subjects within them in particular ways, discourses limit what can be said and done" (132). From here, particular behaviours, thought processes and pillars of knowledge become legitimized over others. These methods of discursive formation come to shape what can be known.

The first subject position can be identified as the protagonist. *Great Mother* is written in the second-person point of view which relies on the pronoun *you* to, as some would argue, converge the subjectivity of the reader/player with the protagonist. The textual use of *you* has been theorized extensively by hypertext scholars Alice Bell and Astrid Ensslin ("'Click = Kill': Textual You in Ludic Digital Fiction"; "'I Know What It Was. You Know What It Was': Second-Person Narration in Hypertext Fiction"; "A Reader Response Method Not Just For 'You'"). Assumptions made about the use of the textual *you* pronoun as a method to ensure identification by the reader/player would be deeply incomplete. Bell and Ensslin argue that the use of the textual *you* in digital fiction is highly multidimensional and becomes a fluid mediation between the interactivity of the medium, the intentions of the author, and the agency of the reader. Most importantly, the use of the textual *you* can produce opposing outcomes for different readers or even the same reader in a different context. Bell and Ensslin argue "Since the reader is integrally involved in the construction of the narrative, 'you' is a particularly pertinent and compelling feature of digital fiction…hypertext can expand the referential capacity and ontological peculiarity of 'you,' because it provides an interactive environment in which to place it" ("'I Know What it Was. You Know What it Was'" 327). For this methodology, it becomes important to consider this analysis of the textual *you* when resisting uniform interpretations of subject positions formed and effects created.

Great Mother unfolds describing an experience of severe abuse and loss of bodily autonomy for the protagonist which creates an inactive position of a subjugated main character who is rendered powerless. Yet, this subject position is more dynamic than this. In fig. 14, near the end of the narrative, in the face of hopelessness, the protagonist maintains a sense of rage and defiance against the violence being enacted on their body. The passage, here, reads: "AND DESPITE ALL YOU'VE DONE TO ME," followed by three hypertext options: "YOU WILL NOT MAKE ME A WOMAN," "YOU HAVE NOT MADE ME A WOMAN," and "YOU WILL NEVER MAKE ME A WOMAN." The subject position of the protagonist formed by the end of the narrative can be interpreted as a moment of active defiance pushing back against the injustice being done to them, despite their loss of bodily autonomy.

In contrast, the second subject position formed in *Great Mother* can be summarized as the Other. The Other consists of the faceless, nameless, collective of cult members who are attempting to mutilate the protagonist's body to produce a "woman." The Other is framed as a mass of indistinction, there are no clear individualized encounters with the protagonist, but rather, they are understood as a monolith with a common desire. The subject positions formed by the protagonist and the Other produce, at first glance, dualistic, opposing forces where one side is an agent of power and the other is a subject. However, the subject position of the narrator complicates this dynamic. The identity of the narrator is not established, but they speak relatively omnipotently by describing both diegetic and nondiegetic actions, including the thoughts of the protagonist. The narrator's grasp on the workings of the story would suggest they side with the protagonist by offering insight such as: "This wouldn't be okay even if you were a woman. It would violate anyone's deepest sense of self regardless of gender." The narrator, as the bridge between the reader/player and the narrative world, creates an emotionally charged subject position that invites the reader/player to feel enraged by the injustice experienced by the protagonist. This subject position pulls the reader/player through the story by describing the action of the plot, followed by commentary on how we should be interpreting what is happening. This interpretation of the story world may have been different in the past or would be different in the near future. In this sense, distinct ideas about bodily agency, gender identity, and reproductive freedom are discursively constructed in ways that propel this narrative into a sociopolitical configuration that marks it as identifiable in a specific place and time in history - a moment grappling with the bodily rights and reproductive freedom of gender diverse people in society.


AND DESPITE ALL YOU'VE DONE TO ME,

YOU WILL NOT MAKE ME A WOMAN
YOU HAVE NOT MADE ME A WOMAN
YOU WILL NEVER MAKE ME A WOMAN

Fig. 14. Screenshot from Ntagonistic, Wally. *You're Going to Make a Great Mother One Day*. itch.io, 13 May 2018, https://ntagonistic.itch.io/mother.

The second prompting question of the third stage of CDADN considers how digital features of the narrative come into relationality with larger social factors. This question centres an analysis of code and is informed by Thurlow and digital discourse studies as well as Marino's work on critical code studies. Marino argues that code, like all discourse, participates in a communicative system with the evoked message, in conjunction with both human and machine audiences and speakers (4). Code becomes an actor in the production, reappropriation, erasure and legitimization of systems of knowledge, and it is important to analyze this data in ways that can understand its impact. Critical code studies is a way to analyze culture through code in order to understand representations of "race and ethnicity, gender, sexuality, socioeconomic status, political representation, ideology, et cetera—all those messy human topics that complicate our social relations because the walls of a computer do not remove code from the world but encode the world and human biases" (Marino 32-33). As discussed above, Marino's analysis is flexible, however, he offers a series of navigational questions to lead an effective analysis of code. For this prompting question, it is useful to turn to Marino's question of how the code responds to the context in which it was created (28). Here, analysts might look at the coding choices made by the author and examine first, what function this code executes in the story, and second, how this function is in conversation with larger sociopolitical discourses.

For this research, the author of *Great Mother* allowed me access to several documents to aid in this analysis including screenshots of the Twine interface that displays the back-end passage layout, the CSS style sheet, and a coded passage example. For this stage of the CDADN methodology, I will focus on simple CSS language coding choices made by Ntagonistic that have contributed to meaning-making processes within and outside of the story. CSS is a popular extension used in Twine and acts as a style sheet programming language used typically for developing the aesthetic and presentation of a document written in a markup language such as HTML. The first section of *Great Mother* makes distinct CSS coding choices that present the story in a specific way. For example, the reader/player will encounter white text on a light pink background which is produced by the HTML colour code [#ECC2EF]. One interpretation of this choice of CSS code is that the story is intending to replicate a performative image of femininity associated with stereotypes of pink holding an affinity with girl/womanhood. This choice is fortified by the author's choice to include an image of a light pink carnation as the cover photo of the story. At a pivotal moment in the narrative, when the protagonist faces the sudden and violent birth of the fetus, some CSS coding choices change. The story is now presented through red text (HTML color code [#B71B00]) set on a dark pink background (HTML color code [#B268B7]). This stark moment of visual difference in the narrative conveys a sense of oppressive sinking deeper into the pink womanhood. The coding style of the red text has also been altered with the text-shadow property, a CSS property that adds a shadow to the text. This effect may have differing results based on how the shadow is defined through a combination of X and Y offsets from the element (horizontal and vertical), colour choice, and the blur radius. For this moment in *Great Mother*, the CSS code [text-shadow: 0 0 3px #fff5ef;] produces a white shadow illuminating the red text. This effect on a dark pink background works to obscure the readability of the text to some degree. This CSS choice can be interpreted as producing an effect of falling into hyper-distortion which matches the narrative experience of the protagonist.

Further, it is telling to review the naming conventions the author chose in their code. In order to select various HTML elements with a particular class attribute, the CSS must use a class selector. What is important here is that the author is attempting to stylistically organize their narrative, and to do so they may employ any class name they want. There are some typical naming conventions that some programmers follow, however, a common practice is to name classes simply and descriptively in order to maintain an organized structure and keep the code "readable" by others where they can easily understand what element is selected. In *Great Mother*, the author uses the class selector [html.pink] in order to apply style to all HTML elements that have the class name [pink]. Elements named as such appear to be the first section of the narrative marked by the light pink background. A new class selector [html.shout] is introduced when the narrative transitions to the dark pink background. This is the moment in the narrative where the protagonist experiences the violent birth of the fetus. One way the change in class name choice can be engaged is by thinking about the word *shout* and its connotation. There is an implication made, through examining this code, that the moment the story shifts to the dark pink and the class [shout] is introduced, the protagonist develops a kindred relationship to that word. Perhaps this may reference the moment the protagonist literally cries out in objection to their loss of bodily autonomy. Or, it may connect to the narrative's ending that sees the mutilation of the protagonist's body in spite of their assertion that they will never be a woman and frames it as a moment of embodying the sentiment of *shout* as a silent, internal protest.

The third prompting question of the third stage of CDADN is a reflexive step that opens space for the researcher to audit their own contribution. The question asks the researcher to consider their responsibility in the project and evaluate how their research is benefiting marginalized humans and more-than-humans in its affect (generated networks, relations, and worlds). In other words, what are the ripple effects generated by this research and is the researcher taking responsibility for their impact? This question is directly informed by this project's theoretical framework of feminist new materialism and Truman's approach to qualitative research. Truman argues that feminist new materialist approaches to research should be concerned with challenging both positivism and representationalism, centring more-than-human agents in the research and implicating the researcher in the process of data analysis (2). The latter point is especially critical for this project and will be discussed in depth in the Analysis and Discussion chapter.

One of the most critical characteristics that Truman uses to define a feminist new materialist approach to qualitative research is that "thinking-with theoretical concepts is also 'empirical' research" (2). Traditionalist perspectives about bona fide research findings stress observational processes that centre physical senses, instruments, and measurable data. These practices may be important for feminist new materialists as well, however, they also understand the value of using theory as a method of understanding/revealing outcomes of research. This is significant for various reasons including that it allows space to think about matter as a deeply vital reality. There is something very material about how the body morphs and evolves with hyperandrogenism, and there is also something material about how these body-stories become embodied in hypertext. Thinking with feminist new materialist theory allows for a consideration of how this matter comes to *matter*.

Truman offers a four-point checklist as a guiding framework to incorporate a feminist new materialist approach to a discourse analysis methodology. At this moment in the CDADN, Truman's fourth point is centered where she asks: "Are you conducting research with QT&BIPOC and disabled adults or, youth? Whose theorizing informs your own research? How helpful is it to the participant humans (and more-than-humans) in your study? How are you taking responsibility for the networks, relations, and worlds created through your research process from design through to dissemination?" (10). These prompts will produce more robust reflections in the Analysis and Discussion chapter where this project's corpus will be analyzed. However, I wonder what insight they may provide for my brief engagement with *Great Mother* as an example text? This notion of taking responsibility for the networks generated by the research reminds me of a moment when, while pulling data from *Great Mother* (excerpts and screenshots), I felt strange about the process. *Great Mother* is a story published on a public website for anyone to access, and writing about the project in this way may not be different than writing about any other published work. However, once I came to the point in the methodology where I had to analyze the coding choices of the narrative, I felt as if I was making unfair assumptions. I can use the web browser's "inspect" element to gain insight into the website's source code, but this is a limiting practice. Therefore, I felt that I needed to have access to more examples of *Great Mother*'s backend in order to analyze it more effectively. I was able to contact Ntagonistic over Twitter and they were enthusiastic about sharing screenshots of the story's backend, and in return, I shared draft excerpts of my analysis of their project. This positive relationship, emerging from a community of creative research and a love of literary hypertext, feels feminist in that it supports collaborative community building around research rather than notions of knowledge gatekeeping.

CDADN Step 4: Ideology and Power

a). Who and what is the narrative affirming and why (what is erased)?

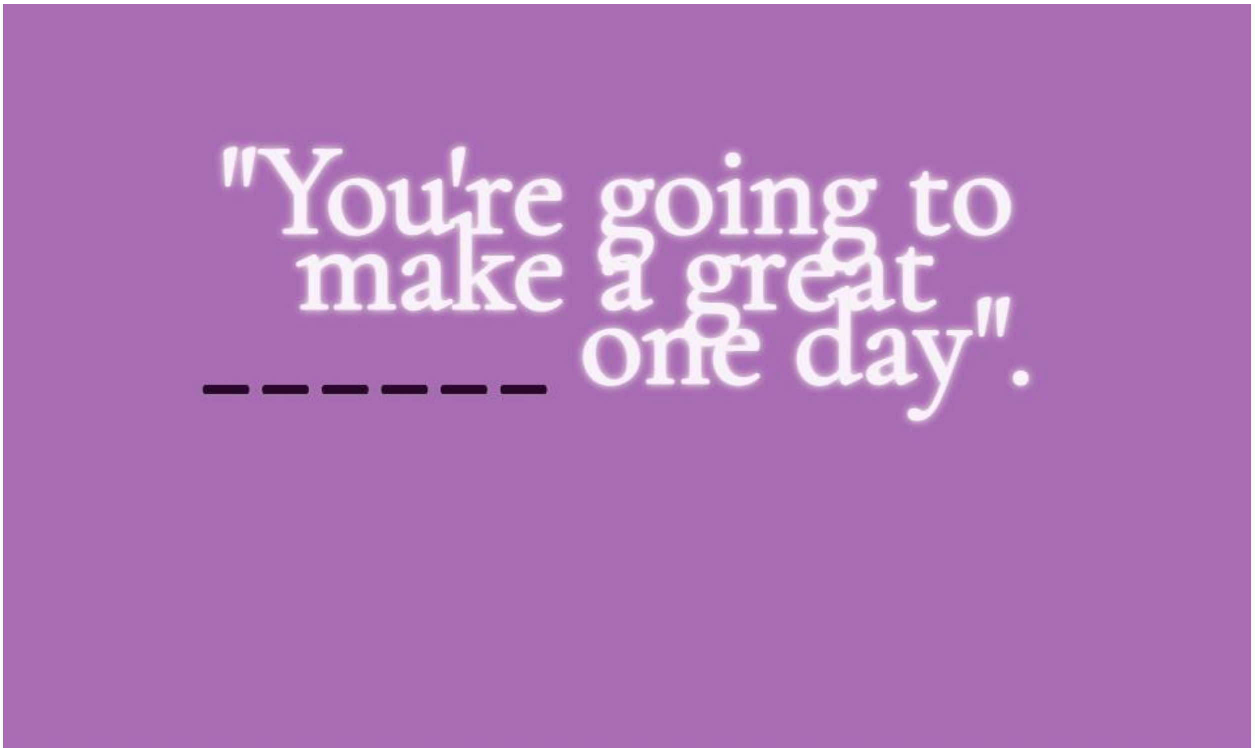
b) Who and what is the research project affirming/erasing and why (consider citations, methods, theory, research collaboration)?

c). In what ways do the digital features of the narrative shape meaning about power relations?

d). How does the research project centre materiality through intersectionality, anti-racism, decolonization, feminism, and/or thinking-as-research?

The fourth and final stage of the CDADN methodology turns to evaluating nuances of *Ideology and Power*, both within the corpus and the research process itself. Jones et al. argue that this fourth methodological step is concerned with "How people use texts to dominate and control others and to create certain 'versions of reality'" (4). The first prompting question asks the analyst to evaluate who or what the narrative is affirming/erasing and why. This prompt is informed by Willig's third stage of Foucauldian CDA which she refers to as action orientation (132). Action orientation is attuned to implications and outcomes of detrimental constructions. In other words, this stage explores what is to be gained from the framing of discourse in a particular way (Jones 11). This stage of Willig's methodology appears to be particularly nebulous as it seems to call on researchers to contribute to a dualistic and premeditated narrative of power. Identifying who is gaining what from a discursive framing is complex. The subject may, indeed, be receiving and relinquishing (status, power, resources, etc.) simultaneously. Perhaps the point of contention may be in the word "gain" as if there is a singular, lateral propelling of goods and resources, which may not always be the case. In thinking about power as a productive rather than restrictive force, it becomes helpful to question the multiplicity of the "payoff," the consequences, and all that is situated in between.

The throughline of *Great Mother* is the repeated mantra: "you're going to make a great mother one day." The protagonist objects to this line each time it is said by the cult, arguing that the de/construction of their biological parts will not make them a mother. Later in the story, followed by a harrowing description of bodily mutilation and a forced birth of a fetus, the reader/player is led through a series of passages that cycle the "good mother" mantra, however, each passage alters the hypertext *mother* to be either *woman*, *man*, and finally, in fig. 15, a blank space. This is a compelling conclusion to the narrative because it makes an assertion supporting the freedom to define one's identity on their own terms - and more significantly, that this identity is, in fact, determinable. When we filter this moment in the narrative through our first prompting question it reveals that rather than suggesting that the identity of *mother* has now been bestowed upon the protagonist against their will, the narrative complicates the definition of motherhood. If the protagonist can proclaim they are not a mother, in spite of birthing a fetus, then what is a mother? The narrative appears to affirm a system of belief that identities are discursively formed and deeply meaningful, and therefore, a just approach to identity formation lies within individual autonomy in the context of gender and beyond. An evaluation of who or what is erased in *Great Mother* can proceed along varying paths, though, for this analysis it may be generative to think about the centering of the embodied subjectivity of the protagonist in this narrative and the decentering of empirical context and narrative observation of the phenomena. Further, the narrator of *Great Mother* is an emphasizing of the internal experiences of the protagonist rather than an observer who might challenge these embodiments or add context outside of their world of knowing. The narrator does not add context to how the protagonist may have gotten captured, what the back story of the cult is, or the internal musings of the cult members. This erasure of a broader imperial contextual framework works to situate the reader/player within the limited perspective of the protagonist, where like the protagonist, the reader/player cannot see outside the boundaries of their subjectivity.



"You're going to make a great
_ _ _ _ _ _ one day".

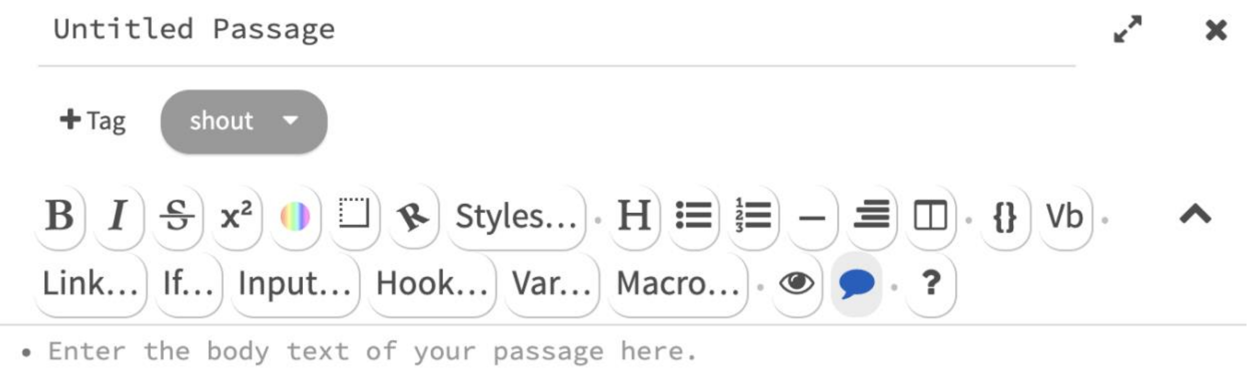
Fig. 15. Screenshot from Ntagonistic, Wally. *You're Going to Make a Great Mother One Day*. itch.io, 13 May 2018, https://ntagonistic.itch.io/mother.

The second question is a reflexive prompt to reflect on who or what is affirmed or erased in the analysis of the narrative, or the research project as a whole. Informed by Truman's feminist new materialist methodological approach, this prompting question sets up a foundation of accountability in the research process to better understand how both sameness is reproduced and difference may be excluded. Truman borrows Barad and Haraway's term *diffraction* as a tool to challenge the process of reflection as "Diffraction attends to difference rather than sameness [of which reflection yields]" (6). For Truman, conducting a diffractive analysis of the research data does two things: it marks both what comes to matter and what is excluded from mattering (6). This stage of the CDADN expands Truman's notion of diffraction, or paying attention to what matters or not, to an analysis of the research process, data extraction, or data presentation. This can include what citations are referred to, methods chosen to extract the data, the theoretical lens the analysis is filtered through, or the context of the communities of research collaboration and how these factors may re/produce or challenge certain ways of thinking.

The second prompting question offers several paths to explore when thinking about erasure/affirmation in the research context, including citation choice, methods, theory, and research collaboration. In the process of employing *Great Mother* as an example text to display how a CDADN methodology may function, the theoretical framework of this project, feminist new materialism, was centred. This is because the methodology being employed is informed by this theory, and further, my analysis of this text is in the wake of writing the Literature Review chapter which has come to influence how I interrupt data. Analyzing *Great Mother* through a feminist new materialist lens works to centre themes of materiality and affect. For example, this methodology asks the researcher to turn to vitality found in the code, the software interface, the hypertexts, and the worlds created as a result of the research. This created space to understand *Great Mother* as existing within a dialectic with other sociopolitical and digital factors. *Great Mother* is not just a story, not just a literary hypertext, not just a block of code, not just an HTML file, not just a political statement but a mediation of all these things and more. What is erased in the centring of this theory is many things, some of which feminist new materialism has been criticized for, such as hollowing out identity politics. As Truman argues "Marginalized populations such as BIPOC, queer, trans, and disabled people who have always been excluded from the category of the Human are wary of claims that decentering the human, flattening ontologies, and redistributing agency will suddenly level the playing field" (8-9). In my analysis of *Great Mother*, I contemplate identity at the level of gender but not beyond.

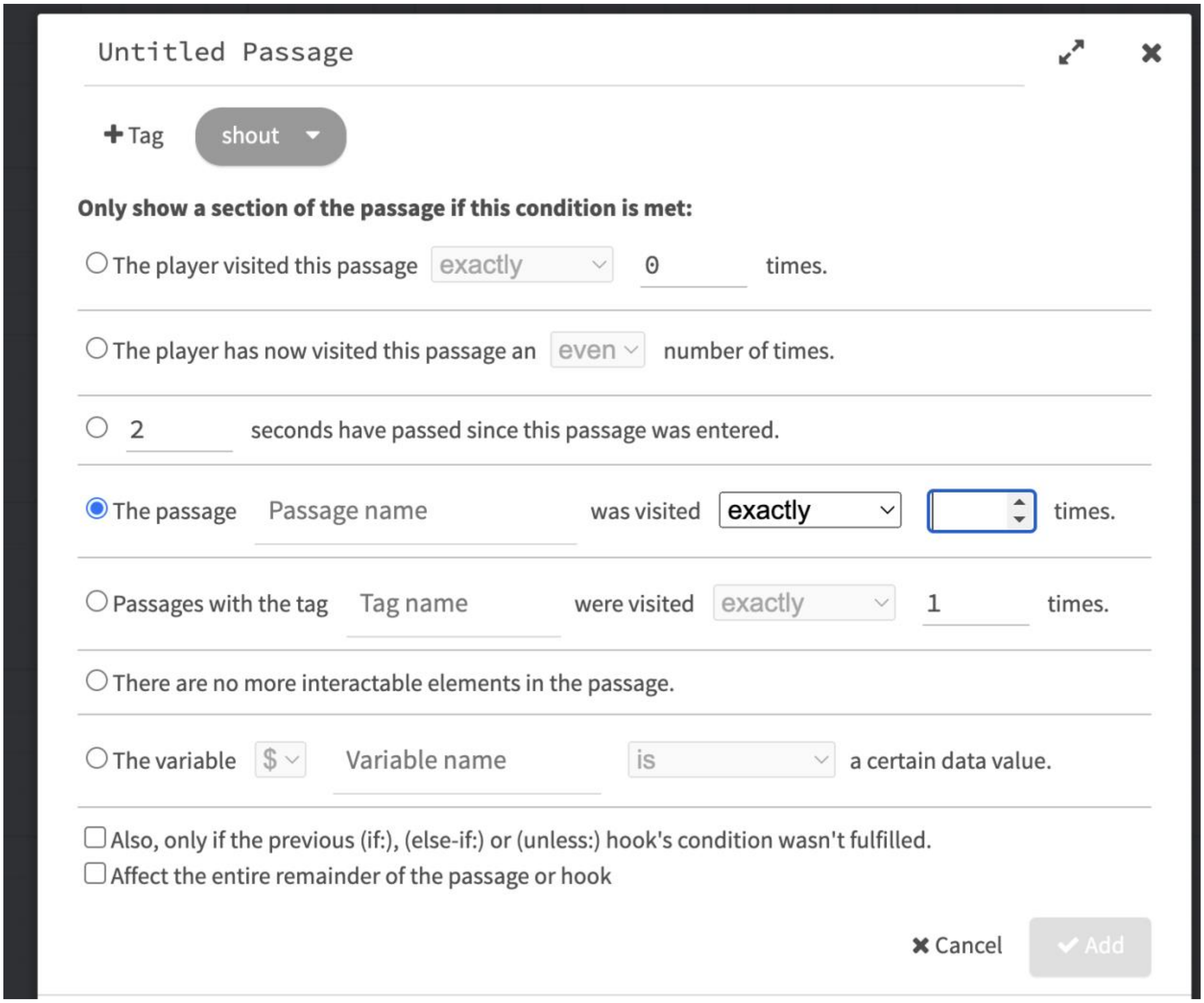
The third prompting question for the last stage of CDADN asks the analyst to consider the ways in which the digital features of the narrative may come to shape the meaning of power relations. This question is informed by Marino's work in critical code studies, and in particular, the ways in which he understands code as dynamic. Marino suggests that researchers examine not only how the code evolves over time, but what kinds of material or social factors have shaped the code, how the code responds to the sociopolitical context, and how the code has been received (28). These are critical questions that position code as one factor in a network of meaning-making processes that contribute to the narrative. Marino cautions that although examining technical elements may be a focal point, analysts must expand beyond the material conditions of the code (28). Analyzing code through the lens of what Marino calls paratextuality, or the relationship between the code and the material and nonmaterial discourse that surrounds it, allows for the flexing of the *critical* in critical code studies to support a dynamic and rich contextual analysis. Informed by Thurlow's work in digital discourse studies the third prompting question centres the digital features of the narrative including, but also beyond, code. Thurlow notes "new/social media are themselves inherently ideological, both in terms of their political-economies of access and control (i.e., some have, some have none/less), but also in terms of their potential as mechanisms for both normative and counter-normative representation; they are used to control people, and they are used to resist control" ("Digital Discourse" 6). As Thurlow argues, putting the digital features in conversation with concepts of ideology and power is what makes the methodological process aligned with a critical discourse analysis ("Digital Discourse" 6). This reflection on ideologically-charged technology is imperative because it allows for a way into understanding the impact of seemingly mundane digital features, such as the ritual of clicking a link or scrolling down a page.

In one of the screenshots that Ntagonistic shared of *Great Mother*, I can see that the class of [.shout] was added to a passage through Twine's tag feature. It looks similar to fig. 16. Rather than relying on more technical or traditional methods for implementing HTML classes or any other coding features for that matter, Twine has worked in features that guide authors through the programming process of their narratives. These guiding features are newer aspects of the latest version of Twine, and they centre the experience of the author in the creation of the narrative. For example, fig. 16 shows that when a passage is opened, the author will see a selection of buttons that they can choose, each referring to a different technical implementation. When the [If…] button is clicked, for example, the author is shown a drop-down box that includes a definition of an if conditional statement, in the context of Twine (fig. 17). The definition reads: "Only show a section of the passage if this condition is met:" and is followed by a selection of conditions that the author can alter using drop-down menus, text-input boxes, and checkboxes. What is meaningful about these updated features is a seeming intention to design for accessibility. The Twine software, through the framing of our third prompting question, cultivates its legacy and reputation as an inviting space for storytellers pushed to the margins. Accessibility features such as these that side-step an expectation to code from scratch attempt to invert stereotypes of programming being exclusive with significant barriers to entry.


Untitled Passage

Enter the body text of your passage here.

Fig. 16. Screenshot of Passage Design Options in Twine Interface for Twine Version 2.5.1


Untitled Passage

Only show a section of the passage if this condition is met:

○ The player visited this passage exactly 0 times.

○ The player has now visited this passage an even number of times.

○ 2 seconds have passed since this passage was entered.

● The passage Passage name was visited exactly times.

○ Passages with the tag Tag name were visited exactly 1 times.

○ There are no more interactable elements in the passage.

○ The variable $ Variable name is a certain data value.

☐ Also, only if the previous (if:), (else-if:) or (unless:) hook's condition wasn't fulfilled.
☐ Affect the entire remainder of the passage or hook

Fig. 17. Screenshot of Passage Design Options in Twine Interface for Twine Version 2.5.1

Although, how inviting, really, is the interface for those who have no coding experience? It is important, here, to complicate seemingly "clean" stories of accessibility and upon deepening the analysis, dislodging of power in terms of access might emerge. For example, Twine supports the use of Story Formats in lieu of a fixed scripting language. The Story Format options are vast but include Harlowe, Chapbook, and Sugarcube - each more or less friendly to differing programming abilities. The Twine Cookbook explains that the newest version of Twine (Twine 2) has altered the Story Formats to work as dialects of the Twine language that interpret style, semantic rules and markup conventions differently. For beginners, understanding the different story format's capabilities and what dialect would be the most appropriate for their story is daunting. There is so much power in what the dialects can achieve and ample resources for Twine learners, but what becomes lost in the mix? For example, how does the Twine Story Format choice affect the narrative's accessibility for screen readers? How does coding accessible features become a barrier? At this moment in the CDADN, there is space to think about how design and technology merge and situate themselves into larger meaning-making ideologies.

The final prompting question of the last stage of CDADN attempts to root the methodology deeper into a feminist new materialist framework. The question leads analysts to consider how the research project may centre materiality through intersectionality, anti-racism, decolonization, feminism, and/or thinking-as-research. Truman argues that "concepts, theories, and praxis are implicated by the situated and specific ethical and political contexts in which they take part" (9) and this opens up a space to think about vital matter. For example, Truman looks to an example of a cell phone and argues that scholars in opposition to feminist new materialism might put forward an analysis of human value considering the worth of the phone over the human. Feminist new materialists understand the phone as deeply intertwined, through vitality, with the human, as one. The phone, Truman argues, is constructed from material drawn typically from the exploitation of racialized, poor, and/or migrant labourers. The phone's material may be a resource mined on land that has been colonized. For Truman, this is the politics of entanglement "In considering the 'value' of a phone, feminist new materialist research might ask questions about the ways that humans and metal and phone and land and capitalism and economy and militarism, and so on, are already imbricated in each other" (9). Through the final prompting question, there is an attempt to capture the political significance of material vitality and what that means for a feminist methodology concerned with power relations.

For the example analysis of *Great Mother*, there is a myriad of doors this prompting question might open for analysis. My engagement with the Twine story in relation to matter paints an interesting story about the siphoning of monetary profit that can be analyzed. When *Great Mother* is framed as a digital-material object, perhaps an HTML file, its trajectory can be mapped in a way that leaves a profit wake in its path. In other words, *Great Mother* was made using the Twine software, perhaps accessed through the author's internet browser. Here, we might ask what device, owned by which company, was used. The story is hosted on itch.io, a platform that describes itself as founded as a marketplace for developers to have control over the sales of their content ("Frequently Asked Questions" itch.io). *Great Mother* can be accessed for free, however, there is an option to select a button that reads: "Support this Game." A potential donor has the option of how much to contribute through the companies Paypal and Stripe, both of which support online payment processing. Within itch.io's "Terms of Service" they note that publishers of games on their site can set their own rate and once a game sale is made "itch.io will be entitled to a share (that you set) and may be required to withhold an amount of the sales for tax, VAT [Value-added tax] and other charges." In some ways, *Great Mother* can be understood as a narrative that disrupts normative boundaries of gameplay - not only in its content but in its remapping of capitalist boundaries. When an author can access Twine and publish their content on itch.io all for free, and a reader/player can offer a monetary donation to the author for accessing their game, this disrupts typical gate-keeping barriers upheld by large game publishers. However, mapping the economic materiality of the game's journey from inception to the hands of the reader/player paints a more complex narrative about who really is profiting.

Chapter Review

In this chapter, I describe a framework for a CDADN methodology developed specifically to analyze the corpus of this project. The chapter begins by detailing a significant gap in the literature for a methodology that can examine how narrativity creates meaning through digital technology. CDADN is described as an amalgamation of important aspects of critical discourse analysis, narrative analysis, digital discourse analysis, critical code studies, and feminist new materialist theory. CDADN is described as a four-step framework informed by Jones et al.'s work in digital discourse analysis. Further influences of the methodology are explored in detail and include Willig's six stages of Foucauldian CDA, Souto-Manning's work on critical narrative analysis, Thurlow and digital discourse studies, Mark C. Marino's guiding questions for research in critical code studies, and finally, Sarah E. Truman's checklist for feminist new materialist researchers. This chapter sets up a foundation for exploring the methodological application by first describing which methods have been used before for digital-born narratives followed by an explanation of why these approaches are not used in this project. Next, a clarification of a Foucauldian stream of critical discourse analysis is offered. Finally, an exploration of how the term discourse is understood in CDADN is provided as Sara Mills' interpretation of Foucault's definition as all articulated expressions and statements of meaning which create an effect.

The latter section of this chapter employs the Twine game *You're Going to Make a Great Mother One Day* as an example text to demonstrate the application of the methodology. In this section, several prompting questions informed by the literature are explored in relation to *Great Mother*. The CDADN methodology incorporates vital questions put forward by various scholars in domains that intersect with this project and categorizes them into four themes: *Texts* which consider the textual and technological aspects of the Twines; *Contexts* which position the Twines in conversation with larger sociopolitical discourses; *Actions and Interactions* which considers the relationality of various elements of the Twines with real-life agencies; and *Ideology and Power* which provokes an analysis of power relations created through the writing and research of the Twines. The next chapter will detail the methods used in this project and will outline the design process of the Twine module used by participants to write their illness narratives. The methodology and methods of this project have been separated into two chapters for clarity and length.

Chapter IV: Methods and Protocol

Introduction

This chapter will focus on the methods and protocol used to both execute the research and analyze the data produced by the study. There were four main stages to the research process that included the module design phase, participant recruitment phase, experiment phase, and data analysis phase. In the module design phase, I spent several months working with narrative therapy perspectives to develop a Twine module for writing literary hypertext illness narratives. The theoretical and technical aspects of this module will be described in this chapter. The structure and efficacy of the module were the central objectives of the research design because the resource had to stand on its own as a pedagogical tool. The experiment phase of the research began at the start of the COVID-19 pandemic which saw social distancing mandates in effect. It was unsafe to be physically near my participants at this time, compounded by the fact that my participants were located expansively across Canada and beyond. The module had to facilitate the learning process in its entirety. Participants, of course, were directed to connect with me if they had questions, but it was important to mitigate any clarity issues at that base level, so participants felt confident completing their stories on their own.

The participant recruitment process will be detailed in this chapter, including a qualitative and quantitative outline of the identity markers of the participant pool. The experiment phase of the research will be outlined including the completion of the Twine module, the submission of a Twine illness narrative, the Closing Interview, and the informal community-building portal created to circulate stories among participants. The final stage of the research process included data collection and analysis. This chapter will describe the process of transcribing Closing Interview transcripts using Otter.ai and the data analysis phase using a private NVivo account, funded by an Intersections of Gender Thesis Grant from the University of Alberta. Data from this research was first thematically coded in NVivo before it was filtered through the critical discourse analysis for digital-born narratives methodology detailed in the Methodology chapter.

The research problem that this project is attempting to respond to is two-fold. First, as described in previous chapters, individuals with hyperandrogenism experience subjugation both culturally through the reinforcement of sex norms and institutionally through the pathologizing of deviant femininity. Due to this subjugation, some women and nonbinary individuals with hyperandrogenism are turning to the writing of illness narratives to grapple with their experiences. Therefore, the second problem this research responds to understands that despite the therapeutic value of traditional illness narratives, the genre has been challenged for upholding barriers to entry for marginalized groups (Couser, *Signifying Bodies* 58). Similarly, the past decade has seen a strong revival of scholarly and public interest in the genre of literary hypertext, stemming from the access it allows marginalized game developers who are often excluded from masculinist, white spaces of game development. (Anthropy 21). However, there is limited scholarly research on the potential for literary hypertext as a tool for writing therapeutic illness narratives. This dualized research problem then leads to the purpose of this project which is to understand how literary hypertext technology may be a valuable therapeutic tool for writing illness narratives for women and nonbinary individuals with hyperandrogenism.

Understanding the purpose of the research leads to the development of the research question: how can women and nonbinary individuals with hyperandrogenism use literary hypertext technology to write illness narratives that construct positive relationships between their identities and the world? The structure of this question is intentionally expansive and invites the researcher to interpret the data in ways that identify both technical aspects of the software and thematic patterns in story worlds that may contribute to the development of positive relationship building for the participant. In this sense, the research question seeks to study both digital features of literary hypertext, as well as themes or insights about the experience of hyperandrogenism that emerge through literary hypertext illness narratives. The research question deliberately avoids asking if literary hypertext for hyperandrogenism illness narratives works as a therapeutic tool or not, and this is for several reasons. First, previous chapters have detailed that the results of this project are not intended to be analyzed as outcomes of a formal therapeutic tool. The Twine module is informed by narrative therapy practices, however, illness narratives are viewed as counter-practice to traditional therapy enacted, at times, outside the walls of the medical institution or without monitoring by a therapy professional (Couser, *Recovering Bodies* 4). It is important in this project that the core of the practice of illness narratives remains an act of resistance that can be made in isolation. Second, this research was approached from a point in the literature that understands illness narratives as valuable, and also literary hypertext as a beneficial outlet of expression for marginalized individuals. At this crux, I am approaching this research at a starting point that understands these two forms as valuable, and from there seeks to explore the nuances of this value for a particular set of individuals. In targeting hypertext's value, space opens up to identify the inverse as well. Through this framework, as the researcher, I can grapple with aspects that did not add value, did not contribute to positive relationship building, or were perceived as inaccessible by participants.

Participant Recruitment and Research Process

Participant recruitment for this study was completed over the course of a year through general calls for participants on public listservs, PCOS Facebook Groups, and PCOS subreddits (a centralized online group on the website Redditt, an online topic-based discussion community).

The first line of contact with participants was a Recruitment Poster (Appendix B) posted in an online space. The poster depicts a pixelized image of an arcade game, to speak to Twine's affinity with game creation, with a neon title that reads: "Living with PCOS can be hard, especially when some symptoms challenge our ideas of what a feminine body should look like. Do you have a PCOS story to share? Writing about your experience can be empowering." The poster outlines various eligibility requirements for participation in the study, how to contact the PI and a note of Ethics Approval (Appendix A). The decision to centre the condition polycystic ovarian syndrome in the recruitment poster, and other onboarding documents, was intentional. Receiving a formal diagnosis of hyperandrogenism is complex. Typically, patients will experience varying symptoms of hyperandrogenism, and upon medical investigation, are diagnosed with one of the many hyperandrogenism-related disorders (e.g., PCOS, Congenital Adrenal Hyperplasia, Cushing's disease, etc.). It is not typical that patients are diagnosed with hyperandrogenism, in isolation, but rather if there are symptoms to suggest hyperandrogenism further diagnostic tests are administered to identify an underlining disease (Oakley). Therefore, hyperandrogenism may not be a word that individuals are familiar with. PCOS, however, is the most common endocrine disorder among women of reproductive age (McGowan 289). A significant number of individuals who experience PCOS experience symptoms of hyperandrogenism as well (Oakley). Therefore, in order to connect with a significant number of relevant participants, the recruitment for the study employed the language of PCOS instead of hyperandrogenism, where the latter was introduced and defined for participants later on.

It was critical for this study to take on this more complicated approach, rather than focusing on PCOS as a whole, for example, because the research in this project is concerned with the experience of androgen excess and how that impacts one's relationship with gender presentation and cultural expectations. Using the disorder of PCOS alone, without the presence of hyperandrogenism, posed a problem because PCOS can produce a multitude of symptoms. For example, in this scenario, a participant with PCOS without hyperandrogenism could have experience with insulin resistance, obesity and ovarian cysts. While these are critical symptoms, they might not explicitly connect to the study's central themes around deviant femininity. The Recruitment Poster outlines three eligibility requirements, including that participants must be 18 years old or over, have the ability to speak and write in English, and have experienced elevated testosterone. This study did not require a formal diagnosis of a disorder, or even elevated testosterone, from a physician. Interested participants who self-identify as having hyperandrogenism as per their lived experience with two or more symptoms were eligible (a list of symptoms will be detailed below). This distinction is critical because it opens up space for participation from individuals who may feel their concerns regarding symptoms have not been appropriately recognized within the patient-physician encounter. There was no maximum age range for this study as hyperandrogenism is a condition that affects individuals across their lifetimes and is found in many people transitioning into menopause. However, all the participants who completed the study were relatively young (between 21-36 years of age). This may be due to the digital recruitment method, the digital aspect of the study, or perhaps the age range that individuals are seeking to cope with their illness. This outcome requires further investigation.

I knew that, as a central part of this research, I wanted to look at the experiences of pathologized, "deviant" femininity. As detailed above, I needed participants who were struggling, either consciously or unconsciously, with the queering of normative femininity. PCOS has an array of symptoms, and many people who have the disease have differing experiences. I knew I needed participants who were experiencing the symptoms of hyperandrogenism specifically (symptoms of excess testosterone). However, the issue with recruiting individuals with hyperandrogenism is that it is not typically a diagnosis that an individual would receive as it is understood as a symptomatic condition that presents itself in other diseases, and therefore a diagnosis may not be present. More likely, an individual would be diagnosed with PCOS with features of androgen excess. According to the literature, majority of individuals with hyperandrogenism will have polycystic ovary syndrome (Yildiz 167). The problem for me became finding a recruitment solution where I could speak to potential participants in a way they understood, while at the same time recruiting individuals who were eligible. I chose to move forward with a symptom criterion list. It was detailed in the Informational Email (Appendix C) and Consent Form (Appendix E) that to be eligible for the study, participants must have the ability to speak and write in English, be 18 years old or over, self-identify as having hyperandrogenism, and have experienced two or more of the symptoms of PCOS. Participants must have experienced one symptom from List A and at least one other symptom from List B which is not the same symptom as List A. List A includes symptoms of hyperandrogenism, such as excess body and facial hair and male-pattern-baldness. The symptoms of List B include all symptoms of hyperandrogenism plus additional non-androgen-excess symptoms of PCOS such as insulin resistance and Type 2 Diabetes. This slightly complex criterion was critical because it allowed for the inclusion of participants who were experiencing at least two symptoms of PCOS, with at least one of those symptoms "threatening" normative femininity. This eligibility requirement would exclude, for example, a participant who has PCOS and is experiencing high blood pressure and diabetes, exclusively. In this example, the participant with PCOS might not reflect on issues of gendered embodiment in their illness narrative.

A two PCOS symptom threshold was chosen to simplify the eligibility markers to ensure potential participants who have lived experience with hyperandrogenism could be included in the study. Most of the symptoms included on List A, and many on List B, encompass recognizing a change in secondary-sex characteristics rather than data from a medical test result. Further, a two-symptom threshold for diagnosis mirrors the clinical diagnosis of PCOS, notably lacking the same nuance and specific symptoms. Due to the complexity of PCOS and hyperandrogenism, both do not have universal diagnostic recommendations. Health care providers may take several approaches to diagnose PCOS that may include a combination of pelvic exams, hormonal blood tests and ultrasounds. Many times, a diagnostic method called the Rotterdam consensus may be used which defines PCOS "by the presence of two of three of the following criteria: oligo-anovulation, hyperandrogenism and polycystic ovaries (≥ 12 follicles measuring 2-9 mm in diameter and/or an ovarian volume > 10 mL in at least one ovary)" (Smet and McLennan 59). In a clinical setting, this may look like a patient being identified as having two of the three experiences: irregular or infrequent periods, a blood test or clinical signs of elevated androgens, and/or a scan showing polycystic ovaries. Clinical signs of elevated androgens indicate a presence of hyperandrogenism and are typically noted as the visual presence of hirsutism determined by using a standardized face and body hair growth scoring system (Yildiz 167). Maintaining lived experience with two symptoms as a threshold for participation acted as a method to circumvent, to an extent, this diagnostic complexity.

Once a potential participant sent an email indicating their interest, I responded with an Informational Email. Over the course of recruitment, I received over fifty emails from individuals requesting more information on the study. The Informational Email includes in-depth descriptions of the study's objectives and process, expectations of participation, and eligibility requirements. If potential participants felt that they were eligible and willing to take part in the study, they were invited to respond to the email with their interest. The next stage of recruitment included a short Screening Interview (Appendix D) over Zoom. The Screening Interview consisted of three parts including an informational preamble, an eligibility check, and diversity markers. I began the Screening Interview by informing potential participants that they were able to end the interview at any time, advised them to say the word "pass" if they felt uncomfortable or unwilling to answer a question, and informed them that audio and video were not being recorded but I would be typing out their answers by filling in a survey form. Participants were asked at this time if they had any questions before we began. The eligibility section of the Screening Interview confirmed that potential participants met the criteria for participation, as detailed above. In the diversity section, participants were told: "Now I'm going to ask you some questions about how you identify. The personal data collected from these questions will not be linked back to you in any way. It may be linked to your anonymous Twine story you create in this module. It will be used to better understand how different experiences of identity can come to shape and be shaped by hyperandrogenism." Further, participants were reminded about their consent in this interview and, different from the eligibility section, they had the choice to answer all, some, or none of the following questions and this would not affect their eligibility in the study. This section recorded information on the participant's gender identity, sexuality, ethnicity, physical and psychiatric disability status, age, residence, and body size. They were also asked about any body image concerns around not feeling feminine enough as well as experience with autobiographical writing. The Screening Interview was designed in a way to enhance the capability of producing qualitative responses that centred lived experience. Although many answers were outlined as checkboxes, there was an effort to include a multitude of options, prompting questions, and space for nuanced notes. Further, the centring if lived experience was prioritized through language such “do you consider yourself to be…, “have you ever experienced…,” and “how would you describe…” An effort was made in each Screening Interview to convey small moments of my own experience with hyperandrogenism in order to establish a deeper connection and to implicate myself as the researcher in the research process, as detailed in my feminist new materialist theoretical framework. Table 2 demonstrates the participant pool makeup in relation to the Screening Interview markers.

Table 2

Participant Identity Markers

Residence		**Age**		**Person of Colour, a racialized person, or mixed race**		**Aboriginal, First Nations, Metis, Inuit, or Indigenous Person**	
Canada	8	20s	6	No	5	No	9
USA	2	30s	4	Yes	5	Yes	1
Disabled person or person with a disability		**Body Size**		**Experienced body image concerns around**		**Gender Identity**	

				not feeling feminine enough			
No	8	Average or Thin	6	Yes	8	Cis/Female/Woman	9
Yes	2	Plus	4	No	2	Nonbinary	1
Sexual Orientation		**Received healthcare treatment or visited a healthcare facility for symptoms of hyperandrogenism**		**Psychiatric disability or mental health issues**		**Prior experience writing about living with hyperandrogenism**	
Heterosexual/ Straight	5	Yes	10	Yes	5	No	5
Queer Identity	5	No	0	No	5	Yes	5

Self-reported participant identity markers were collected in the Screening Interviews of this study.

If a potential participant was eligible and willing at this stage, I would share with them the Consent Form for their review and signature. I also allowed space for potential participants to ask any questions they may have had. The Consent Form goes into further depth on the purpose of the study, the expectations of participants, methods for data collection and protection, and finally, resources for emotional wellbeing. Fourteen individuals signed the Consent Form. Once the form was signed, I sent the participant a link to the Twine Writing Module with instructions on how to complete and upload their Twine stories to a secure Google Drive folder once they were finished. Participants were made aware that they can complete the two-hour module at their own convenience in their browsers. They also were able to pause and return to the module if they chose to. Participation at this stage fluctuated. Ten participants in total completed the module. Some participants took weeks or even months to complete it, while others finished the next day. Of the fourteen participants who were sent the link to the module, four did not complete it. Most of these individuals did not respond to follow-up emails, and it was assumed that they were no longer interested.

The module design phase consisted of developing a Twine illness narrative module. The module was created using Twine itself and published on itch.io, a website for users to host indie video games. This platform was selected as a host (over other websites such as Google Drive) because the resource avoids compromising the technical features of the Twine module. The module is accessible completely in the browser. This meant that there was less potential for technological issues in comparison to if participants had to download files onto their personal computers. The module includes images, sounds and interactive components, which will be discussed below. I created this module with a specific theme of a 1980s arcade game to play with a notion of old-school computer features, such as hypertexts, being employed for gameplay. The text I used mirrored Web 1.0 computer code, the colour scheme I incorporated (bright green, purple and fuchsia) reflected the neon lights of a gaming arcade of that decade, and finally, the sounds I built into the module were free-sourced arcade game melodies that reflect climactic moments in the game being played. The module was informally beta-tested by a small number of individuals who were not participants in this study, in order to correct any technical bugs or design flaws. At the time of the study, participants used the Twine 2.3.8 release in the Harlowe 3.1.0 story format. The design and content of the Twine module will be detailed at length in later sections of this chapter.

Once a participant completed the module and uploaded their Twine story, I scheduled a Closing Interview (Appendix F) over Zoom. Ten participants met with me virtually, to complete the Closing Interview where they were asked to discuss their experience using Twine to write an illness narrative which will be detailed in-depth in a later section of this chapter. These interviews were recorded through the Zoom feature, as well as through an audio backup device, with the consent of the participant. The audio files of ten interviews were transcribed by myself using the transcription software Otter.ai. Following the completion of the Closing Interview, participants were informed that their participation in the study was complete. However, as detailed in the consent form, participants were given the option to share their Twine stories in a communal, secure Google Drive folder that other participants had access to. This process was set up to speak to the community-building aspect of illness narratives. All ten participants submitted their stories to the communal drive. Participants were informed that the portal would be open for one month. They were also advised to permanently delete any Twine story files that they downloaded to their personal computers. Finally, after successfully receiving a research grant through the Intersections of Gender at the University of Alberta, participants were each given a fifty dollar in-kind reward in the form of a gift card for their participation. In this study, I am working with underrepresented groups. Through diversity markers in screening interviews, I understand that all of my participants identify as a marginalized identity (either a Person of Colour, Indigenous, a person with a psychiatric or physical disability, Queer gender identity, and/or Queer sexual orientation). Reflecting on feminist research methods scholarship (Warnock et al. 195) about compensating underrepresented groups for their labour and time in research I concluded that an in-kind reward was appropriate. In thinking critically about how compensation affects consent, I chose to recruit participants without advertising an in-kind reward in order to connect with participants who were interested in volunteering their time to advance research on hyperandrogenism. The in-kind reward was offered to participants at the completion of the study.

All identifying information in this study was kept confidential, and the identity of participants will remain anonymous. All data from this study is stored securely on a password-protected and encrypted Google Drive. For further security, an ID has been issued to participants upon the completion of the consent form and used to label their Twine stories, Screening Forms, and Closing Interview files. The only files displaying the participant's real name and contact information are the consent form and the ID legend which are securely stored in a separate Google Drive folder. I am the only individual who has access to the ID legend. The ID legend could be made available to the Research Ethics Board at their request.

The final stage of the research was the data analysis phase. Data in the form of the anonymized Twine stories and the Closing Interview transcripts were coded first thematically using the NVivo qualitative coding software. Themes in the data were analyzed using nodes in this software. The data was then analyzed using the critical discourse analysis methodology for digital-born narratives detailed at length in the Methodology chapter. NVivo was chosen as the data analysis tool because of its capability to engage with data beyond traditional transcripts, including image captures of Twine stories. A student NVivo license for this study has been purchased through a research grant from the Intersections of Gender at the University of Alberta.

Module Design

In the first stage of research for this project, I developed a Twine module to support the facilitation of writing illness narratives in literary hypertext. The Twine module was designed using some perspectives of narrative therapy, in particular the work of Renee Dumaresque, Taylor Thornton, Daniela Glaser and Anthony Lawrence in their article "Politicized Narrative

Therapy" which uses anti-colonial discursive frameworks, critical race theory and counter-storytelling, Black feminist thought, and anti-sanist theorizing to reimagine narrative therapy as a means to enact political change. Dumaresque et al.'s political framing of narrative therapy was chosen as a framework to inform the development of the Twine module because of its affinity with Martinez and Fleck-Henderson's notion of health liberation (as discussed in the Introduction chapter). Health liberation, and in this context political narrative therapy, positions illness as a social justice issue rather than an individualized aliment and turns to social, institutional, and political-based solutions. Akin to illness narratives' sociohistorical identity as a political tool of counter-practice to normative medical approaches to healing, "Politicized Narrative Therapy" argues that traditional approaches to narrative therapy are deeply saturated in colonial perspectives that uphold neoliberal foundations in healthcare (Dumaresque et al. 109). The authors work to situate the practice of narrative therapy within a neoliberal desire to commodify recovery as an economy of therapy which sees illness narratives taken up as marketing content. Within this structure, the work of getting well becomes the responsibility and financial burden of the individual which upholds the psychiatric institution as an authority (Dumaresque et al. 109). The authors argue that narrative therapy, "born from the intersection of whiteness and social work," (Dumaresque et al. 111) has a legacy rooted deeply in Eurocentric origins and engagement with this framework must be concerned with the ways in which perspectives of Indigenous and racialized cultures become legitimized through their cooption by formal psychiatry and medicine (Dumaresque et al. 113). This project has worked to reposition hyperandrogenism as a political identity and therefore it became important for the framework used to develop the therapeutic perspectives of the module to reflect this. Dumaresque et al. offer a four-step framework for politicizing the practice of narrative therapy, by which the design of this project's Twine module, Closing Interviews and community-building portal are informed.

According to Dumaresque et al., the practice of narrative therapy did, in fact, emerge from a desire to resist traditional methods and approaches to medicine, such as a biomedical model that pathologized emotional distress as an ailment of the body. Informed by Foucault's conceptualization of discourse and power as constructive and productive, narrative therapy, in theory, understands language as a political agent and the ways in which people narrativize their lives work to shape experiences of reality. As the authors describe "Knowledge created by bodies in power results in taken-for-granted truth claims that discredit, displace, and silence subjugated knowledges, producing norms, defining deviance, and therefore governing lives" (Dumaresque et al. 115). In the process of externalization of narrative in narrative therapy, Dumaresque et al. argue that while some therapists appropriately work to support the flourishing of alternative truths that challenge oppressive knowledge systems, many fail to effectively deconstruct or intervene in the insuperable nature of dominant discourse (116). The authors give the example of therapists who treat neurodiverse children. When a narrative therapy approach fails to call into question the mechanics of diagnosis, "therapists are complicit in reinforcing the violence inherent in the medical model" (Dumaresque et al. 116). Yet, beyond complacency, therapy professionals are offered limited resources in the biomedical model that may work to challenge ineffective approaches to supporting the well-being of the patient (Dumaresque et al. 116). The research question for this project intentionally avoids veering into the realm of a formal medical-therapeutic inquiry. It does not ask about measurable outcomes regarding mental health questionnaires and/or reduction of symptoms (although these factors are significant and valuable). By asking about the development of positive relationships between the self and world, the crux of the research question of this project is attempting to grapple with meaning made between the individual and the structural-political in a way that foregrounds the individual's experiences with systems, structures, and institutions that may participate in the pathologizing of their identity. Therefore, Dumaresque et al.'s interpretation of narrative therapy not as an individualized treatment method, but as a political act, offers generative methods to inform the research.

The initial step in the process of narrative therapy is to identify the problem story or an unhelpful sense of reality that a person may hold about themselves (Dumaresque et al. 118). In a typical approach to the method, a therapist may engage with the patient to identify the problem story and then work to challenge the inherent assumptions that uphold it. Dumaresque et al. argue, though, that the act of destabilizing the problem story must go further to make visible the dominant discourses that underpin this story and become the foundation of our belief systems. This is the process of connecting the problem story to larger sociocultural, historical, and political contexts (Dumaresque et al. 118). For the Twine module, it became important that an identification of the problem story relating to the experience of hyperandrogenism as a political identity had to be unearthed prior to the participants writing their illness narratives. This was because, although all participants in Screening Interviews framed their illness to me in a way that acknowledged their experience as political, I wanted to ensure that each participant understood the sociohistorical context. This was done through several choices made throughout the module.

The module is divided into six parts with the second section devoted to the topic of hyperandrogenism. Participants read passages that describe a clinical description of the illness as well as common symptoms that can arise. Participants are then prompted to think about the distress many individuals with hyperandrogenism experience, not only from the physical manifestations of the disease but from perceptions of failing to meet a particular standard of womanhood. The rest of the section focuses on the story of Caster Semenya, a South African Olympic track runner who was mandated by the International Association of Athletics Federations (IAAF) to undergo a "sex-verification" test following a public inquiry into her biological sex. As described in depth in the Introduction to this paper, the IAAF ruled that Semenya had to pharmaceutically lower her natural levels of testosterone in order to compete in the women's category of her sport. In the telling of Semenya's story, participants click through passages that describe Semenya's public reflections on the injustice of her experiences, as shown in fig. 18, and further context into how the IAAF facilitates bans on particular bodies over others. Near the end of this section of the module, the participants read a passage that outlines several assumptions that underpin the IAAF's decision, including that biological sex is a binary where there are only male and female bodies, athletic competitions are already level playing fields for those who compete, and high testosterone always gives an athletic advantage. These assumptions are informed by Julian Savulescu's article for *The Conversation* called "Ten Ethical Flaws in the Caster Semenya Decision on Intersex in Sport." Rather than overtly challenge these beliefs, the module invites the participant to consider: "what do you think?" This moment of reflection opens space for the participant to engage with the information provided by the module in relation to their own experience with hyperandrogenism to perhaps connect their experience to Semenya's.

Although Semenya was raised as a girl and has always identified as a woman*, over many years she has endured a public legal battle with the IAAF who have ruled that she must lower her natural testosterone in order to compete in the women's* category of her sport.

Semeya has discussed her experiences over the years being mandated to undergo intrusive and dehumanizing examinations from the age of 18. Her experience of hyperandrogenism, and the experiences of many other women* competing in professional and amateur sport, has included a public defense of their gender identity.

Fig. 18. Screenshot of Twine Illness Narrative Module

It is important to locate the problem story within the sociocultural context, as through the experience of Caster Semenya, however, it is equally vital to identify the problem discourse within the participant's individualized reality. In part three of the module, participants were led through a storyboarding exercise that later becomes the foundation for their Twine illness narrative. Participants are asked to reflect on the moments that have defined their illness experience. As brief or descriptive as they prefer, participants are asked to write down, on a piece of paper, three titles that represent three of the most important moments of their illness. For each moment, participants are invited to choose a colour to represent how they felt in that moment, along with descriptions of what that colour represents to them. Using colour association is one task-oriented approach to some methods of therapy for trauma treatment (Rankin and Taucher 140). At this point in the module, participants engage in a seven-minute, low-stakes free writing exercise. The module explains that free writing is a technique for building narratives where the author writes about a topic continuously for a set amount of time. What is important for free writing is that thoughts about grammar, spelling, or punctuation should refrain from impeding the flow of writing. Participants are encouraged to use their "moments" as a home base to build their narratives and are offered different options for connecting with one, two, or all three of their moments.

For the next 7 minutes you will Free Write about your experience in Moment 1, 2 and/or 3.

You can use a Writing Prompt to guide you:

In this Moment, how did it *feel* to be in your body?

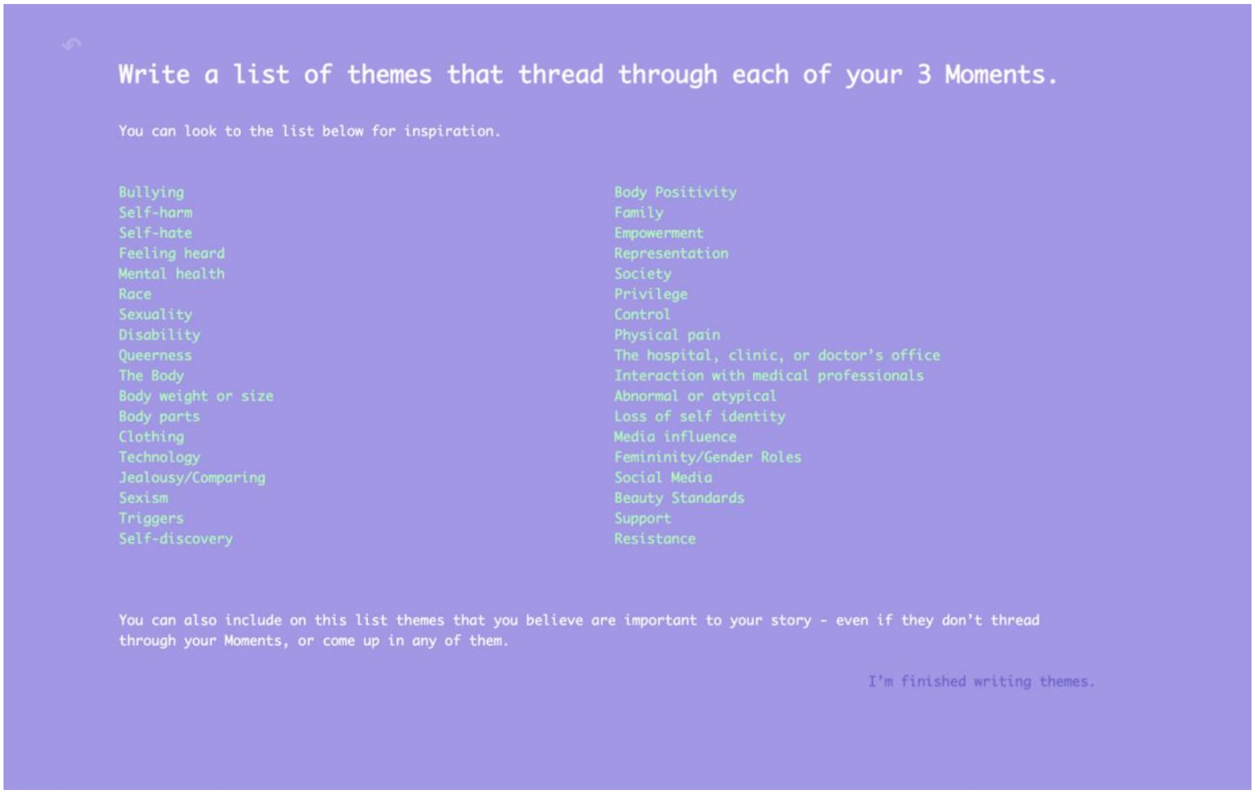
What did you see, smell, taste, or hear?

I'll move you to the next passage after 7 minutes is up.

I'm done Free Writing early.

Fig. 19. Screenshot of Twine Illness Narrative Module

Fig. 19 shows the free writing passage with the following writing prompt that centres embodiment: "In this Moment, how did it *feel* to be in your body? What did you see, smell, taste, or hear?" This passage is set on a seven-minute timer and plays instrumental music in the background which participants are given the option to silence. The choice to offer background music during Twine writing exercises was informed by feedback from participant workshops for a related research project I contributed to, Writing New Bodies (Ensslin et al.). The participants in Writing New Bodies suggested a popular YouTube stream called "lofi hip hop radio - beats to relax/study to" which was used in the Twine module for this study. Following the encouragement of a break to respond to physical or emotional needs brought up during the free writing process, participants are asked to complete the final step of storyboarding their narratives. As shown in fig. 20, participants are asked to brainstorm a list of themes that may thread through each of their three defining moments. The passage provides some example themes that may be a helpful starting point, such as control, body positivity, and social media. An example of what a participant's paper may look like at this final stage is shown in fig. 21. This closes the third part of the module and participants are encouraged to use this exercise as the foundation for their Twine illness narrative if they choose. The practice of storyboarding the illness narrative, at this stage of the module, is an effort to identify the problem story and dominant discourse by pulling out the embodied experience of the participant in the wake of engaging with the political context of the disease.



Write a list of themes that thread through each of your 3 Moments.

You can look to the list below for inspiration.

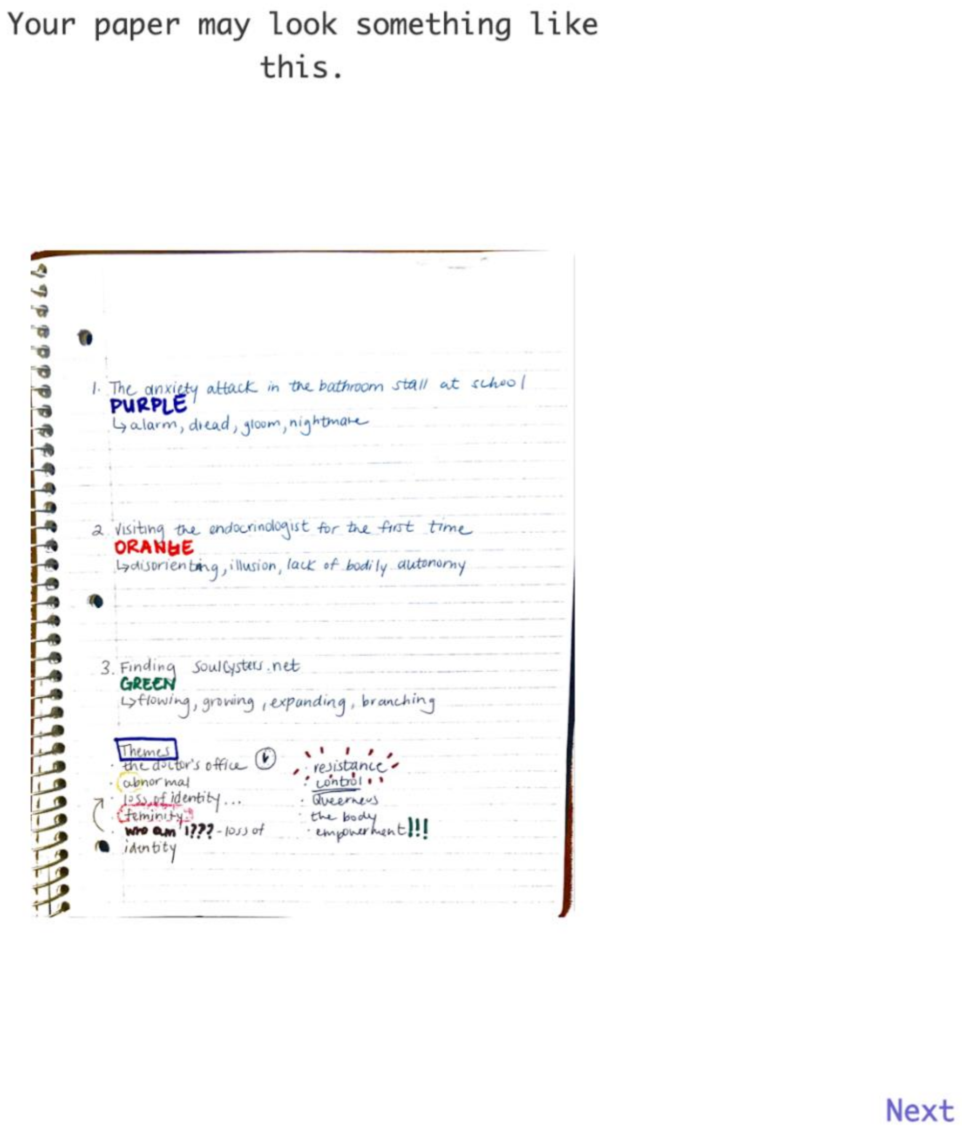
Bullying
Self-harm
Self-hate
Feeling heard
Mental health
Race
Sexuality
Disability
Queerness
The Body
Body weight or size
Body parts
Clothing
Technology
Jealousy/Comparing
Sexism
Triggers
Self-discovery

Body Positivity
Family
Empowerment
Representation
Society
Privilege
Control
Physical pain
The hospital, clinic, or doctor's office
Interaction with medical professionals
Abnormal or atypical
Loss of self identity
Media influence
Femininity/Gender Roles
Social Media
Beauty Standards
Support
Resistance

You can also include on this list themes that you believe are important to your story - even if they don't thread through your Moments, or come up in any of them.

I'm finished writing themes.

Fig. 20. Screenshot of Twine Illness Narrative Module



Your paper may look something like this.

1. The anxiety attack in the bathroom stall at school
PURPLE
↳ alarm, dread, gloom, nightmare

2. Visiting the endocrinologist for the first time
ORANGE
↳ disorienting, illusion, lack of bodily autonomy

3. Finding SoulCysters.net
GREEN
↳ flowing, growing, expanding, branching

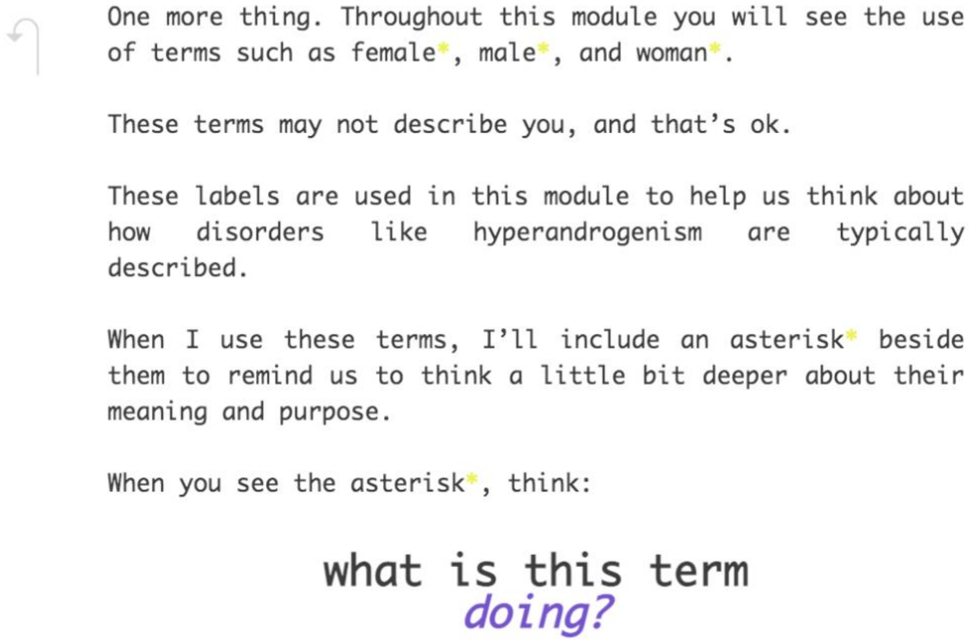
Themes
- ~~the doctor's office~~
- abnormal
- loss of identity...
- femininity
- **who am I???** - loss of identity

- resistance
- control
- Queerness
- the body
- empowerment!!!

Fig. 21. Screenshot of Twine Illness Narrative Module

In typical approaches to narrative therapy, the second step in the therapeutic process is to externalize the problem story. According to Dumaresque et al., externalizing work is a direct response to what narrative therapists believe is a chronic internalizing by the patient (119). Individuals seeking therapy, within this framework, have over time become skilled at framing the problem story as a personal character trait that embodies who they are. This maneuver to unify the individual with the problem story makes it difficult to connect experiences to the larger sociopolitical context and understand the systems of power that contribute to upholding the structure of the problem story. Dumaresque et al. call these “totalizing self-narratives” and argue that they often cause individuals to “experience feelings that negatively impact their life, such as blame, guilt, and isolation” (119). The process to externalize the problem story begins by “mapping the influence of the problem on the service user’s life, such as when, where, and in what ways the problem is impacting the person, and how the problem has survived over time” (Dumaresque et al. 120). Then, the therapist and the patient collectively agree on a label to name the problem. This act works to identify the problem story as an entity separate from the self. However, Dumaresque et al. push this practice further through a call to not only externalize the problem story but to politicize it. The authors argue that the act of identifying the problem story and removing it from the internal self fails to dislodge the larger sociostructural factors that may have situated the problem story as a political experience of oppression.

As described in the Introduction chapter, the use of gendered language is complex in this project. Hyperandrogenism is a deeply gender-saturated illness where clinical diagnosis is reliant on understanding an incongruence between biological sex and embodiment. It is critical to speak about these gendered implications, however, participants in this study and individuals diagnosed with the disease are not only women. One of the initial acts of externalization taken in the Twine module was attempting to destabilize the relationship between the individual and their gender identity. This was not an attempt to claim that gender identity is somehow not inherent to identity, however, it was important to have participants look at the concept of womanhood as outside of themselves so they may have a vantage point to interrogate its presumed coherence. Fig. 22 shows a passage that appears during the instructional section of the module. The passage explains that gendered and sexed terms will be used throughout the module, but that they may not reflect the identity or experience of every participant. During every instance of gendered and sexed language throughout the module, participants will see a flashing yellow asterisk beside the word. This feature is intended to remind the participant to take up an externalized vantage point to think deeply about what function that term is performing.



One more thing. Throughout this module you will see the use of terms such as female*, male*, and woman*.

These terms may not describe you, and that's ok.

These labels are used in this module to help us think about how disorders like hyperandrogenism are typically described.

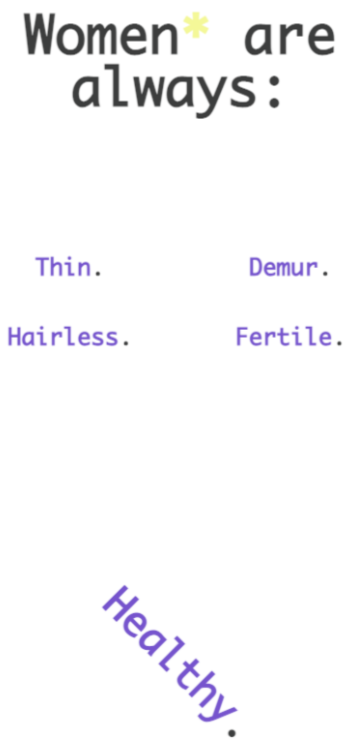
When I use these terms, I'll include an asterisk* beside them to remind us to think a little bit deeper about their meaning and purpose.

When you see the asterisk*, think:

what is this term *doing?*

Fig. 22. Screenshot of Twine Illness Narrative Module

As the module progresses, a passage details several of the many symptoms that hyperandrogenism may cause, followed by the note: "Dealing with any of these symptoms is scary because we live in a culture that sets high standards for what it means to be a woman*." The flashing asterisk beside the term *woman*, here, is intended to encourage the participant to reflect, not only on what these high standards may be but what being a woman might mean to them. In fig. 23 and fig. 24, participants are led through a series of passages that grapple with some basic stereotypes of womanhood that hyperandrogenism disrupts, including the terms thin, demur, hairless, and fertile. When the participant chooses one of these options, they are brought to a jarring passage with red letters that challenges the reader/player to consider: “Are They?” This passage sequence is intended to invite the participant to engage with a gendered stereotype, and then pause them in a passage to question these assumptions. Once the participant chooses the hypertext “Healthy” the next passage asks the reader to consider: “What does it mean to you to be healthy?” This moment is designed to position the participant to think about binaries such as *health* and *illness* and how hyperandrogenism fits into that narrative. For example, a participant might consider, here, that they may have internalized beliefs that a hairless body means a healthy body. Ideally, the participant has an opportunity here to reflect on the distress that hyperandrogenism embodiment causes and make a link to any internalized assumptions around gender expression that may contribute to this distress. This is a small moment to begin to shift the distress from an internal failure to meet standards of gender to the external cultural expectations of how the body should present.



Women* are
always:

Thin. Demur.

Hairless. Fertile.

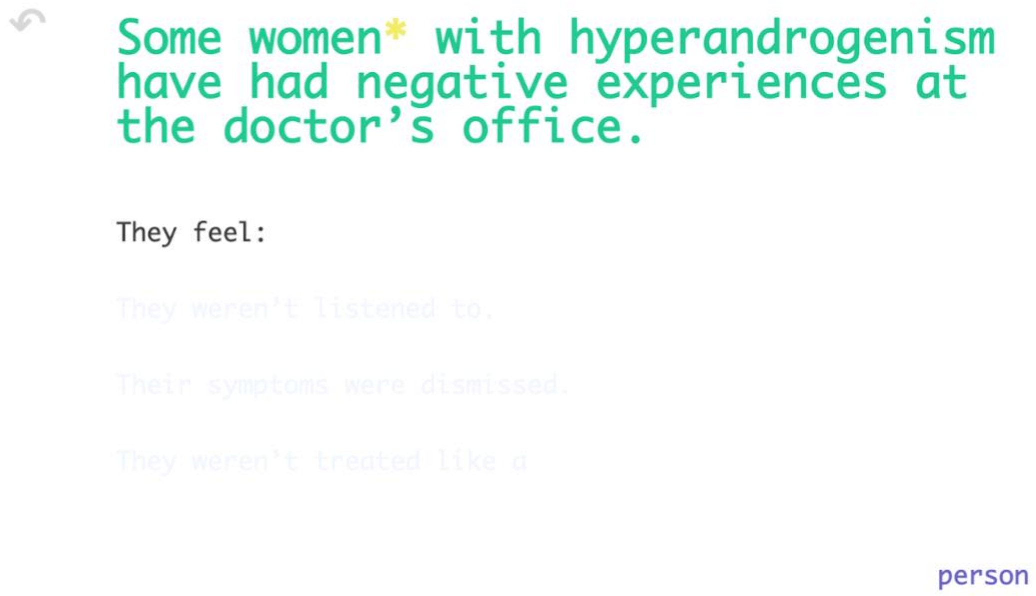
Healthy.

Fig. 23. Screenshot of Twine Illness Narrative Module

Are They?

Fig. 24. Screenshot of Twine Illness Narrative Module

One of the most critical aspects of this project is grappling with the experience of individuals with hyperandrogenism in the normative healthcare system. Therefore, working to externalize distress around the patient-healthcare provider encounter and connect it to larger political contexts was important. During a section of the Twine module, participants are asked to reflect on how they may feel when they visit the doctor. Fig. 25 shows a passage that explains how some individuals with hyperandrogenism have a difficult time when they visit the doctor, followed by a list of example reasons, including “They weren’t listened to,” “Their symptoms were dismissed,” and “They weren’t treated like a person.” These examples are barely visible and only become legible once the participant hovers their cursor over them, a design choice to convey a sense of revealing hidden notions of shame. The module continues: “It’s almost impossible to block out all these messages that say something is wrong with your body. Some women* have even described their bodies as: Dysfunctional, abnormal, or sick. It isn’t talked about very much, so hyperandrogenism can be lonely, too." This section is followed by a passage that explains that many individuals deal with hyperandrogenism and some of them use writing as a method to cope with emotional distress. This section is intended to externalize and politicize negative experiences born from hyperandrogenism's contact with the healthcare system. If participants have felt dehumanized in their healthcare encounters, rather than situating themselves or their bodies as the problem origin, the module attempts to shift the narrative to challenge the system's capacity to appropriately respond to differing bodies.



Some women* with hyperandrogenism have had negative experiences at the doctor's office.

They feel:

They weren't listened to.

Their symptoms were dismissed.

They weren't treated like a

person

Fig. 25. Screenshot of Twine Illness Narrative Module

After the identification and externalization of the problem story, what follows in the narrative therapy process is typically the development of alternative, generative stories of the self. For the therapeutic process, identifying alternative stories begins first with interrogating the power of the problem. According to Dumaresque et al., narrative therapists might work with clients to identify moments, both historically and currently, where the problem lacked control over the individual, or the individual gained power over the problem (122). Mapping moments of agency for the individual, according to the authors, works to destabilize the perceived omnipotence of the problem as all-encompassing to the life of the individual. The authors refer to these moments of exception as “unique outcomes” and argue that these details can be used to construct an alternative narrative of the individual’s experience (Dumaresque et al. 122). Individuals, here, “are able to think of their identities, lives, and relationships without the problem, and are able to begin exploring new and preferred ways of being in the world” (Dumaresque et al. 122). In this process, narrative therapists might ask individuals to think deeply about their lives absent from the context of their dominant story, how it would look, and how they might feel. This enacts the process of re-authoring their dominant story in a way that opens up space to develop an alternative, productive narrative of the self. For Dumaresque et al., however, the reauthoring of the alternative story must also include the production of alternative discourses that challenge the dominant, restrictive ways of knowing that facilitate complex forms of oppression. The authors argue that “Alternative stories often provide an opportunity to create new meaning for an individual, whereas alternative discourses challenge dominant social conversations with ideas informed by subjugated knowledge and values” (Dumaresque et al. 122). The authors use the case study of a “Latin American woman named Sofia” who was seeking therapy due to perceived feelings of “worthlessness” in her marriage. Sofia’s dominant discourse of worthlessness was identified, externalized and reframed in a political way as domestic abuse and “white colonial patriarchy” (Dumaresque et al. 123). Sofia was led to identify moments where the dominant discourse of worthlessness may have been absent, such as during “community organizing with other women [which] made her acknowledge all of her skills, passion, and labour, which go unappreciated and undervalued in much of society and in her home" (Dumaresque et al. 123). Through this process of political narrative therapy, the practitioner was able to counter Sofia's initial self-loathing for a perceived inability to be a "good" wife and reframe the narrative in a way that the patient understood and embraced as race and gender-based cultural oppression, reinforced through the abuse of her husband.

As discussed in depth in the introduction to this chapter, the Twine module in this study was not intended to facilitate formal therapy, narrative or otherwise, for participants. It stands as a tool for individuals to use to write illness narratives. There is no therapy professional guiding the writing process and the experience is intended to be accessed by individuals in isolation if needed. Therefore, the third step in Dumaresque et al.'s narrative therapy process is not directly implemented into the Twine module of the study, however, there are moments and outcomes that do reflect the impact of reauthoring and alternative discourse formation. Most notably, participants appeared to have engaged with the processes of alternative story building in the writing of their Twine illness narratives, which will be discussed in the Analysis and Discussion chapter. In the final section of the module, participants are invited to write their own illness narrative in Twine based on their experience with hyperandrogenism. Participants are instructed to think deeply about what story they desire to tell. The illness narratives can be new or an expanded version of the storyboarding exercise, but critically, the module notes that there are no expectations for this piece of work and participants are free to build their story the way that feels right to them. Participants are reminded: "You are the author. Your story can be long, or very short. Don't worry about writing a 'perfect' or even 'finished' piece of work, instead, focus on reflecting on your memories in a new way." Once the participant is ready to write, they click the hypertext that brings them to a new writing prompt: "What is it like to live in a body with hyperandrogenism?" The writing process of the module is designed to take around 45 minutes, however, participants are able to allow the amount of time they prefer. Fig. 26 shows the writing prompt passage which includes a list of hypertexts to remind participants of the technical aspects of Twine detailed in earlier sections of the module. This passage is coded with sound-adjustable instrumental music and a timer of forty-five minutes. The module will bring the participant to the next passage when the time runs out, but participants are able to leave the passage early or return to it afterwards.

For the next 45 minutes (or so), write a Twine story that responds to the following Writing Prompt:

What is it like to live in a body with hyperandrogenism?

Please remember to regularly save your work.

Common Questions

How do I set up Twine?

How do I write a story in Twine? How do passages work?

How can I “test” my story

How do I save my story? How do I reopen a saved story?

How do I change my story background color? How do I change my text color?

How can I add style to my text? How do I change where my text appears on the screen?

I’m finished my Twine Story

Fig. 26. Screenshot of Twine Illness Narrative Module

An additional and critical opportunity to engage with the process of alternative discourse writing was during the Closing Interview of the study. Following the completion and submission of the Twine illness narrative, participants were invited to meet briefly over Zoom for a Closing Interview to discuss their experiences in the study. The Closing Interview begins by thanking the participant for their contribution to this study, a detailed reiteration of expectations for consent and (revoking) participation, a reminder about processes for data collection including audio recording, and finally, a description of the intention of the interview. Participants are informed that, at the core, the information provided will help decipher if and how nonlinear digital writing is a valuable tool for individuals with hyperandrogenism to write their experiences of illness. The Closing Interview is intentionally brief and open-ended, consisting of two questions, with various prompts to expand responses. The first question asks what the participant's experience was using Twine and the second how the participant might describe their feelings toward their body, identity, or ideas about where they fit in the world after writing about their illness. The second question includes a caveat that this may look like having a new, positive perspective on how the body is perceived in the world or perhaps developing a kinder evaluation of the body. The first open-ended question of the interview is intended to gather information and feedback on the accessibility and usability of Twine as a tool. This speaks to understanding, beyond the therapeutic value of illness narratives, the feasibility of the technical aspects of the method as enabling or inhibiting the writing process (or, likely, a combination of both). The second question seeks to explore the therapeutic value and contribution to a more generative relationship to the self, facilitated through the writing process. Both questions, in relation to one another, seek to answer the research question of this study: how can women and nonbinary individuals with hyperandrogenism use literary hypertext technology to write illness narratives that construct positive relationships between their identities and the world? In this sense, how can positive relationships be constructed both through the therapeutic and technical process of writing literary hypertext?

The final step in Dumaresque et al.'s political approach to narrative therapy is what the authors refer to as "thickening the thread" of the alternative story (124). In a typical approach to narrative therapy, this may look like cultivating strategies with the individual to fortify the new, alternative story and stabilize it within their lives. Strategies may include “affirming art work, support groups, or investing deeper in new knowledge that has been raised through the therapeutic process” (Dumaresque et al. 124). The political reimaging of narrative therapy’s thickening of the thread, for the authors, is the act of establishing the alternative discourse as a collective narrative. Dumaresque et al. argue that rather than halting at the reinforcement of the alternative narrative, “In politicizing this step, individual experiences of oppression should be connected to the broader community or communities of people experiencing similar struggles” (124). This is a critical step in the process to understand the alternative discourse as a sociohistorical actor that comes to shape not only the individual but the community with which the individual identifies. The authors argue that if the biomedical model intends to treat the distress of the individual, healing and resistance must begin at the root of experience, or the community. This approach, according to the authors, will bring sustainable social change by positioning individualized distress as a responsibility for the larger collective.

The practice of thickening the thread and collectivizing experience that is central to political narrative therapy is similarly at the heart of the illness narrative genre. As discussed in the Literature Review chapter, locating a community through writing in the face of individualized subjugation, culturally and/or medically, has been a central way illness narratives have been taken up in scholarship. Finding a method to thicken the thread for this project, however, was complex. Protecting identities, respecting consent, and nourishing a safe space to share vulnerable stories were the highest priorities for conducting this research. Inserting the Twine illness narratives submitted by participants into a public online space where they could be mediated by communities of reader/players, theoretically, would speak to the essence of illness narratives as a community-building tool. However, this was not considered for this project for various reasons, including maintaining the anonymity of participants and shielding their personal stories from potential online discord. Therefore, I decided to include a small-scale community-building aspect to the study where participants were invited to share their Twines in a secure and private Google folder for other participants to read. This was not a formal aspect of participation, and participants were informed that they were not required to share their stories. If they chose not to submit their Twines to the folder, their stories would still be included in the study. The community-building portal, to which all ten participants chose to contribute to, became one of the most vital aspects of the research process. The portal was open during the month of April 2021. As this was not a formal aspect of the study, participants were not interviewed about their experiences exploring the Twine stories of others, however, one participant noted informally over email: “I just spent the evening reading through everyone's story and I've been crying the entire time. I feel seen, heard and validated within my own experiences and feel a kinship with the other participants (even though they are anonymous).” This feedback from a participant, who granted consent to publish this quote, validates the intention of health liberation and thickening the thread of the illness experience, in this study and beyond.

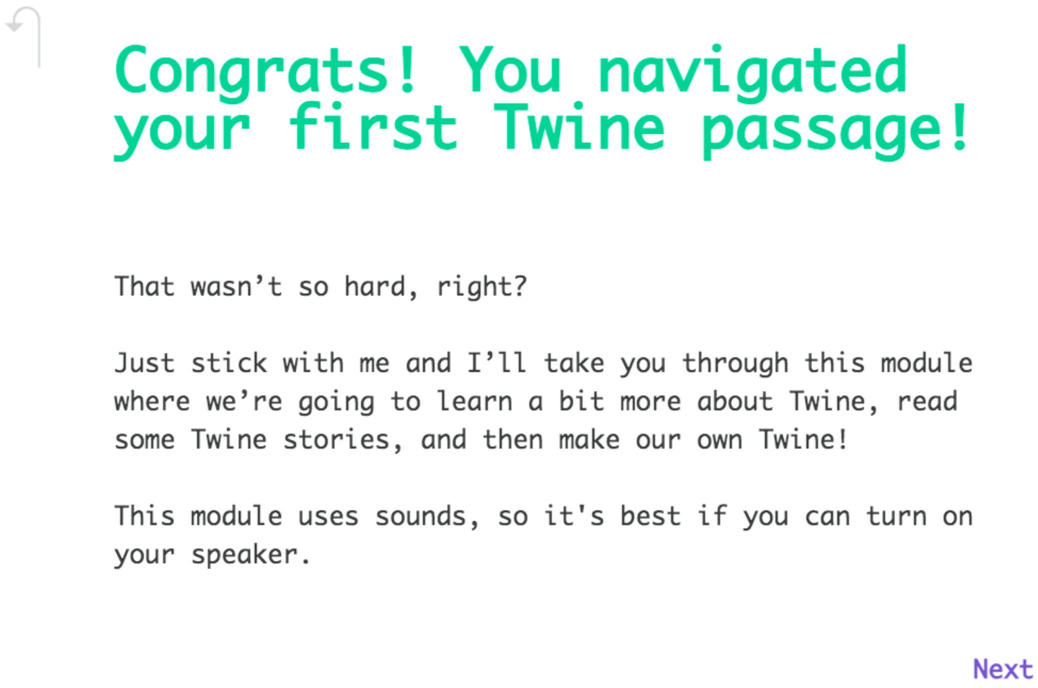
Teaching Twine

In addition to design elements of the module that engage with the process of narrative building and the political framing of pathology, the module also had to stand as a pedagogical tool for the Twine technology. Building a comprehensive tutorial for new authors of literary hypertext was complex. Due to pandemic and geographic restrictions, participants completed the study in isolation and while they had access to me for any questions or guidance they required, it was important that they felt empowered to complete the writing process rather than discouraged.

Further, having the participants complete their Twine stories alone, in the privacy of their own space, was an intentional choice to reflect the identity of illness narratives as counter-practice to established medical institutions. This counter-practice, as described in the Literature Review chapter, has assumed a culture of speaking back to normative medicalized discourses where, oftentimes, an author's only act of resistance might be their individualized writing process. Therefore, it was important for the module of this study to embody an understanding of this sociohistorical context and stand as a comprehensive resource. In order to accomplish this, the module was designed with six various sections including an introduction, a political framing of hyperandrogenism, an introduction to Twinery.org, storyboarding, a Twine tutorial, and the final illness narrative prompt. Several of these sections have been discussed above in relation to their relationship with narrative therapy. This section will discuss the design of the technical instructive sections of the module as a pedagogical tool for teaching literary hypertext and the Twine technology. Much of the technical instructions of this module were heavily informed by feedback from the informal beta-testers of the module.

As the majority of participants had no previous experience with literary hypertext, it was critical that the opening passages of the module include a linear and explicit navigation path, rather than rhizomatic, branching options that could have the potential to confuse a new reader/player. However, it was even more imperative that the module resisted making assumptions about a participant's previous knowledge of the functionality of hypertext. I did not want to assume that participants would inherently be familiar with even typical displays of hypertext, such as a body of black text that includes a distinctly coloured, underlined word. The opening passages of the module, therefore, set the foundation for understanding where to click to move forward and through the exercise. The module opens with a blinking hypertext that reads:

"Click Me." This becomes the first indication that clicking certain text in the module will bring you to a new passage. As shown in fig. 27, once the participant clicks the text, they are brought to a passage that reads: "Congrats! You navigated your first Twine passage!" The hypertext in this second passage is intentionally discernable and reads: "Next." However, not all the hypertexts in this module are intuitive in this way. Feedback from informal beta-testers noted that hypertext must be marked in a specific and uniform way that is obvious to the user who is navigating the module. The evident solution was to colour code the hypertext and make this known to the participant. Although this method was successful with the participants in this study, future research should consider accessibility in relation to hypertext colour. Fig. 28 shows a passage explaining the colour code and ensures that participants understand this code before they move forward in the module. The passage contains various red herrings in the form of different coloured text and text marked in other ways that participants may recognize as hypertexts (for example, underlined text and blinking text). But it is only the purple text that will bring the participant forward in the module. In fig. 28, participants must click the word "Forward" to move to the next passage. Finally, informal beta-testing noted that it was not intuitive that you may have to scroll down in the module to find the purple hypertexts. Therefore, fig. 29 shows the next passage of the module that explains this feature: "Here's a tip: sometimes you might have to scroll down to find the purple hypertext links!" Once the participant scrolls down on this page, they find a small hypertext that reads: "You found me!" In beta-testing, these instructional passages proved to be sufficient to effectively convey the nature of literary hypertext navigation.



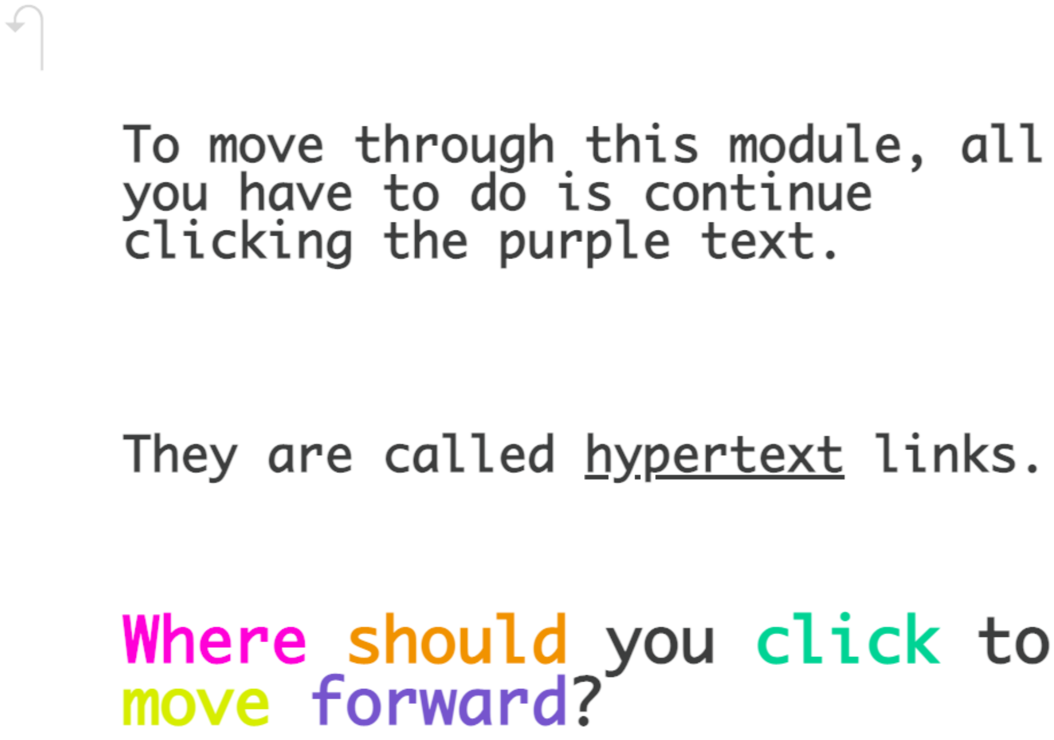
Congrats! You navigated your first Twine passage!

That wasn’t so hard, right?

Just stick with me and I’ll take you through this module where we’re going to learn a bit more about Twine, read some Twine stories, and then make our own Twine!

This module uses sounds, so it's best if you can turn on your speaker.

Fig. 27. Screenshot of Twine Illness Narrative Module

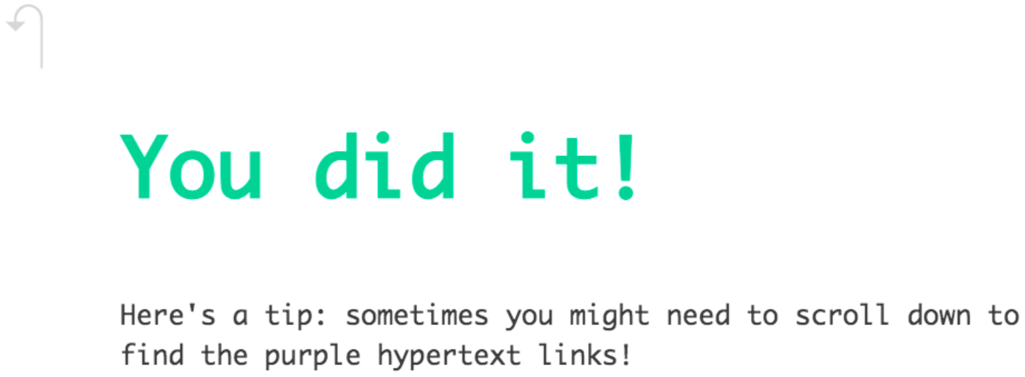


To move through this module, all you have to do is continue clicking the purple text.

They are called hypertext links.

Where should you click to move forward?

Fig. 28. Screenshot of Twine Illness Narrative Module



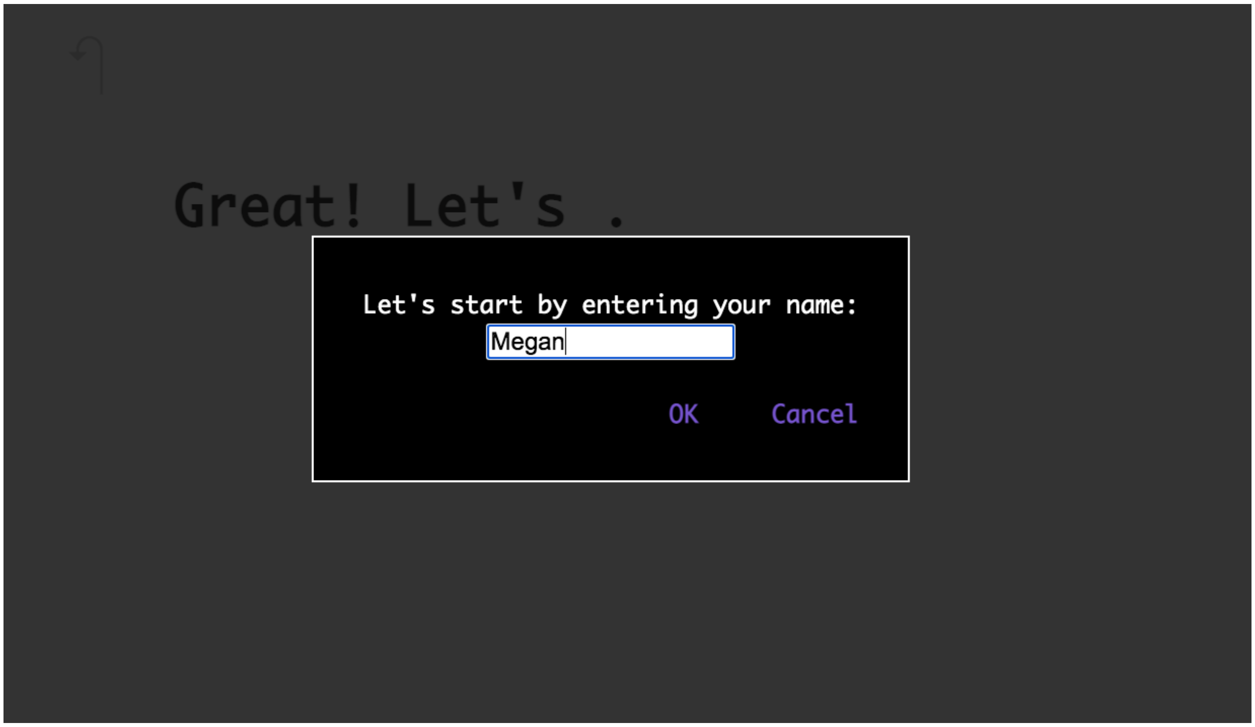
You did it!

Here's a tip: sometimes you might need to scroll down to find the purple hypertext links!

Fig. 29. Screenshot of Twine Illness Narrative Module

It was critical for this module to be designed in a way that showcases how dynamic Twine stories can be and also the tool's identity as an interactive and rhizomatic storytelling technology. Through various coding elements, I built in interactive features that allowed participants to input certain information about themselves. For example, in fig. 30 participants are asked to write their names into a text field. After this information is inputted, throughout the module this data is inserted into different sections to create a sense of a personalized experience for the participant. In addition to a more connected experience, this passage is intended to display how Twine can incorporate interactive elements.

In order for participants to receive more robust encounters with Twine's interactive capabilities beyond what was possible in the module, it was important to connect them to a variety of dynamic published Twines. In the section that introduces participants to the Twine technology, they are invited to spend fifteen minutes reading through at least two different Twine games. Fig. 31 shows seven different game options, including Anna Anthropy's *Queers in Love at the End of the World* and Zoë Quinn's *Depression Quest.* The module explains that some Twines are more complex than others, but not to let that discourage them as by the end of the module they will have all the tools required to build a simple story themselves. Following this exercise, the module explains that the intention of engaging with other Twine stories is to reveal how multifaceted the medium can be, noting: "funny, sad, shocking, autobiographical, make-believe, science fiction, disorientating…You Decide." While the majority of participants were new to literary hypertext and programming and this module did not focus on skills for building complex aspects of Twine found in many of the stories participants read, there was an intention to embolden the participants to think deeply about what their stories can do.

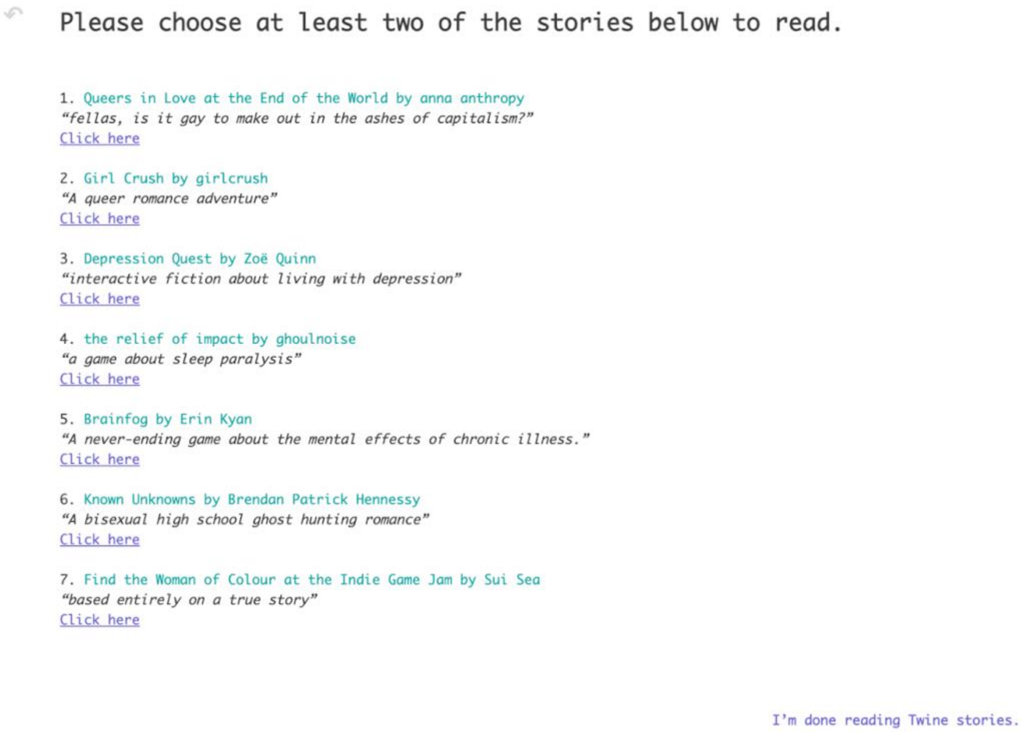


Great! Let's .

Let's start by entering your name:

Megan

Fig. 30. Screenshot of Twine Illness Narrative Module



Please choose at least two of the stories below to read.

1. Queers in Love at the End of the World by anna anthropy
“fellas, is it gay to make out in the ashes of capitalism?”
Click here

2. Girl Crush by girlcrush
“A queer romance adventure”
Click here

3. Depression Quest by Zoë Quinn
“interactive fiction about living with depression”
Click here

4. the relief of impact by ghoulnoise
“a game about sleep paralysis”
Click here

5. Brainfog by Erin Kyan
“A never-ending game about the mental effects of chronic illness.”
Click here

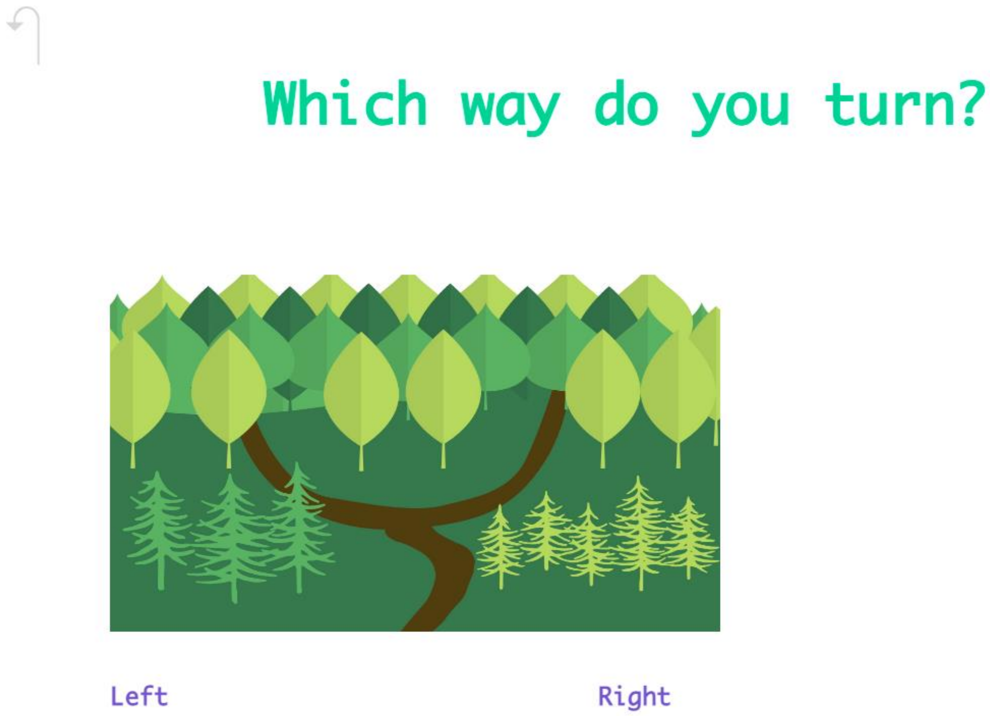
6. Known Unknowns by Brendan Patrick Hennessy
“A bisexual high school ghost hunting romance”
Click here

7. Find the Woman of Colour at the Indie Game Jam by Sui Sea
“based entirely on a true story”
Click here

I’m done reading Twine stories.

Fig. 31. Screenshot of Twine Illness Narrative Module

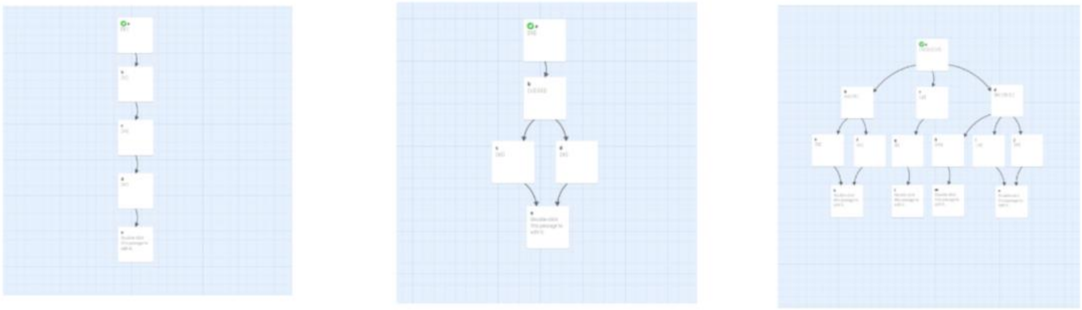
Understanding the capacity for multiplicity in the Twine story structure was a key learning outcome of the module. The module itself was not rhizomatic in that it produced an identical user path for all participants. This was a critical design choice to ensure every participant received the same information in their experience of the module. However, there were moments of rhizomatic multiplicity built into two separate sections. The first section is a scene with a simple A versus B hypertext path choice. A passage explains that Twine can build nonlinear stories and “by nonlinear, I’ll show you what I mean.” The following passage is marked by the clicking sound of a typewriter. Soon text begins to appear, letter by letter, writing the beginning of a familiar story. The passage reads: “Once upon a time... [Name pulled from interactive input] was walking through the woods. Suddenly they come across a folk in the path ahead.” As shown in fig. 32, the participant is asked to choose a direction to turn: right or left. Either hypertext can be chosen and this is the first moment in the module that displays a multiple path choice. If the participant chooses left, they are confronted with a loud snap of thunder and subsequent sounds of rainfall. A dark image of a forest in a storm appears on the screen. The text explains that the storm is raging, and the forest path begins to flood at their feet. The passage probes: “Turn around and go right.” Once the participant chooses the right option, they hear birds chirping and are shown a sunny forest landscape accompanied by text that describes a warm and pleasant stroll as they eat raspberries from the bush. If the participant chooses the right direction initially, the experience would be the same, but inverted. This is a basic, binary, and oppositional structure for displaying choice in the narrative path that the participants can build into their own stories. The final passage in this section notes that “Building stories in Twine can be about choice. Where do you want your story to go?” Ultimately, this simple navigational exercise is intended to demonstrate the concept of a rhizomatic, multiple path narrative plot that participants may utilize in their own stories.



Which way do you turn?

Fig. 32. Screenshot of Twine Illness Narrative Module

This navigational tutorial is supplemented later on in the module during the Twine Tutorial section where participants are given an outline for three story path options, which I call a forward path, a weaving path, and multiple paths. A forward path is when the story moves the reader/player through a straight line. The module is an example of a mainly forward path where the intention is to cultivate a uniform experience for every reader/player of the Twine. A weaving path branches the narrative into two or multiple hypertext passages but ultimately comes back to a single path. The final narrative structure, multiple paths, incorporates a multitude of hypertext paths for the reader/player to follow. In this structure, each path may describe a different plot and narrative conclusion. The module explains that multiple paths may be more complex and time-consuming to build, but they have the potential to be a generative method to “play through” different scenarios or dream up alternative ways things could have been in relation to illness experience. Fig. 33 shows example screenshots of what the Twine backend may look like following each story structure. The module explains that participants have the option to build their stories using any structure they prefer. The Analysis and Discussion chapter will discuss what story structure was utilized most in the study and the potential reasons for this.



Forward Path **Weaving Path** **Multiple Paths**

Fig. 33. Screenshot of Twine Illness Narrative Module

Before participants encountered their final writing prompt to build their illness narratives, the module led them through a comprehensive Twine instructional tutorial. This section opens with a passage explaining the process of the tutorial, the expected outcomes for the participant, and further resources for support including the popular Twine Wiki resource (Twine Wiki has retired at the end of 2020 and rolled into the [Twine Cookbook](#)). Participants are then taken through an eight-step tutorial on how to access and set up Twine from scratch, including how to access Twine in the browser, set up a new story, and name a new Twine file. Fig. 34 shows the final step in this section which is describing how participants can change the story format of their Twine. The module instructs participants to select the Harlowe 3.1.0 version to ensure that the subsequent instructions in the module align for all participants. In the design process of the module, it was important that all textual instructions were supplemented by explicit visual cues to ensure that all participants felt confident moving through the module while producing their own work. I decided to include screenshots of the sections of the Twine interface the module was referring to, supplemented by stark red arrows and boxes to highlight the action. Each action that required the participant to click on something was distinguished with the word “click” displayed in a turquoise text (HTML colour code [#69FFB9]) using a blinking feature ([text-style: “blink”] macro).

Step 8: Before we start

Click the upward facing arrow next to your story name in the bottom left hand corner.

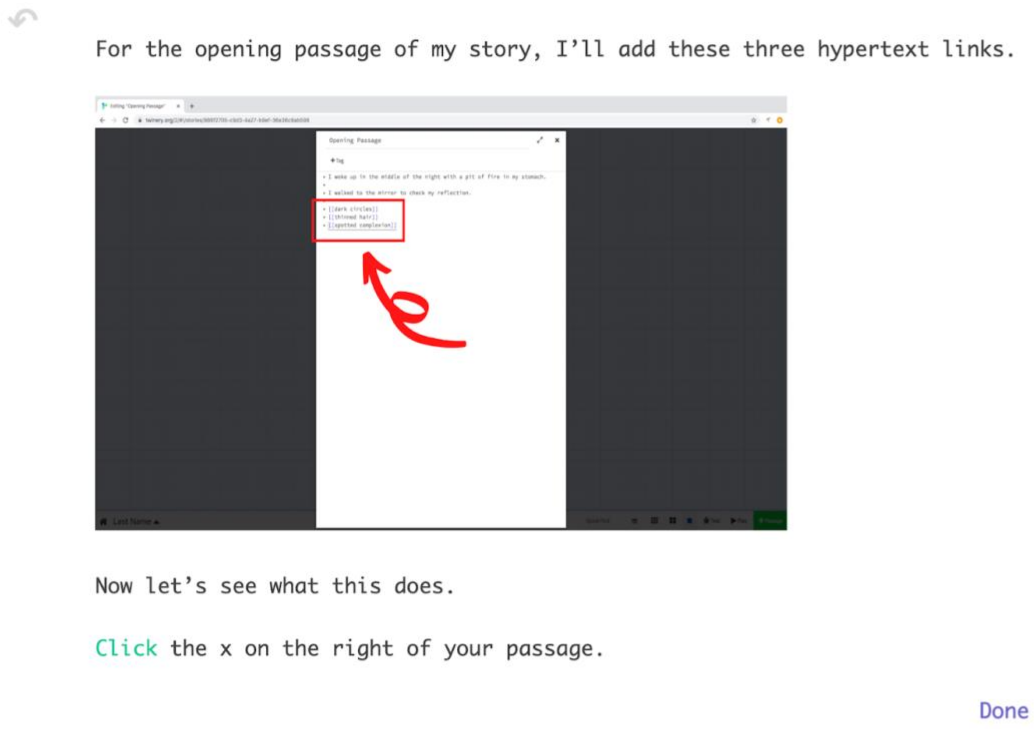
Click “Change Story Format”.

Make sure Harlowe 3.1.0 is selected. There are other story formats that you can use, but for this workshop we will use the latest version of Harlowe.

Now, let's get started!

Fig. 34. Screenshot of Twine Illness Narrative Module

The remainder of the tutorial goes in-depth into how to write and publish a Twine story, including what a passage is, how to create an opening passage, how to test a story, what a hypertext is and how to code one (or more) hypertexts into a passage, how to create a linked passage through hypertext, saving a story, and leaving and returning to a work. Participants are also led through some basic codes that can be used to manipulate the style of the Twine including changing the colour of text and background, changing text features like italics and bold, and changing where the text appears on the screen (alignment). Fig. 35 - 37 show a section of this tutorial that explores how to create multiple hypertext links in a single passage to produce a series of new passages. The module uses the example prompt: “I woke up in the middle of the night with a pit of fire in my stomach. I walked to the mirror to check my reflection.” In fig. 35, participants are shown how to enclose various statements into double square brackets creating three separate hypertexts (a step they learn in the previous passage). Fig. 36 shows the backend of the Twine interface following this action, where three new passages appear. Finally, fig. 37 shows what the three hypertexts appear as once the story is tested. Following the comprehensive Twine tutorial, participants are led to the Twine illness narrative writing prompt discussed in a previous section of this chapter, where they have access to the Twine technical instructions through various hypertexts. Once the participant completes their illness narrative, the module offers instructions on how to submit their file, thanks the participant for their contribution and bravery, and details the next steps of the study. The module ends with the note: "just because you're finished your Twine story, doesn't mean the story's over. How do you think the next chapter will go?"



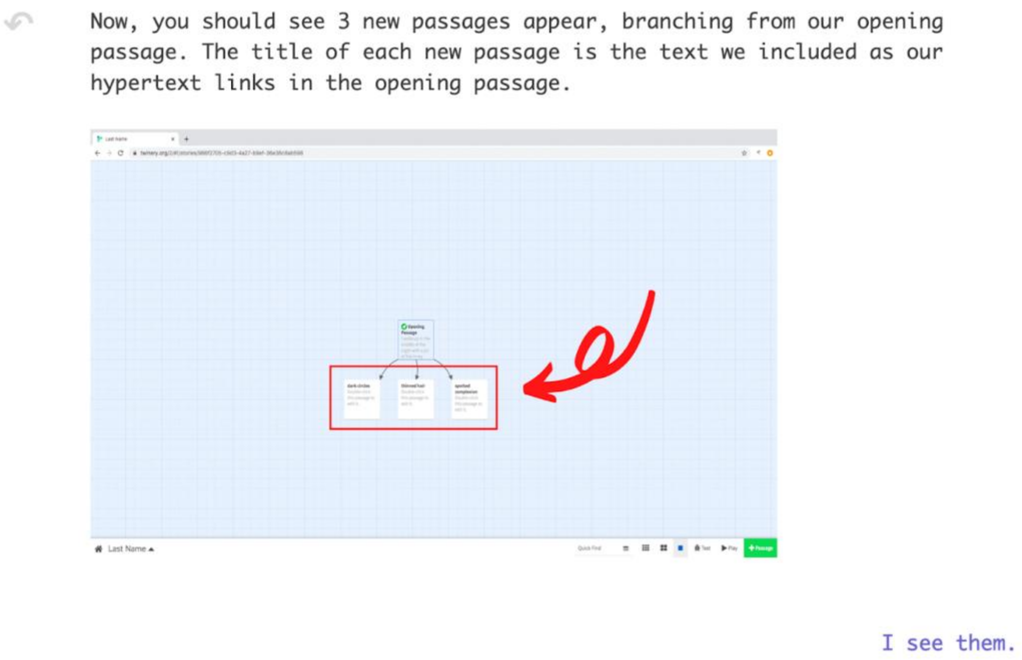
For the opening passage of my story, I'll add these three hypertext links.

- I woke up in the middle of the night with a pit of fire in my stomach.
- I walked to the mirror to check my reflection.
- [[dark circles]]
- [[thinned hair]]
- [[spotted complexion]]

Now let's see what this does.

Click the x on the right of your passage.

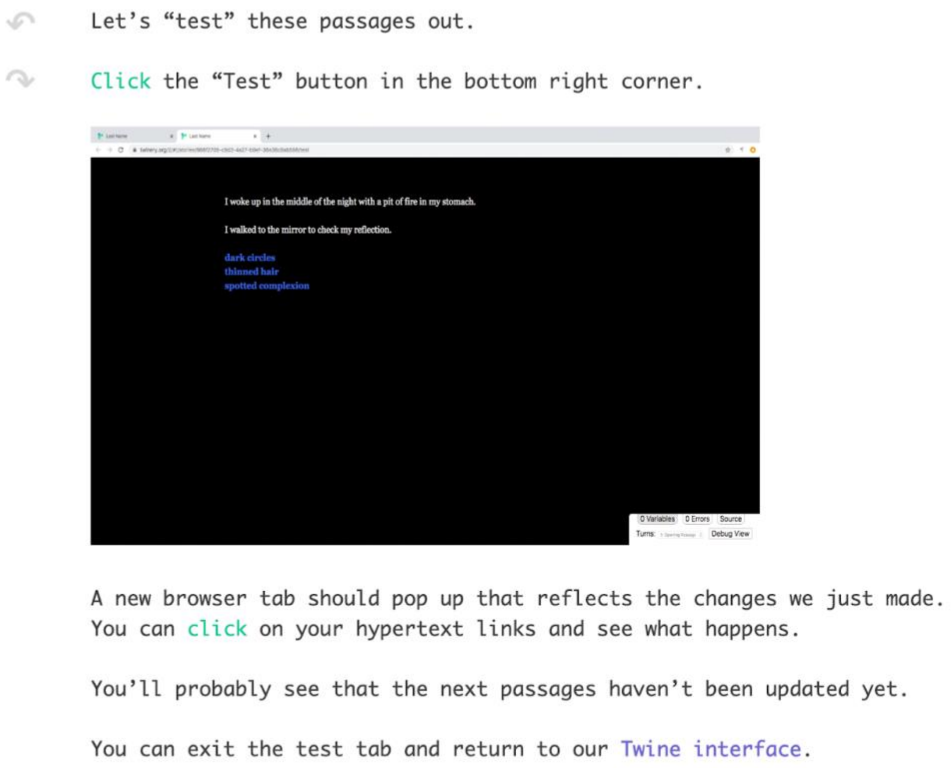
Fig. 35. Screenshot of Twine Illness Narrative Module



Now, you should see 3 new passages appear, branching from our opening passage. The title of each new passage is the text we included as our hypertext links in the opening passage.

I see them.

Fig. 36. Screenshot of Twine Illness Narrative Module



Let's "test" these passages out.

Click the "Test" button in the bottom right corner.

I woke up in the middle of the night with a pit of fire in my stomach.

I walked to the mirror to check my reflection.

dark circles
thinned hair
spotted complexion

A new browser tab should pop up that reflects the changes we just made.
You can click on your hypertext links and see what happens.

You'll probably see that the next passages haven't been updated yet.

You can exit the test tab and return to our Twine interface.

Fig. 37. Screenshot of Twine Illness Narrative Module

Risk Assessment and Accessibility

This study includes writing about past experiences of illness, which can potentially cause psychological or emotional stress for the participant. Thinking about and writing about one's experience in the healthcare system or reflections on one's body can be potentially trauma-inducing. Further, because of the unfortunate stigma of hyperandrogenism, participating in a study such as this could have adverse effects on participants if their participation was made known to those in their life who may not know they have this disease. Finally, there is minor concern over mental fatigue due to the concentration and effort required to complete the module. Participants were informed, informally in discussion and formally in the consent form, that their participation and consent are voluntary, and that consent to participate can be withdrawn at any time throughout module completion, Closing Interview, and during data analysis up to one month following the interview. If a participant were to withdraw from the study during this timeframe, they would be given the option of their data being destroyed or retained. It was explained to participants that participation in this study requires writing about one's experience with hyperandrogenism, in any way they choose, so their stories may take the form that is most comfortable for the participant. Further, participants were given information on mental health resources that they could access in the Consent Form and were also advised to connect with me to help them navigate help. The online module was an effective way to lessen the risk for exposing participation in this study to people in the participant's life. Participants were able to access the study wherever or whenever is most comfortable and appropriate for them and complete the study at their own pace. Participant information and identity are stored in a secure Google Drive folder and in a password-protected computer, including the ID legend, to eliminate associating participant names with any data. Due to the nature of the module, the risk for mental fatigue was managed by the ability to complete the study at any chosen rate. Participants had the option to take breaks. The module was designed to be completed in a two-hour timeframe but could be completed over the course of weeks/months if needed. This online-only nature of participation supported social-distance guidelines that were in effect across Alberta and globally during the experiment phase, as it took place during the COVID-19 pandemic.

The Twine module for this study was not comprehensively accessible, for several reasons. First, it relied heavily on colour distinction in order to navigate through passages. Although stark colour contrast was implemented through most of the module, this was not consistently carried out (in some passages the dark purple hypertexts are on a light purple background). Further, sounds were incorporated throughout the module, but these were intentionally included to supplement the experience and were not imperative for the completion of the exercises. Participation in the study also required access to a computer and internet browser which is a limiting requirement for some individuals. Finally, and critically, Twine stories are not inherently accessible through screen readers and have to be manipulated through code to ensure their accessibility for these various technologies. This is a significant issue when using Twine, or other literary hypertext software, as a teaching tool for groups of individuals who may need differing forms of access.

Chapter Review

This chapter reviews the methods employed in the research of this study. First, the trajectory of the research process is outlined including the recruitment of participants through social media platforms. The initial contact with participants in the form of the Recruitment Poster is described. The choice to utilize the language of PCOS, over hyperandrogenism, in recruitment and onboarding material was explained as an attempt to connect with participants who may not be familiar with the term hyperandrogenism. The Informational Email is outlined, including the purpose of the study, expectations of participation and the eligibility criteria. To participate in the study participants must be 18 years of age or older, have the ability to speak and write in English, and have lived experience with two or more symptoms of PCOS. The Screening Interview is described as having two parts, first the eligibility check, and second, a qualitative and quantitative questionnaire on diversity markers. Table 2 outlines the diversity makeup of the participant pool and shows that all participants identify as a marginalized identity in terms of race, Indigeneity, disability, sexuality, body size and/or gender identity. Finally, participants learned more about the purpose and research process of the study, data collection and storage, consent, and resources for mental health in the Consent Form. This step included fourteen participants who signed the form and were sent the link to the Twine module, of which ten completed.

This chapter details in depth the design choices of the Twine illness narrative module used by participants in this study. The module can be classified into two sections, the parts informed by narrative therapy perspectives and the technical tutorial for Twine. Various sections of the module including the political framing of hyperandrogenism, storyboarding, writing the illness narrative, the community-building portal, and the Closing Interview was informed directly by Dumaresque et al.'s perspectives on politicizing narrative therapy in ways that dislodge the practice from individualized experiences and insert it into larger sociocultural contexts. The remaining sections of the module included pedagogical approaches to teaching the rhizomatic identity of literary hypertext, as well as technical instructions on how to use Twine. Finally, this chapter concludes with an assessment of the risk potential for participation in the study and a reflection on the accessibility of the Twine module. In the following chapter, the analysis of the data produced through the methods detailed above will be presented.

Chapter V: Analysis and Discussion

Introduction

Returning to the question of this project, I am reminded that the intention of this research is to expansively interpret the data to understand both the technical aspects of the software and thematic patterns in story worlds that may contribute to the development of positive relationship building for the participant. The research question asks how women and nonbinary individuals with hyperandrogenism can use literary hypertext technology to write illness narratives that construct positive relationships between their identities and the world. The purpose of looking at hypertext's value is to open space for the inverse as well. Through this approach, as the researcher, I am able to analyze aspects of the research that did not add value, did not contribute to positive relationship building or were perceived as inaccessible by participants. Utilizing critical discourse analysis for digital-born narratives (CDADN), outlined in the Methodology chapter, this chapter will have dual intentions: analyze the research findings and discuss the meaning generated from those findings. In previous chapters, CDADN was outlined using a series of structured questions that generally fell into four steps: *Texts, Contexts, Actions and Interactions,* and *Ideology and Power*. The Methodology chapter used an example hypertext, *You're Going to Make a Great Mother One Day,* to outline the steps of conducting a CDADN. In this example section, the analysis is structured in an explicit order, taking the reader through each of the four steps, including the series of questions housed within the steps. This was an intentional approach in order to concretely outline the methodological process in a transparent way. However, when conducting CDADN in this research project, the analysis will be presented differently, paying particular attention to thematic connection and progression rather than adhering to the order of the steps. The four steps, and series of questions, were used to pull out important information in the corpus but they will be presented in a way that supports responding to the research question in particular.

Many dissertation projects organize the Analysis and Discussion as distinct chapters. Typically, the Analysis chapter is a presentation of the data “without” bias or interpretation (which is saved for the Discussion chapter). However, this research project (and it could be argued all research) is saturated in bias. From the initial stages of making choices about literature inclusion, theoretical frameworks, and conceptualizing the research design, to conducting the data analysis, I have made distinct and impactful choices as the researcher. For example, the data was analyzed through the questions outlined in CDADN, however, this analysis was supported through a thematic coding in NVivo. Prior to conducting the methodological process of analyzing the data, I organized the interview transcripts and Twine stories into a coded system. Codes were organized into six meta categories, known as parent codes, that house child codes (codes within codes): Affect, Embodiment, and Identity Themes, Feminist New Materialist Theory, Health, Identity Markers, Participant, and Twine.

Table 3 shows a list of Affect, Embodiment, and Identity, Feminist New Materialist and Health related codes and the frequency in which they were coded in the data. The meta-category of Affect, Embodiment, and Identity includes codes such as The Body, Shame and Resistance. It also includes parent codes that house child codes. For example, the parent code Family houses the child code Sister. Each time a Twine narrative referenced the topic of Sister, the text excerpt would be coded under the Sister code. When reviewing the data, the researcher would be able to see that text excerpt coded within both Family and Sister. Feminist New Materialist Theory was included as a parent code to ensure that in the process of analysis I was paying particular attention to my theoretical framework. This parent code includes child codes such as Matter, Situated Feminisms, and Intra-Action. Coding within this framework sets up the analysis for particular moments of the CDADN, including questions regarding how the research centres materiality and more-than-humans in its affect. The next parent code, Health, includes three child codes: Health Care System, Symptoms, and Mental Health Disorders. Not included in Table 3 are the remainder of codes used in the analysis of the data. The remaining codes were excluded from the presentation of the data in Tables 3 and 4 because they include identity markers of participants, related parent codes housing child codes that label files with the appropriate participant ID, as well as the participant's identity markers outlined in their Screening Questionnaire (excluding any true identifying information such as names or specific locations). These parent codes were important during analysis because they allowed me to, for example, view a Twine narrative that discusses the effects of healthcare costs and lack of insurance coded as not only the participant's ID but their residence as America. This offered me more nuance in analyzing this particular participant's experience in a for-profit healthcare system. Finally, Table 4 shows the parent code Twine that houses child codes relating to the technological choices and software experiences of the participants and the code frequency. In this parent code, I was able to mark stylistic code choices, narrative path structures, and hyperlink classifications.

Table 3

Affect, Embodiment, and Identity, Feminist New Materialist and Health-related Code Frequency

Code	**Number of Coding References**
Codes\\Health\Symptoms	116
Codes\\Health\Health Care System	95

Codes\\Affect, Embodiment, and Identity Themes\The Body	71
Codes\\Affect, Embodiment, and Identity Themes\Change in Perspective	47
Codes\\Affect, Embodiment, and Identity Themes\Connected Experiences	33
Codes\\Affect, Embodiment, and Identity Themes\Identity	32
Codes\\Affect, Embodiment, and Identity Themes\Unknown or Answer Seeking	32
Codes\\Affect, Embodiment, and Identity Themes\Family\Mother	28
Codes\\Affect, Embodiment, and Identity Themes\Relationships	28
Codes\\Feminist New Materialist Theory\Rhizome	27
Codes\\Affect, Embodiment, and Identity Themes\Adolescence	26
Codes\\Affect, Embodiment, and Identity Themes\Education and Knowledge Dissemination	26
Codes\\Affect, Embodiment, and Identity Themes\Support	25
Codes\\Feminist New Materialist Theory\Difference	24
Codes\\Affect, Embodiment, and Identity Themes\Empowerment	23
Codes\\Affect, Embodiment, and Identity Themes\Femininity	22
Codes\\Feminist New Materialist Theory\Space	21
Codes\\Affect, Embodiment, and Identity Themes\Reflection	20

Codes\\Feminist New Materialist Theory\Matter	20
Codes\\Affect, Embodiment, and Identity Themes\Shame	18
Codes\\Feminist New Materialist Theory\Senses	17
Codes\\Affect, Embodiment, and Identity Themes\Trauma	15
Codes\\Affect, Embodiment, and Identity Themes\Abnormality	14
Codes\\Affect, Embodiment, and Identity Themes\Family\Sister	14
Codes\\Feminist New Materialist Theory\Dualism (Complicating)	13
Codes\\Affect, Embodiment, and Identity Themes\Control	12
Codes\\Affect, Embodiment, and Identity Themes\Family	12
Codes\\Affect, Embodiment, and Identity Themes\Oppression	11
Codes\\Affect, Embodiment, and Identity Themes\Self-hate	9
Codes\\Affect, Embodiment, and Identity Themes\Beauty Standards	8
Codes\\Affect, Embodiment, and Identity Themes\Family\Father	8
Codes\\Health\Mental Health Disorders	8
Codes\\Affect, Embodiment, and Identity Themes\Social Media	7
Codes\\Affect, Embodiment, and Identity Themes\Society	7
Codes\\Affect, Embodiment, and Identity Themes\Representation	6
Codes\\Affect, Embodiment, and Identity Themes\Jealousy or Comparing	5
Codes\\Affect, Embodiment, and Identity Themes\Resistance	5

Codes\\Feminist New Materialist Theory\Researcher Implication	5
Codes\\Feminist New Materialist Theory\Speculative Fabulation	5
Codes\\Affect, Embodiment, and Identity Themes\Triggers	4
Codes\\Affect, Embodiment, and Identity Themes\Family\Brother	3
Codes\\Affect, Embodiment, and Identity Themes\Media Influence	3
Codes\\Affect, Embodiment, and Identity Themes\Privilege	2
Codes\\Feminist New Materialist Theory\Intra-action	2
Codes\\Feminist New Materialist Theory\Situated Feminisms	1

Table 4

Twine Code Frequency

Code	**Number of Coding References**
Codes\\Twine\Code\Hyperlinks	176
Codes\\Twine\Twine Structure\Navigational Linking	111
Codes\\Twine\Twine Structure\Unified Construction	99
Codes\\Twine\Twine Writing Experience	69
Codes\\Twine\Code\Style Codes	65
Codes\\Twine\Twine Structure\Bifold Construction	38
Codes\\Twine\Twine Software Experiences	32
Codes\\Twine\Twine Structure\Dead End Linking	32
Codes\\Twine\Twine Structure\Other Linking	30

Codes\\Twine\Twine Visuals	26
Codes\\Twine\Twine Structure\Procedural Linking	23
Codes\\Twine\Definitions	9
Codes\\Twine\Twine Structure\Weaving Path	9
Codes\\Twine Twine Structure\Multiple Paths	7
Codes\\Twine\Code\External Links	5
Codes\\Twine\Twine Structure\Bi-Uni Construction	5
Codes\\Twine\Twine Structure\Forward Path	4
Codes\\Twine\Twine Structure\Conversational Linking	2

Because NVivo supports mainly textual, auditory and visual data with limitations on hypertext-based and digital-born narratives, I had to make decisions about how to record the data in ways that upheld the integrity of its nuance. I chose four file structures: the Interview Transcripts, Twine Content, Twine Structure, and Twine Visuals. The audio of the interviews was maintained and stored as a backup, however, only the transcribed data was analyzed. A limitation of this approach is the potential to lose the nuance of the auditory interaction and meaning created through volume and intonation. The Twine content files consisted of the text of the Twine story converted into a single text document. In these files, passages were numbered sequentially, and hypertext was indicated through double square brackets. There are immense limitations to this file format for hypertext narratives. For example, the sequentially numbered passages hinder the intention of a rhizomatic story structure by forcing the narrative into an ordered path. Because of this, the Twine Structure file format was included. The Twine Structure files are image screenshots of the Twine story in the interface. These files enabled the path structure codes to be included, such as Multiple Paths, Forward Path, and Weaving Path. The files that included Twine Visuals were an additional way to capture the nuances of how Twines are intended to be consumed. These files include screenshots of different colour and text styling choices made by participants as well as images that were included in some stories. Without the Twine Visual files, images, for example, would only be captured in the data as the URL link inserted into a line of code.

Because of the intricate decisions made towards a thematic coding structure, and because I believe this data cannot be analyzed without discussion, the Analysis and Discussion chapters will be amalgamated into one. The following sections will include a presentation of the data, analyzed through CDADN, and a discussion of the produced meaning-making processes and how they respond to the research question.

Part I: Matter

As a precursor to the analysis of this research it is important to begin with situating the theoretical framework of feminist new materialism (FNM) within this project. It was helpful, in the analysis of this research, for me to engage with FNM concepts in ways that first deconstructed the theory into parts. I started by asking: what is inherently feminist about FNM? Rebecca Coleman, Tara Page and Helen Palmer argue in “Feminist New Materialist Practice: The Mattering of Methods” that the feminism of FNM is embodied in an approach to challenging power relations in non-dualistic and potentially generative ways. The authors argue “the energy required to overthrow conventional (abstract, ideal) reasoning in favour of messy mattering of methods is precisely the energy that is required to break down barriers and borders that prevent us from understanding and affirming difference without prejudice.” This energy, according to the authors, is feminist energy concerned with not only concepts, but bodies, ontologies, nature, and biology. The CDADN built to analyze the data in this research is attuned to the feminism inherent in FNM. In particular, the methodology positions the researcher to question how they have acted responsibly in their research. Responsibility, in this context, is described as actively benefiting marginalized humans and more-than-humans in its affect. This affect may look like networks that become generated, various relations or worlds built in the wake of the research.

This need for responsibility, I believe, was met in this project in several ways. Most notably the outcomes of the research discussed below, aim to contribute a resource for marginalized individuals to respond to illness. But I also grappled with this responsibility through my relationship with participants. As discussed in the Methodology chapter, Sarah. E. Truman's approach to qualitative research, adopted in this project, argues that FNM approaches to research should be concerned with implicating the researcher in the process of data analysis (2). The latter point is especially critical for this project. I am a researcher who also lives with the disease I am studying. I share similar experiences with my participants and can empathize with their stories. This is a truth that will inevitably affect research outcomes and the interpretation of the data. However, rather than resisting my implication, I chose to make it an intentional aspect of my feminist research design. This FNM approach to researcher implication harkens back to Heidegger's approach to hermeneutic phenomenology discussed in the Literature Review. A hermeneutic phenomenology is a reflective approach where the story of the participant is situated within the context of their lifeworld (Neubauer et al. 94). An important element of the hermeneutic phenomenological method is that the influence of the researcher's subjectivity and lifeworld is both inevitable and a valuable contribution to the analysis. This is akin to FNM which sees researcher implication as not only vital but always already entangled within the research.

I made an effort in every participant encounter to find moments to articulate aspects of my own story or to note that I had experienced something similar to what a participant was sharing. Returning to hermeneutic phenomenology and FNM theory, my mark on the research and the outcomes of the research is present, even if I chose not to actively share my own illness experience with participants. This choice to do so, although, was an attempt to embrace the implication in the open. These efforts were later represented in the code "Researcher Implication", as depicted in table 3. The strategy I took in both Screening and Closing Interviews was to contribute snippets of my own illness experience in an authentic way. These moments typically involved responding to a participant's descriptions of a dehumanizing experience in the healthcare system or with their illness in general and echoing that sentiment through my own personal experience. For example, in response to a participant revealing feelings of subjugation following a doctor's appointment, I responded: "I think the common experience that I'm hearing amongst my participants, and also my own experience with PCOS, in the healthcare system, has been, like, extremely dehumanizing. Not all the time, but like these, like microaggressions, I guess, like, these small encounters that really just are dehumanizing, right?" In other moments, I chose to affirm, through personal experience, statements made by participants who discussed the benefits of writing about their illness. For example, to one participant I explained:

> That's, that's amazing because that's exactly how I feel. I think it's so like, helpful to tell your story. But I have a hard time like talking out loud about what I'm going through with people because it's just like, kind of awkward, right? But when I write about it, I find it so much better. And especially if it's anonymous, because then it's just like your name is on it. You can actually just really like get everything out there.

Ultimately, the feminist foundations of FNM were a sentiment I actively tried to foreground in the methodology. I believe this approach harkens back to Coleman et al.'s description of a mirrored energy between feminism and new materialism. This energy, in both cases, is concerned with deconstructing barriers and binaries and embracing difference. For this project, this energy also includes challenging traditional belief systems around the removed researcher yielding unbiased results. The research is a tangled myriad of agents: participants, the Twine software, memory, stories, bodies, symptoms, etc. And I am in this mess, too.

The second question I considered in my approach to a FNM methodology was: how am I centering matter in this research? Coleman et al. argue that "A central tenet of new materialist thinking is that 'matter' is fundamentally multiple, self-organising, dynamic and inventive, moving between nature and culture, the animated and automated, bodies and environments." Materiality, then, is embodied entanglement of a multitude of matter. The authors argue that academia has resisted the simple uptake of the mattering of matter through sensory perception. For the authors, "sensory perception cannot be ignored in material thinking and practice" (Coleman et al.). To centre matter in this research came down to designing the writing prompt of the literary hypertext illness narrative in a way that called on participants to explore sensory embodiment. The free writing storyboard prompt asked: "In this Moment, how did it feel to be in your body? What do you see, smell, taste, or hear?" The final writing prompt for the hypertext illness narratives strategically builds on the previous question to ask: "What is it like to live in a body with hyperandrogenism?" The prompts in this module intentionally call on participants to centre their embodied, rather than conceptual, experience of the disease and to think about how illness feels growing into the body.

The framing of these writing prompts situated matter in the participants' stories in ways that may not have been captured otherwise. Table 3 shows the concept “Matter” was coded twenty times throughout the corpus of this research. What constituted as matter in the stories was informed by Rosi Braidotti’s concept of neo-materialism as “a method, a conceptual frame and a political stand, which refuses the linguistic paradigm, stressing instead the concrete yet complex materiality of bodies immersed in social relations of power” (Dolphijn and van der Tuin 21). Like all concepts, the practice of coding this concept was highly mediated by my interpretation. It did, however, pinpoint compelling references to how the hyperandrogenous body becomes a relational force within power dynamics. For example, one participant explores how their disease feels like the prickly sensation of coarse hair growing from their chin. Another participant wrote: “The hot wax feels like it burns as its spread thin across my face. Without warning, it is soon ripped off, occassionally taking bits of the top layer of skin with it due to carelessness.” In this research, this is how matter is centred - through the embodied interactions between body parts, wax, technology, hyperlinks, stubble, and code.

Part II: Narrative Themes

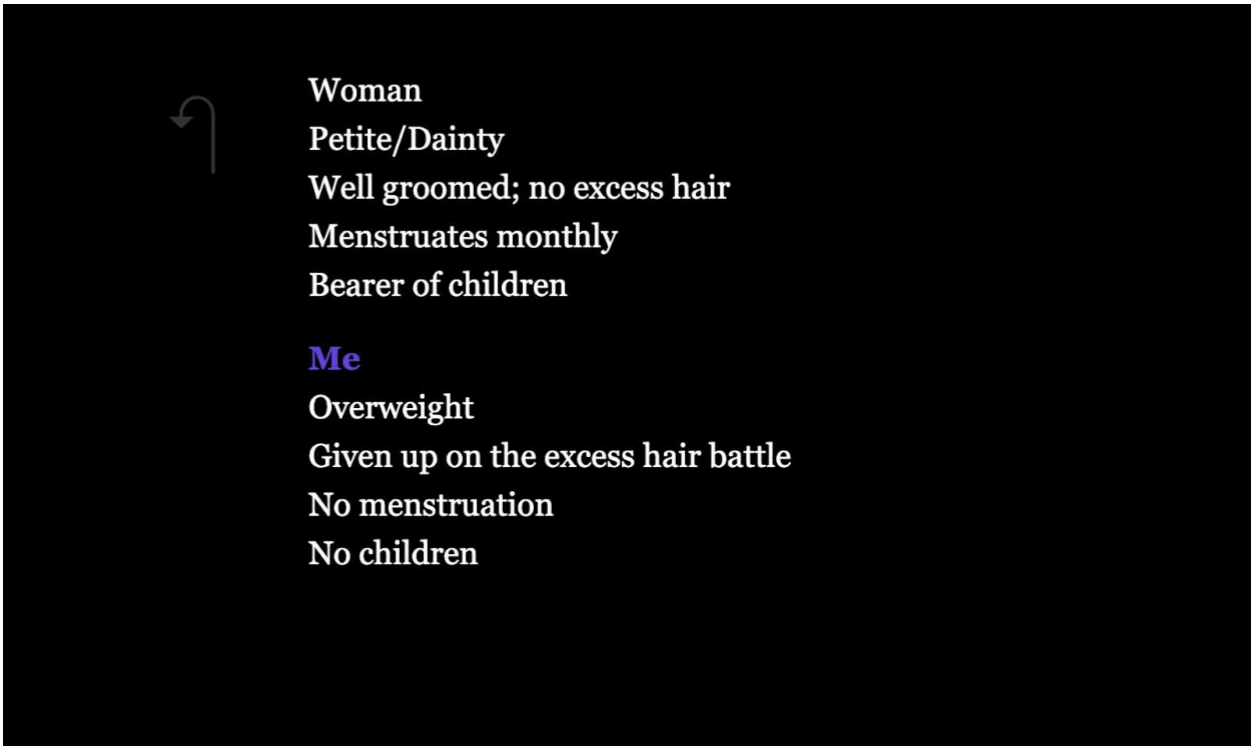
The Abnormal Body

The third most frequently coded theme in the Twine narratives was the topic of the body. This was an expected outcome. The writing prompt offered to participants for constructing their illness narratives asked how it felt to live in a body with hyperandrogenism. The wording of this prompt expectantly produced a body-related narrative from all participants. However, it was surprising that every narrative constructed a similar discursive object: the abnormal body. Every participant in the study wrote a narrative that framed their body, in some capacity, as an abnormal object. This discursive framing of the abnormal body typically fell into six thematic categories: the abnormal body as uncontrollable, the intense physical and mental labour of maintaining normative femininity, the first menstruation as the initial moment of "discovering" the abnormality of the body, dualized abnormality both in the body and mind, and the abnormal body as a mystery that must be deciphered.

All ten participants employed similar language describing the abnormal body as uncontrollable. Participants constructed the theme of the uncontrollable body by framing the body as requiring control, being uncomfortable, or failing to fit into standard femininity. This concept of the abnormal, uncontrolled body harkens back to Julia Kristeva's concept of the abject, expanded by scholars such as Judith Butler and detailed in the Literature Review. Butler argues that there is an exclusionary system at play that produces subjects at the same time that it forms a domain of abject beings, or the not-yet subjects. Butler defined the abject space as "those 'unlivable' and 'uninhabitable' zones of social life which are nevertheless densely populated by those who do not enjoy the status of the subject" (*Bodies That Matter* 3). This concept of the abject situates an idea of excess matter that is seeping out of its proper boundaries. This excess matter is repulsive, useless waste. This concept of the abject body in relation to excess matter is explicit in the narratives of this study. Participants frame their bodily symptoms of hyperandrogenism as abject, excess matter that needs to be eradicated. There is rarely mention of a lack of bodily matter in association with the disease (hair loss, perhaps, but this symptom was not mentioned frequently). Instead, participants write about unruly, unrelenting dark hair growing on the face like a weed. They lament the "extra" matter of body fat and "weight" that must be removed from the body. Authors even describe a surplus of menstrual blood flowing from the body. These bodily symptoms are framed, in the narratives, as the excess matter of the unlivable zone and once the matter is overpowered, the body returns to a space of normalcy.

Participant 1 writes in their Twine: “I think in a lot of ways living in a body with PCOS is like living in most bodies. Confusing and at times uncontrollable and uncomfortable, but also wonderful.” There was a strong thread throughout many narratives of a desire, or requirement, to control the sick body. Participant 10 writes: “I was convinced that my PCOS was caused by something external and that if I could somehow cut out the ‘bad’ foods, I’d be cured.” Many participants discussed expansive avenues of healing taken throughout their lives, most with the intention to rid their bodies of symptoms. As Participant 3 notes: “By stripping myself of my more ‘unique’ traits, I could finally be [[the fairest of them all]],” they continue that they “Have to remove the abnormality to find the beauty.” The abnormal body as a discursive object, for many narratives in this research, is framed as a project that needs work, labour, and maintenance in order to restore a state of normality.

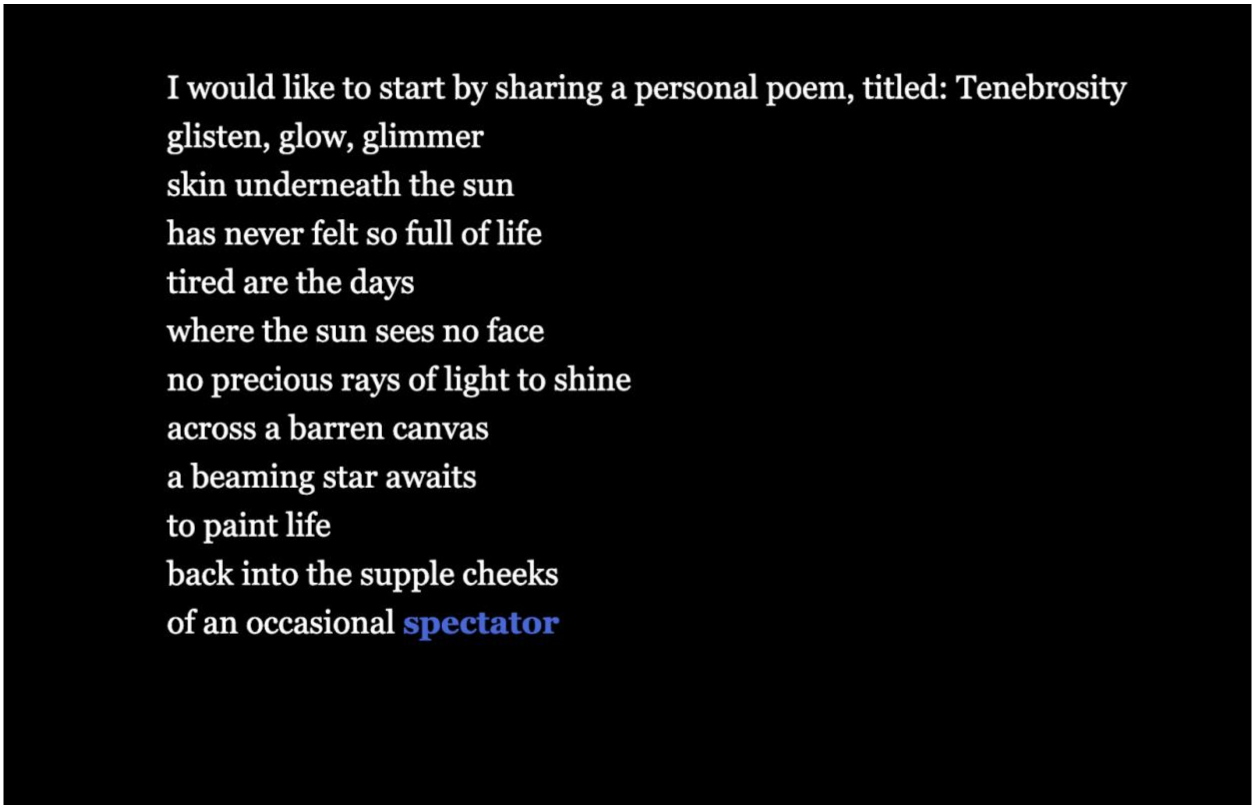
In some narratives, the construction of the abnormal body was done in an explicit way. In fig. 38, Participant 11 includes a passage with distinct, contrasting lists. The first list appears to include language that describes a normative understanding of womanhood including “no excess hair” and “Menstrates monthly.” Below this list is a second list titled with a hypertext reading “Me.” This list includes opposing language to normative femininity such as “Given up on the excess hair battle,” and “No menstruation.” In other narratives, as reflected in fig. 39, this framing of bodily abnormality is done in more abstract ways, including in poetry. The opening passage of Participant 5’s story, for example, is a poem entitled “Tenebrosity” referring to a state of being dark or shadowed. Participant 5 notes in a subsequent passage that “This is how I feel on some days. I feel like staying inside all day, in the dark, never wanting to see the light again.” In both of these examples, Participants 11 and 5 paint a picture of shame where one feels cast aside in their difference.



Woman
Petite/Dainty
Well groomed; no excess hair
Menstruates monthly
Bearer of children

Me
Overweight
Given up on the excess hair battle
No menstruation
No children

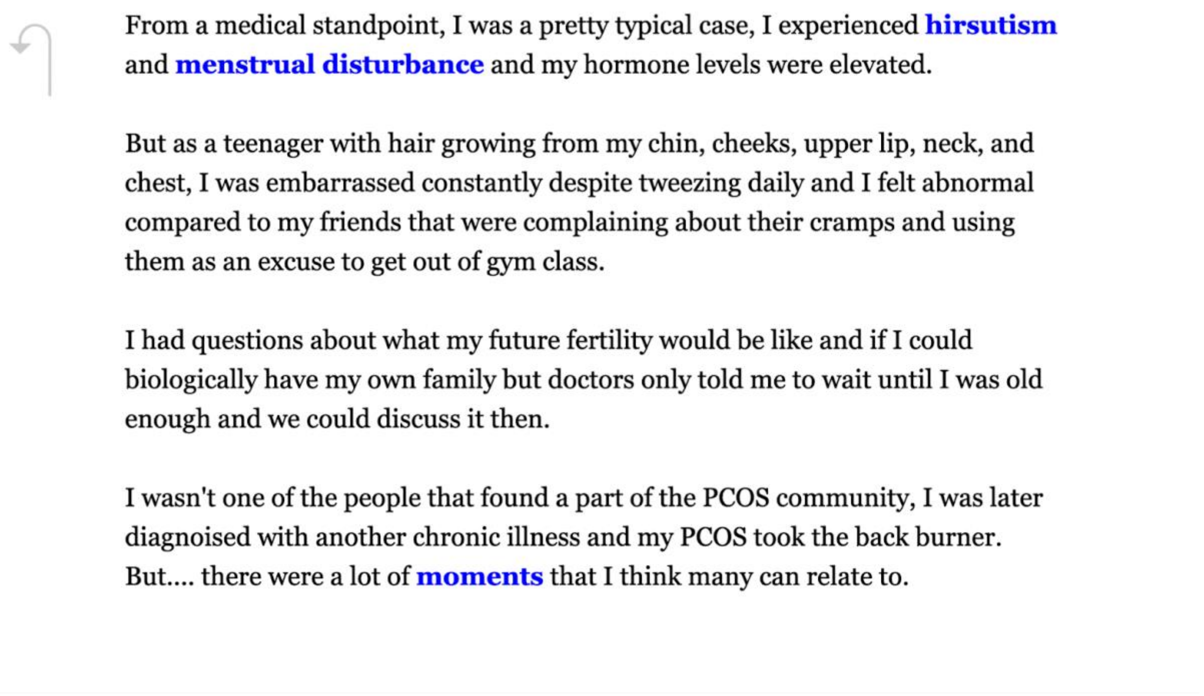
Fig. 38. Screenshot from Participant 11's Twine Story



I would like to start by sharing a personal poem, titled: Tenebrosity
glisten, glow, glimmer
skin underneath the sun
has never felt so full of life
tired are the days
where the sun sees no face
no precious rays of light to shine
across a barren canvas
a beaming star awaits
to paint life
back into the supple cheeks
of an occasional **spectator**

Fig. 39. Screenshot of Participant 5's Twine Story

Fig. 40 depicts a passage from Participant 7's Twine story where they describe their experience learning about and coming to terms with their illness diagnosis. Participant 7, in this passage, refers to themselves as a "typical case" of hyperandrogenism due to their predictable symptoms. This is a significant language choice because it reveals one of the two ways participants in this study understand and talk about the abnormal body. In the first way, participants, like Participant 7, speak about themselves as the abnormal body. There is no separation between the self and the illness and in this sense, their body and identity are deviating as one. We see this in the way Participant 7 declares that they are a "typical case" rather than they are experiencing typical symptoms of the illness. This positions the illness as the identity, rather than an external force that has attached to their standard femininity and altered it. In fig. 40, Participant 7 goes on to ponder what their fertility might be like in the future, not what the disease would do to their "intact by default" fertility. In comparison, Fig. 41 shows a passage from Participant 16's story where they discuss their hopes for their body in the future. In this example, Participant 16 uses strong, externalizing language when referring to their body and body parts. They hope that next month "the" skin will become lighter, rather than "their" skin. Participant 16 goes on to note: "Maybe my body will love me back the way I want to love it." The participant, in this example, refers to their body as an external entity that holds agency and notions of free will separate from themselves. These are important language decisions because Participant 16 is framing illness in an opposing way to Participant 7 where the body becomes a suit of abnormal skin in which their true selves are trapped inside. This creates a distinction between Participant 7 who frames illness as something that changes the core of who they are and Participant 16 who frames illness as an external force attaching to their true self. Participants in this study utilized one of these two framing styles, and at times, even oscillate between the two within the same story.



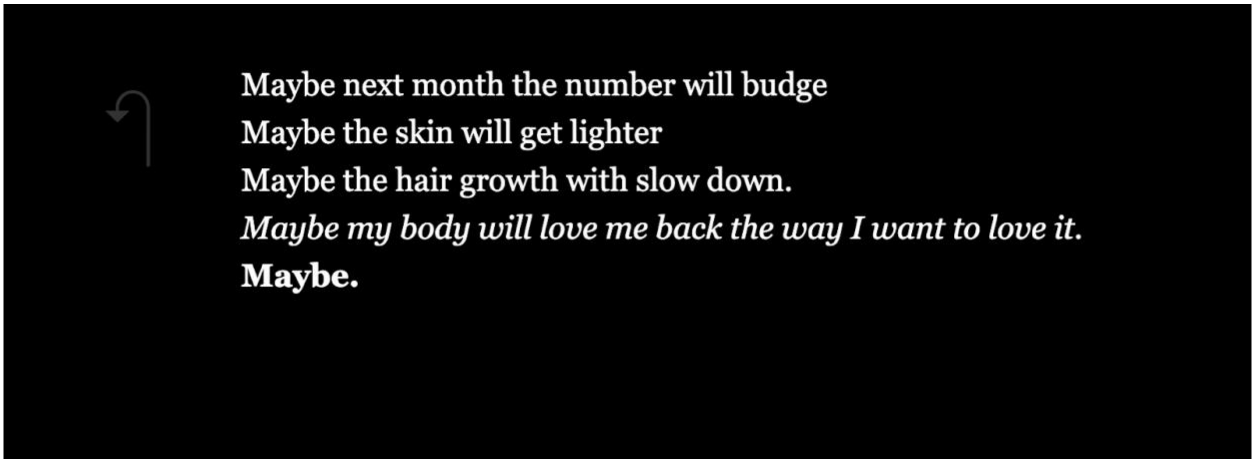
From a medical standpoint, I was a pretty typical case, I experienced **hirsutism** and **menstrual disturbance** and my hormone levels were elevated.

But as a teenager with hair growing from my chin, cheeks, upper lip, neck, and chest, I was embarrassed constantly despite tweezing daily and I felt abnormal compared to my friends that were complaining about their cramps and using them as an excuse to get out of gym class.

I had questions about what my future fertility would be like and if I could biologically have my own family but doctors only told me to wait until I was old enough and we could discuss it then.

I wasn't one of the people that found a part of the PCOS community, I was later diagnoised with another chronic illness and my PCOS took the back burner. But.... there were a lot of **moments** that I think many can relate to.

Fig. 40. Screenshot from Participant 7's Twine Story



Maybe next month the number will budge
Maybe the skin will get lighter
Maybe the hair growth with slow down.
Maybe my body will love me back the way I want to love it.
Maybe.

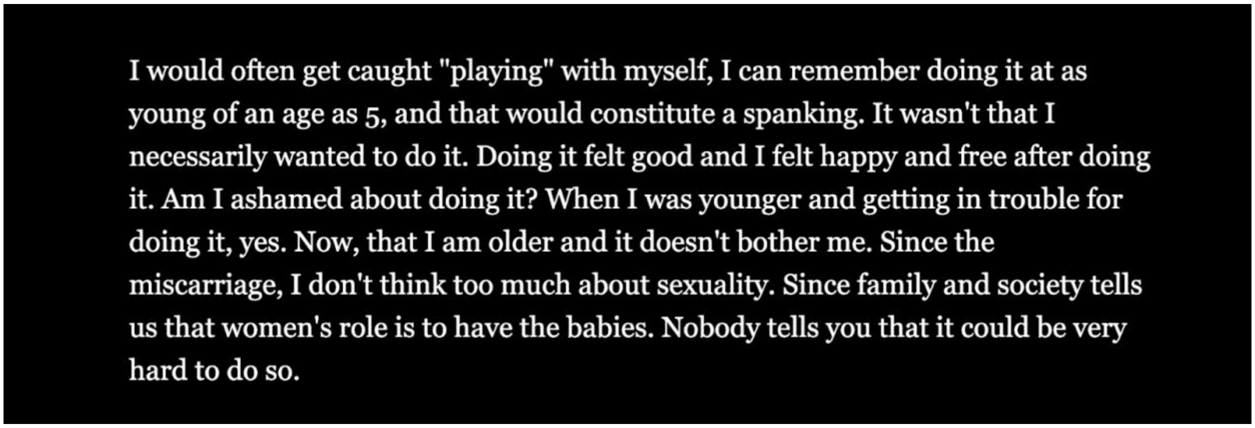
Fig. 41. Screenshot of Participant 16's Twine Story

A reoccurring theme when discussing the abnormal body in participant narratives was conveying a sense of intense physical labour to "combat" abnormality or "maintain" normative femininity. In these narratives, the abnormal body is framed as inherently "feminine" where the illness of hyperandrogenism continuously pulls the body into masculinity through unruly symptoms. Through this framing, participants discussed feelings of responsibility to engage in relentless labour practices to "restore" the body to the original state of normality. For example, Participant 10 writes: "I met with acupuncturists and therapists. I tried regular massages, starving myself, yoga, countless dietary adjustments and running. [[I tried pleading with my body to get better]]. Nothing worked." One of the most prominent labour practices discussed by participants was body hair removal. Participant 1 writes about attending over twenty laser hair removal treatments for facial hair, with no results. The author explains: "For almost a decade now I have been shaving my chin every other day in the shower, hoping that no one ever notices the longer hairs on my chin on the second day." Participant 7 describes as a teenager tweezing daily black hairs growing from their chin, cheeks, upper lip, neck, and chest. They note that "There's moments of trying to hide [[hirsutism]], feeling a stray hair outside of the house caused me great anxiety so I began carrying tweezers everywhere I went. Logically I knew the hairs were small but they felt as visible a neon hazard sign." This is a compelling passage because the visual of body hair symbolizing a neon hazard sign leads me to wonder what danger it intends to warn against. What kinds of belief systems are functioning that translate human body hair as a public hazard? I read this passage to mean that the author fears their body hair will signal to others that they are ill and/or abnormal and, as a consequence, the author may face social prejudice. This is aligned with Butler's claim that in the process of the body being read as abnormal, the individual moves out of the space of subjecthood as they inhabit the uninhabitable site of abjection (Butler, *Bodies that Matter* 3).

Participant 3 uses hypertexts to link back to a previous passage in order to construct a circuit or loop within their Twine narrative. The narrative asks, “what method would you like?” followed by the hypertext options of waxing or threading. If the reader/player chooses to wax, for example, they are brought to a passage that reads: “The hot wax feels like it burns as its spread thin across my face. Without warning, it is soon ripped off, occassionally taking bits of the top layer of skin with it due to carelessness. The sensitive skin on my face is left painfully red for the next 24 hours.” Beneath this text is a hypertext the reads “at last, the hair is gone.” When the reader/player chooses this hypertext, they are brought to a passage with large black letters that seem to sneer “Just kidding.” Below this title the narrative continues: “A week later, the hair sprouts back like a stubborn weed. If I truly want to be [[beautiful]] then this cycle must continue every few weeks. Seemingly endless removal and regrowth.” The sole hypertext [[beautiful]] must be chosen to move the narrative to the next passage, however, when the reader/player selects this link, they are looped back to the original passage describing the hair removal methods. This narrative loop designed by the participant effectively creates a sense of a loss of agency and an obligation to engage in these labour practices indefinitely. Narrative loops will be discussed in further detail in a later section of this chapter.

Although the Twine narratives in this study repeat some similar experiences of illness, many of the narratives discussed the same initial moment of recognizing the body as abnormal: the first menstruation. This prevalent anecdote found in many of the narratives discusses how the first experience of menstruation deviated from the author’s beliefs around “normal” menstruation, including frequency, duration, and heaviness. Ultimately, this dissonance between expected experience and reality leads the author to understand their bodies as abnormal. Participant 4 writes: “My first period started a [[chain reaction]] in my body that would persist for almost two decades.” In this narrative, the first menstruation becomes a defining moment in their illness experience and is situated as instigating a domino effect of subsequent symptoms over the course of their life. Participant 7 writes: “Like most females, I entered puberty, began developing breasts, body hair, and got my first period. Initally, [sic] my periods came monthly but after six months they became bi-monthly, then annually.” In this passage, the participant begins by establishing a description of what they believe defines a puberty experience, followed by a stark framing of their different puberty experiences in relation to “most” females. The author writes: “I wasn't comfortable in my own skin and definitely not comfortable discussing my cycle with my family or doctor.” The reader comes to understand that the author feels shame in discussing their perception of dysfunctional bodily processes.

When participants write about the first menstruation as the moment of discovering their body as irregular, there are both over and undertones of sexualization. Not only do the authors become aware of their abnormality during this time, but they are made sexual in their encounters with the healthcare system. Participant 1 explains in their interview that they spent time reflecting on their uncomfortable interactions with their male family doctor at a young age during puberty. The author notes that “I have no idea why I went to see a fertility specialist like it's weird like, finding out you have PCOS when you're young and like your parents are making a lot of medical decisions for you so I have no idea why I had a fertility specialist when I was 14 but I did.” Not only is the author coming to terms with a new identity of being ill, but they are made to understand, by their doctor and parents, that their body’s purpose is to bear children. In some narratives, like Participant 1’s, the child is sexualized by adults in ways that do not allow for decision-making or agency for the author. In other narratives, there were themes of childhood sexuality that when claimed by the child, incite a concealing response in adults. Fig. 42 shows an excerpt from Participant 12’s Twine story that discusses their memories of experiencing sexual pleasure at a young age, and receiving discipline, including “spanking” from their parents as a result. The author explains that they felt shame from this pleasure in their adolescence because of the response it garnered from the adults around them, however, coming into their own adulthood and experiencing miscarriage has altered their perception of the past. In these two different accounts of childhood sexualization offered by Participants 1 and 12, sexuality is framed as something that can only be imposed onto the body by adults and not discovered by children.



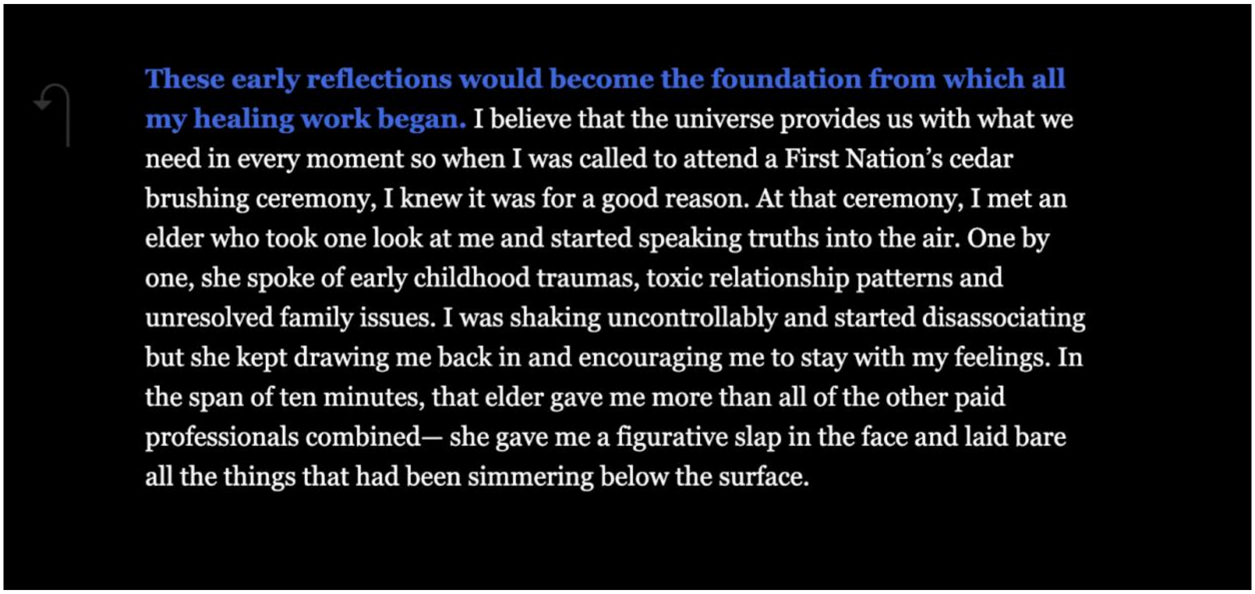
I would often get caught "playing" with myself, I can remember doing it at as young of an age as 5, and that would constitute a spanking. It wasn't that I necessarily wanted to do it. Doing it felt good and I felt happy and free after doing it. Am I ashamed about doing it? When I was younger and getting in trouble for doing it, yes. Now, that I am older and it doesn't bother me. Since the miscarriage, I don't think too much about sexuality. Since family and society tells us that women's role is to have the babies. Nobody tells you that it could be very hard to do so.

Fig. 42. Screenshot of Participant 12’s Twine Story

A strong thread reiterated in the Twine narratives was the concept that the abnormal body is bound to an additional abnormality of emotional issues or nuanced identity. This notion of dualized abnormality, both in identity and body, was constructed in different ways. As described in the Literature Review, I argue in “Illness of the Gendered Body, Freud’s *The Uncanny*, and ‘being-in-the-world’” that the phenomenological experience of gendered illnesses such as hyperandrogenism mirrors the uncanny by rendering the body and therefore identity and selfhood abnormal. A hyperandrogenous body poses the threat of “morphing” into the alien unfamiliar where suddenly one’s understanding of their identity in relation to the past and future is challenged. I argue “With hyperandrogenism, the destabilization of subjecthood is twofold.

Supplementing the otherness of our human body, another layer - the gendered body - ties together sociocultural, historical, and political framing of biological sex, bodily appearance, and behaviour. We are not only bodies but gendered bodies" (Perram, "Sigmund Freud's *The Uncanny*" 594). When our understanding of health is tied to cultural notions of normative, binary sex expression, a distortion of the body across sexed lines forces one to relinquish their sense of identity. This was mirrored in the narratives of this study in various ways.

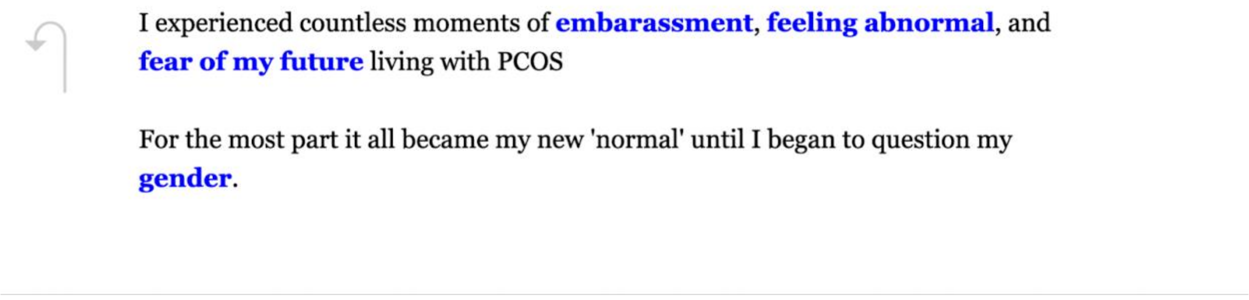
Some narratives enforced a perspective that physical abnormality was linked to emotional bankruptcy where the body's sickness is attributed to not being connected to oneself, not doing the "inner" work, and that "healing" is a lifelong journey. In Participant 10's narrative, they discuss having a realization that dehumanizing encounters in their life appear to have a correlation to their physical symptoms of bleeding. The author explains that "when my partner would touch me or try to have sex, I would bleed. I noticed that when he would ignore my emotional needs, [[I would bleed]]. I noticed that when I was overworked, I would bleed." In fig. 43, Participant 10 writes about their experience attending a traditional Indigenous cedar brushing ceremony where the advice of an Elder helped forge a new emotional journey for the author. The narrative continues by detailing a series of "self-discovery" endeavours undertaken by the author including ending a harmful relationship, leaving a negative work environment, and establishing boundaries with family members. Participant 10 writes: "You may think that PCOS is simply a medical issue but for me, it was rooted in this journey of healing and self-discovery. [[As I began to live in my truth, my symptoms started to ease.]]" For Participant 10, the abnormality of the body, in relation to symptoms of hyperandrogenism, is a manifestation of emotional trauma.



These early reflections would become the foundation from which all my healing work began. I believe that the universe provides us with what we need in every moment so when I was called to attend a First Nation's cedar brushing ceremony, I knew it was for a good reason. At that ceremony, I met an elder who took one look at me and started speaking truths into the air. One by one, she spoke of early childhood traumas, toxic relationship patterns and unresolved family issues. I was shaking uncontrollably and started disassociating but she kept drawing me back in and encouraging me to stay with my feelings. In the span of ten minutes, that elder gave me more than all of the other paid professionals combined— she gave me a figurative slap in the face and laid bare all the things that had been simmering below the surface.

Fig. 43. Screenshot of Participant 10's Twine Story

Other narratives positioned the concept of the abnormal body as linked to the queerness of identity. Fig. 44 shows an excerpt of Participant 7's narrative where they discuss their experiences coming to understand their illness in relation to their Queer identity. The author writes in a subsequent passage that "It took me until 2 to know my favourite colour, until 4 to discover my passion for reading, until 14 to realize I was queer, and until 27 to realize I was non-binary." In their interview, Participant 7 grapples with the question of how intertwined their illness and their gender identity may be. The participant considers the relationship between hormonal levels, medication and Queer identity by questioning: "had my hormones not been, like artificially balanced, what would my like sense of being be?" They note a sense of uncertainty with how biological nuances and interventions have come to impact their gender, "because you can't go back and undo it, and then see how somebody's life is gonna turn out." Participant 7 notes that they recognize that identifying the relationship between biology and identity is a complex, abstract, inconclusive, and possibly dangerous task, however, living with an illness like hyperandrogenism as a nonbinary individual positions you on the frontlines of this debate. The participant concludes these thoughts with an insightful description of intersectionality, noting that their illness is one piece of their identity that intersects with the other factors of who they are, including their gender identity and other chronic illnesses.

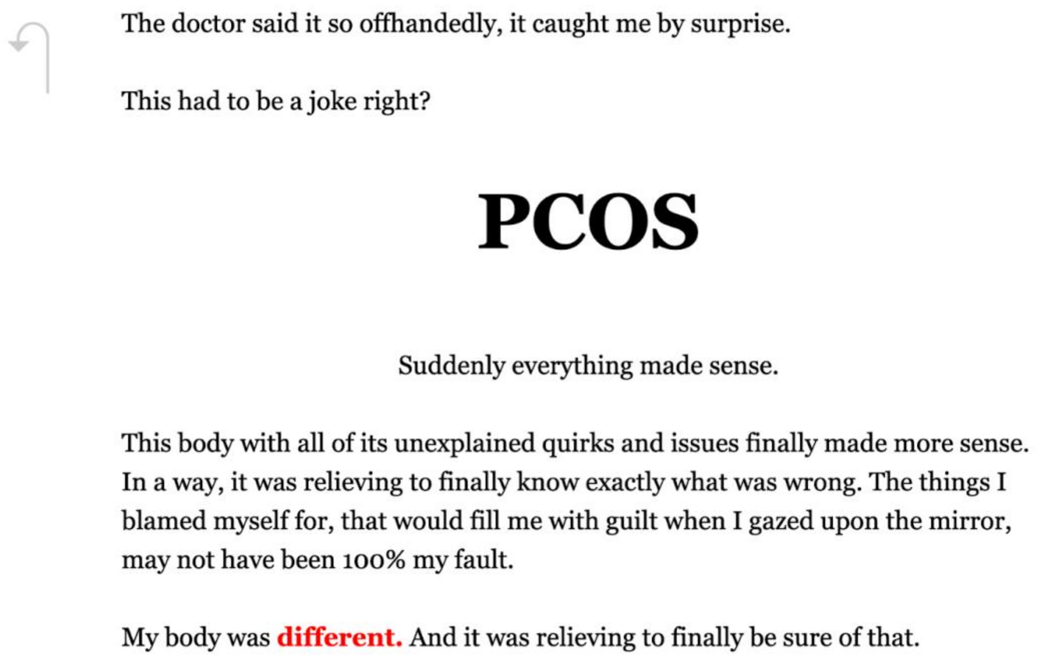


I experienced countless moments of **embarassment**, **feeling abnormal**, and **fear of my future** living with PCOS

For the most part it all became my new 'normal' until I began to question my **gender**.

Fig. 44. Screenshot of Participant 7’s Twine Story

A final, dominant theme that weaved throughout most of the Twine narratives in this study was the abnormal body as a mystery that requires deciphering. Table 3 shows that this theme was coded thirty-two times as Unknown or Seeking Answers. Many participants wrote passages that discussed, in diverse ways, a deep obligation to uncover the “true” cause of the illness, ultimately to achieve a cure. Participant 12, for example, writes that their mother was asked to bring the author back to the hospital for further testing after their birth, but the results came back missing or inconclusive. The author laments: “I am not sure if a blood test would be something that could really prove that a baby has all the markers that would could [sic] predict that they might have PCOS in the future. That would be an interesting thing to study.” The participant suggests that identifying the illness early in life would have value for those affected. We see this similar quest for answers in Participant 7’s story. The author discusses receiving a report of ovarian cysts that validated their PCOS diagnosis and “also an increased sense of uncertainty. How long have I had cysts? When did they develop? Are they stable or growing?” Answering one question, for this author, mushrooms into a series of further questions that require answers. Participant 3 writes about their journey in seeking an answer to what was causing their symptoms. The author declares that "It had to be stress. That would explain the hair loss, the acne, and even the weight gain, right? What else could explain it?" In fig. 45, Participant 3 describes feelings of relief upon receiving an official PCOS diagnosis. The author explains that the desire to search for answers and the "root" of the illness stems from a need to relieve themselves of a sense of guilt that they may have "caused" their bodily symptoms. PCOS, in this sense, becomes an external force that enacts deviance onto the participant, and with the illness label, the author is relinquished of responsibility for their abnormal body.



The doctor said it so offhandedly, it caught me by surprise.

This had to be a joke right?

PCOS

Suddenly everything made sense.

This body with all of its unexplained quirks and issues finally made more sense. In a way, it was relieving to finally know exactly what was wrong. The things I blamed myself for, that would fill me with guilt when I gazed upon the mirror, may not have been 100% my fault.

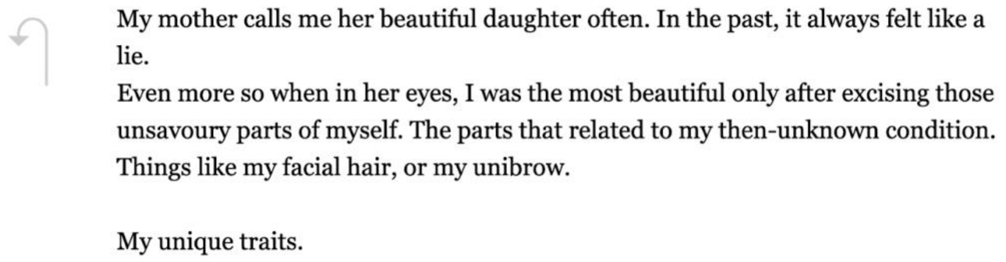
My body was **different.** And it was relieving to finally be sure of that.

Fig. 45. Screenshot of Participant 3's Twine Story

Relationality

All the narratives in the study include compelling and nuanced accounts of the ways in which relationships with other people come to form meaning around the illness experience. In this section, relationality, as an affective force that generates kinship and connection, will be discussed as an agent of relationships in the narrative story. The participants show in their narratives that the ways in which they come to understand themselves as sick are formed not solely by the experience of symptoms, but through their encounters with other people. The most prevalent relationships coded in the narratives include the relationship with the mother, the sister, and the romantic partner. Themes that emerged around the mother include shame in revealing the abnormality of the body to the mother, the mother's role to gatekeep the normality of the daughter's body, fear of becoming your mother and fear of not experiencing motherhood. Narratives that included the theme of the sister centred on jealousy, comparison, and a belief structure that the sister is outperforming womanhood. Finally, themes around the romantic partner include anxieties around illness disrupting the body's sexual appeal and actions of a supportive versus an unsupportive partner.

The narratives in this study were saturated with themes of the mother. Table 3 shows that the concept of the "Mother" was coded twenty-eight times and more than any other family member. It became evident, in the analysis of the narratives, that the idea of the mother and conceptualizations of motherhood are foundational belief systems that construct the way participants have come to understand hyperandrogenism and their bodies. A typical initial mention of the mother in the narratives correlated to the first menstruation anecdotes discussed in the previous section. When the author first perceives that their menstruation is abnormal, there is collective anxiety in having to reveal this to the mother. Participant 1 writes: "My first period lasted for 6 months. I was too emberassed [sic] to talk to my mother about my period, and none of my friend [sic] had theirs at the time, so I continued to navigate dramatically irregular periods for a few years, before I got up the courage to talk to my mom about it." In the participants' narratives, there is a common thread of shame around revealing to the mother that the body was not, in fact, "progressing" into womanhood as expected. Participant 11 writes: "Summoning the courage as a 16 year old girl to tell your mom you've missed your last couple [[periods->Opening Passage]]." For Participant 11, disclosing to the mother their lack of menstruation is an act that requires courage. This shame and fear described by participants appears to come to a crux at a collective perception that the mother desires normative femininity for the daughter. We see this in fig. 46 where Participant 3 describes their belief that their mother only finds them beautiful when they successfully "rid" the body of their masculinizing traits such as excess facial hair.

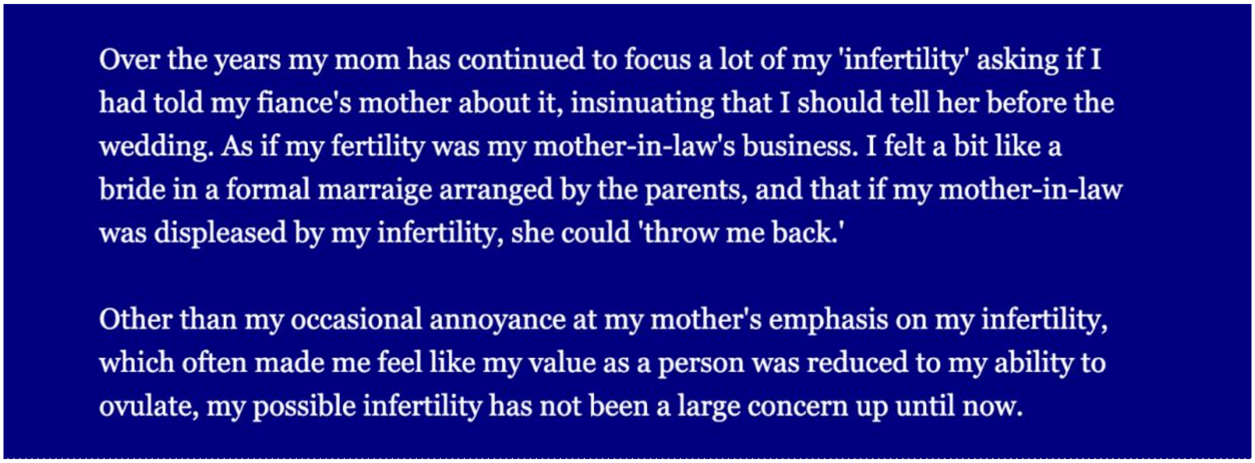


My mother calls me her beautiful daughter often. In the past, it always felt like a lie.
Even more so when in her eyes, I was the most beautiful only after excising those unsavoury parts of myself. The parts that related to my then-unknown condition. Things like my facial hair, or my unibrow.

My unique traits.

Fig. 46. Screenshot for Participant 3's Twine Story

Going deeper into the belief structure that the mother desires normative femininity for the daughter revealed the theme that beyond desire, it was, in fact, the mother's role to do so. Through various narrative anecdotes, coloured by the ways in which authors constructed meaning, there is a notion that the mother's job is to monitor the normality of the daughter's body and to intervene when dysfunction is perceived. Participant 1 constructs this belief system effectively in their narrative. The author writes about their mother first taking them to visit the doctor to address their absent periods as a teenager, but soon they would attend appointments on their own to assert their “independence as a young woman.” Following receiving a diagnosis of PCOS and discussions of future infertility, Participant 1 writes: “This stuck with me because when I returned home my mother asked me about my appointment and I distinctly remember her being very upset about this one piece of information. Up until I told my mother I had not been that concerned about possible infertility. But my mother's reaction made me wonder if I should be more concerned.” In fig. 47, Participant 1 explains that their mother, throughout their life, focused excessively on the daughter’s potential infertility. Before the author’s wedding, the mother told them that they should disclose their potential infertility to the mother-in-law. The author writes: “I felt a bit like a bride in a formal marraige [sic] arranged by the parents, and that if my mother-in-law was displeased by my infertility, she could 'throw me back.'” Through the ways in which Participant 1 writes about their experiences with infertility in relation to their mother, the author becomes objectified. In this formation, the author is reduced to an object of ovulation, and the mother becomes the agent of femininity maintenance.



Over the years my mom has continued to focus a lot of my 'infertility' asking if I had told my fiance's mother about it, insinuating that I should tell her before the wedding. As if my fertility was my mother-in-law's business. I felt a bit like a bride in a formal marraige arranged by the parents, and that if my mother-in-law was displeased by my infertility, she could 'throw me back.'

Other than my occasional annoyance at my mother's emphasis on my infertility, which often made me feel like my value as a person was reduced to my ability to ovulate, my possible infertility has not been a large concern up until now.

Fig. 47. Screenshot of Participant 1’s Twine Story

An anchoring theme at the centre of relationality was both implicit and explicit fear of becoming the mother. Becoming the mother figure, for participants, was both physical in terms of “inheriting” an illness or experiencing masculinizing symptoms, and emotions relating to the mother’s disposition and her beliefs about the world. This theme was most strongly constructed in Participant 12’s narrative in compelling ways. The initial mention of the mother in this narrative begins when the author is describing their first months of pregnancy: “The congratulations start and I am reminded of what my mom told me in the past about her having at least one miscarriage. This isn't my mom's story, I think to myself. It's mine, and it will have a better outcome.” Participant 12 goes on to describe a cruel and complicated mother. A child of the 60s, with “progressive” views on women’s liberation, she was often combative with the author’s father who was a dangerous man, suspicious of doctors and the education system. In one passage, the author describes how their mother and aunt would take them shopping in the boy's section. The author writes: “She and my aunt would often tease me about my body, the clothes I wear, and asking me what I would do with a husband. While I was a teenager, I had no idea.” In another passage, Participant 12 describes watching their mother lament plucking “disgusting, long, black hairs” from her face, then “she would tell me to come closer and would proceed to pluck the hairs off my face as well.” The author’s declaration that “this isn’t my mom’s story” is a compelling, generative statement. What is generated is, in fact, a version of the mother’s story told by the experiences of the daughter. It is a narrative about a struggle to sever self-identity from the mother, but in this pursuit, the mother’s story becomes deeply intertwined with the daughter’s.

A strong but inverse theme of fear around becoming the mother was fear around not becoming a mother at all. This topic was expected to emerge in the narratives. Infertility is a common symptom of PCOS, and concerns about the ability to conceive were a theme in the Screening Interviews. However, the way in which infertility was written about in the narratives was specific. Issues around current infertility were mentioned, however, most participants spoke about the diagnosis of PCOS igniting a life-long fear of the future regarding motherhood. In many narratives, after receiving a PCOS diagnosis as a teenager, no further medical intervention is taken but the author is told to visit the doctor when they want to get pregnant. This fertility anticipation creates a looming sense of uncertainty for the author's future and, at times, positions them to contemplate their intentions for parenthood before their peers. Participant 7 writes: "Initally, [sic] I felt extremely disconnected from my diagnosis, I wasn't necessarily 'unwell', my body was just functioning differently. The root of my fear was thinking about my future. I had always wanted to be a parent and PCOS seemed to be stealing this way from me." For this participant, they had constructed an idea of their future, and a diagnosis of PCOS disrupts this trajectory. Participant 9's narrative centres on the experience of trying to become pregnant. In one passage, the author describes receiving their first vaginal ultrasound where they were not "prepared at how invasive it was, but I pretended not to care." Through the outcomes of this test, the author learns that there is a strong chance they will experience infertility, as they note: "And that was the beginning. The beginning of a life-long struggle." For Participants 7 and 9 a life path of anxiety around the potential of motherhood emerges alongside the illness diagnosis.

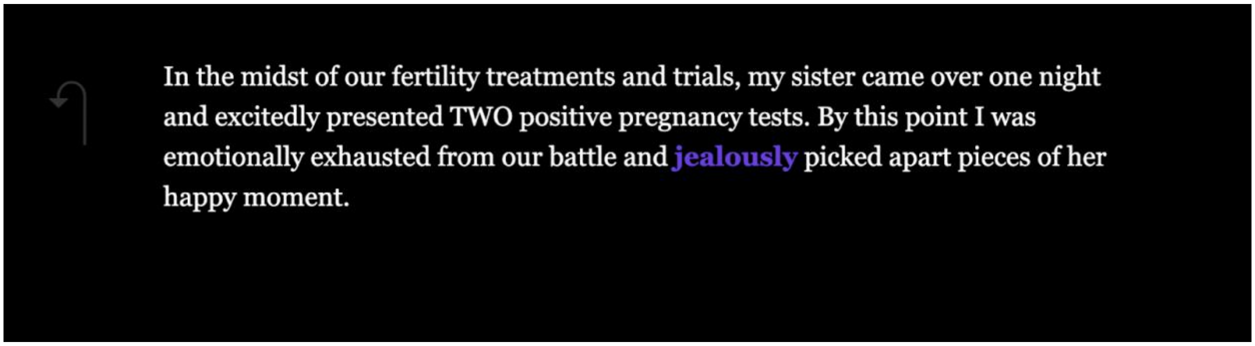
In reflecting on the larger veins of meaning that emerge from the analysis of the mother it would be simple to conclude that the mother, in the narratives of this study, is a domineering presence that is generally harmful to the positive identity formative for the author. However, when we dig deeper into this construction of the mother, concepts of internalized misogyny emerge. In light of the negative portrayals of the mother characters in these narratives, I wonder if there is space to consider the social roles we place on motherhood and how we frame failure as a society, in this context. After all, mothers, in many cases, stand as primary caregivers, both physically and emotionally for children. Factors that could be considered here include what support mothers receive, possible misattribution of the mother’s impact, roles of other parents, and societal judgement of the mother’s behaviour. In their interview, Participant 1 astutely reflects on the way in which writing about the negative experiences of illness led to narratively constructing their mother in a similar light. They note: “And so at the beginning, I was writing like really negative things about like my experiences with doctors and the way that my mom had reacted, especially, which was weird. I was like, ‘oh, why am I like villainizing my mom?’” The participant goes on to note: “She's, like, probably my most like, formative person.” This encapsulates, in this research, how relationality comes to shape narrative construction. The mother, like the illness, becomes a dominant oppressor. They become intertwined and interchangeable.

The second most prevalent family member to be referenced in the narratives of participants was the sister. Reference to the sister was made fourteen times throughout participant stories, and the majority of these references unearthed themes of resentment in being compared to the sister, particularly because of a perception that the sister is performing womanhood more effectively than the author. In fig. 48, Participant 11 discusses the moment when their sister happily reveals two positive pregnancy tests. Emotionally exhausted from their own infertility journey, the author reflects on responding with jealousy and ultimately ruining their sister’s joyful moment. Later, in the closing interview, Participant 11 revisited this moment in their narrative and concluded that participating in this study and writing about their illness experience helped recontextualize their response to their sister’s pregnancy news. They explain:

> I think it helped me to like, kind of realize like, like, there was the part in there where I talked about, like my sister getting pregnant. That was a really big moment, because she actually just found out she's pregnant again. We reacted much differently this time. And

> we've talked about that. And it's kind of funny how would like timing of all of this, but I'm realizing that it was the shame that was actually causing that, like, the fact that I've been working so hard and couldn't get something that's so easy for other people. I think it gave me a better understanding of the emotions attached to it, I guess.

A similar sentiment emerges in the narrative of Participant 12. This author discusses how their sister was always deemed "the beautiful one" who received endless gifts from men who were interested in her. The author explains that rather than feeling emotions of jealousy, they noticed a stark difference in how the world treated them. The author writes: "There was a difference." Their mother, for example, would ask the author why they couldn't be more like their sister. What reference to the sister in these narratives reveals is, rather than a literal sibling, the sister becomes a symbolic concept of a feminine ideal that the illness of hyperandrogenism prevents the author from achieving.



In the midst of our fertility treatments and trials, my sister came over one night and excitedly presented TWO positive pregnancy tests. By this point I was emotionally exhausted from our battle and jealously picked apart pieces of her happy moment.

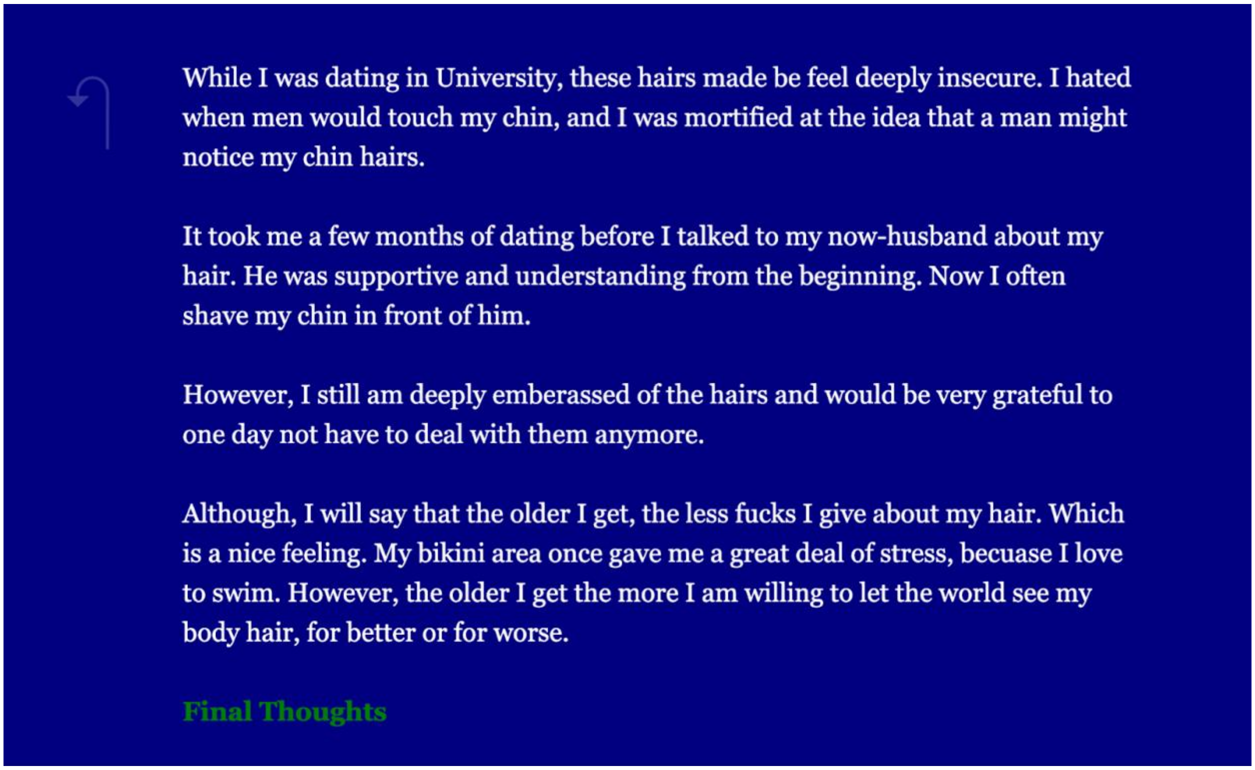
Fig. 48. Screenshot of Participant 11's Twine Story

A final, albeit significant, relationship code was that of romantic partners. This theme was coded twenty-eight times throughout participant narratives under the relationship code. Discussions of romantic relationships in the Twine narratives were diverse but relatively fell into one of three themes. First, participants discussed feeling as if the disease of hyperandrogenism strips them of femininity and therefore renders them undesirable to romantic partners. Second, in longer-term heterosexual relationships, participants wrote about feeling as if they are failing in their role of womanhood, a role that is required of them in a romantic partnership. Finally, there was ample discussion of moments of unsupportive actions from a romantic partner in contrast to the partner acting as the sole, safe companion to discuss anxieties and fears regarding the illness.

Participant 1 includes a passage in their narrative dedicated to their experiences of not feeling desirable to men because of their hyperandrogenism symptoms. The hypertext that grants access to this passage is labelled, in the narrative, as [[Dating: a Hairy Situation]]. Fig. 49 details the participant's experience dating with excess body hair. They describe how body hair, particularly on their chin, made them insecure when dating as they feared a partner would touch their face and feel the pricks of stubble. They note that it took time to share their vulnerabilities with their current husband, and enough trust has built between them that the author often shaves their face in front of him. The author concludes this passage by explaining how time has helped them to gain more confidence in their body. Where they once used to feel ashamed of the hair on their bikini line when they would wear a bathing suit, they now swim in public with body hair exposed.

Participant 11 discusses feelings around perceived blame in their partnership, particularly in relation to the author’s perceptions around their body failing to perform womanhood as expected. The author discusses their long and painful journey with infertility in their marriage: “I know the suffering is not just my own. My spouse, excited as he was at the first positive also feels the pain of each negative test as well. Sometimes I think he blames me. And I don't fault him on that. I blame [[me->Opening Passage]] too.” This passage is compelling and speaks to underlining assumptions around gender roles in heterosexual relationships as well as assumptions around health and illness. There are belief systems emerging that establish the female body as inherently fertile and when a heterosexual couple is unable to get pregnant there is an assumption that it is a failure of the female body. This removes the role of the male body in fertility while also establishing binaries of biological sex and health: healthy women are always fertile and therefore not conceiving means the women's body is ill.

Finally, participant narratives conveyed vivid anecdotes that explored what support looks like to the author in a partnership. For example, Participant 9 explained that their husband acted as their support system because: "he comforts me when I feel physical pain brought upon by my medications, and emotional pain brought about my period (aka when my medications did not work)." This is in contrast to Participant 10 who writes about what an unsupportive partnership looks like to them. They describe attending a couples therapy session with their partner of a decade where the therapist asks to see the author alone for the next session. In this private meeting, the therapist advises the author to end the relationship with their partner. The author notes how difficult it was to come to terms with this advice, but ultimately it helped them begin to make other large changes in various aspects of their life. The romantic partner, in many of the participant narratives, stands as a robust, dynamic symbol: the partner may be a stable, safe force, a site of instability, or a space to project fear of rejection.



While I was dating in University, these hairs made be feel deeply insecure. I hated when men would touch my chin, and I was mortified at the idea that a man might notice my chin hairs.

It took me a few months of dating before I talked to my now-husband about my hair. He was supportive and understanding from the beginning. Now I often shave my chin in front of him.

However, I still am deeply emberassed of the hairs and would be very grateful to one day not have to deal with them anymore.

Although, I will say that the older I get, the less fucks I give about my hair. Which is a nice feeling. My bikini area once gave me a great deal of stress, becuase I love to swim. However, the older I get the more I am willing to let the world see my body hair, for better or for worse.

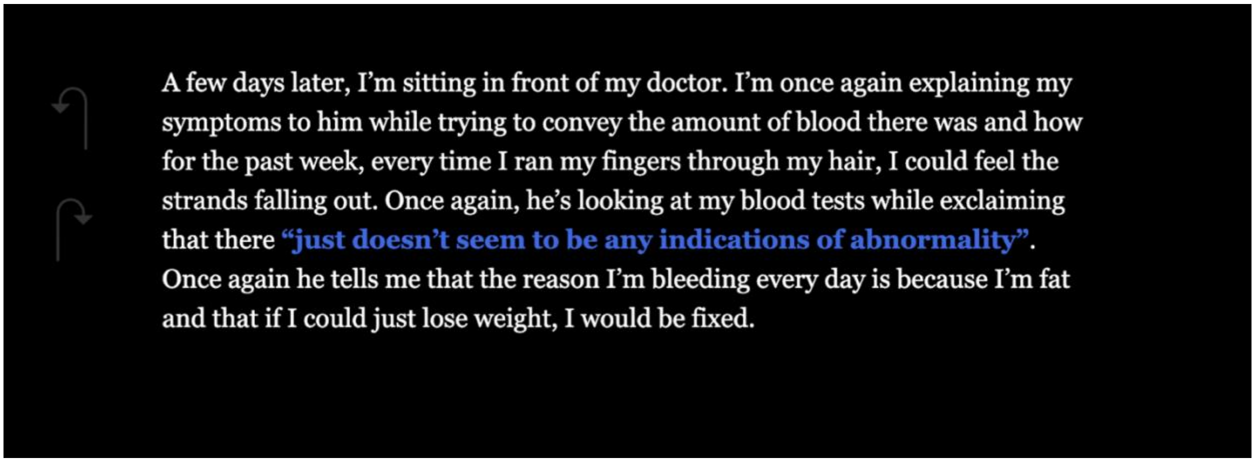
Final Thoughts

Fig. 49. Screenshot of Participant 1's Twine Story

Healthcare Experience

Table 3 shows that the second most frequently coded theme was Healthcare System Experiences. Narrative reference to healthcare, in any way, was made ninety-five times in participant narratives. Although the module's writing prompt centred the embodied experience of the disease, grappling with experiences in the healthcare system was a recurring topic throughout participant Screening and Closing Interviews, as well. Similarly, in the political framing section of the Twine module, there are passages that reference the experience of visiting the doctor with hyperandrogenism. The module calls the reader to consider: "Anxious? Alone? Optimistic? Cared for? Dismissed? How do you feel when you visit the doctor?" The following passage reads: "Some women* with hyperandrogenism have had negative experiences at the doctor's office. They feel: They weren't listened to. Their symptoms were dismissed. They weren't treated like a person." The subsequent passages situate the disease as a collective experience by describing how, despite a lack of awareness, hyperandrogenism is a prevalent condition that many individuals live with. The module then leads the participant to consider methods, such as creative writing, to respond to the emotional impacts of the disease. It is likely that these passages that frame hyperandrogenism's intersection with the healthcare system led participants to consider their own healthcare experiences and possibility reflect on them in their narratives.

Participants, overwhelmingly, framed their experiences in the healthcare system as negative, mainly through feeling subjugated, dehumanized, or dismissed by their physicians. An additional negative experience included perceiving the physician to lack knowledge on the topic of polycystic ovarian syndrome (PCOS). Fig. 50 shows a passage from Participant 10's story where the author describes feeling their symptoms are dismissed by the physician despite experiencing alarming symptoms. The physician, in the narrative, notes that he does not recognize any signs of abnormality, as the author explains: "Once again he tells me that the reason I'm bleeding every day is because I'm fat and that if I could just lose weight, I would be fixed." The next passage in the participant's story is a single line that reads: "I want to spit in his face. But I don't." This anecdote creates a dynamic understanding of what constitutes abnormality for the physician that centres around blame. The physician, in this story, seems to link the term abnormality, not to unexpected bodily symptoms that distress the patient, but rather, to some sort of core, buried, inherent bodily malfunction. The abnormality, in this case, would not be the "fault" of the patient, but rather something biologically faulty. The participant's body size, in contrast, is framed by the physician as both the fault of the patient and the cause of the symptoms.



A few days later, I'm sitting in front of my doctor. I'm once again explaining my symptoms to him while trying to convey the amount of blood there was and how for the past week, every time I ran my fingers through my hair, I could feel the strands falling out. Once again, he's looking at my blood tests while exclaiming that there **"just doesn't seem to be any indications of abnormality"**. Once again he tells me that the reason I'm bleeding every day is because I'm fat and that if I could just lose weight, I would be fixed.

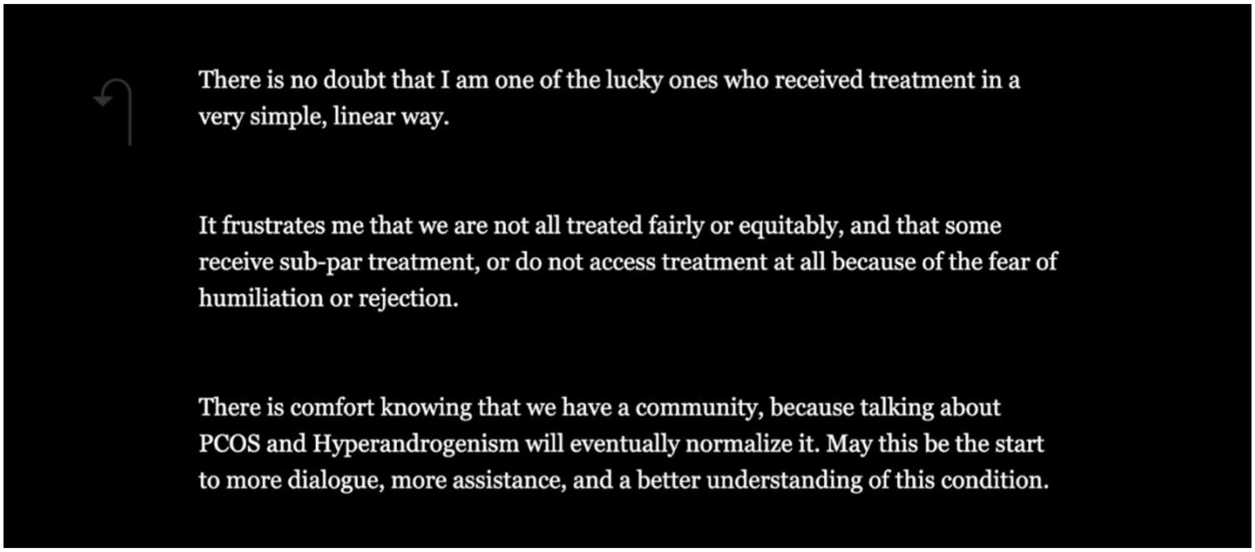
Fig. 50. Screenshot of Participant 10's Twine Story

Participant 10 revisits this narrative moment in our Closing Interview where they describe viewing TikTok content that explores women's dehumanizing experiences of "being fat at the doctor's office." The participant explains that encountering other women who had similar experiences was a validating and community-building moment for them. The participant explains: "I would say like writing [the] experience and reflecting on the whole like fatphobic doctor thing that was kind of powerful for me because I was like, it just reaffirms, you know what I've always been thinking," mainly that "there's really a lot of fatphobic doctors out there that just think that fat is like that's the only problem and then if you could just get rid of the fat that everything else would be like fine." Ultimately, the participant notes that it was the process of writing about the experience in conjunction with finding kinship with other women that allowed them to feel validation.

A thematic throughline in many participant narratives was experiences of violation during particular medical procedures, mainly transvaginal ultrasounds. Participant 12 describes receiving their first Papanicolaou test as a young adult and feeling fear because they lacked instructional communication on what to expect. The author describes: "Each time I have a pap done, I feel a little violated, I think due to the invasiveness of the procedure. The doctors were female, and told me they would be gentle.” This is a similar sentiment articulated by Participant 9 who wrote: “It was my first vaginal ultrasound. I was not prepared at how invasive it was, but **I pretended not to care**.” The author’s coded emphasis on the phrase “I pretended not to care” centres the idea that the author was compelled to camouflage their feelings of violation during the procedure, rather than intervene. This anecdote raises questions about how patients with hyperandrogenism might come to understand their role in the healthcare encounter and the level of agency or bodily autonomy they hold in that setting.

How relationality comes to shape experience was a recurring theme in both the Twine narratives and the Closing Interviews where participants reflected on how the entanglements of matter, identities, histories, biology and technology impact negative healthcare outcomes. One interpretation of this theme might be intersectionality, a term that was used by several participants to describe their experience. As explored in depth in the Literature Review, however, this paper will frame the phenomenon as assemblage theory. As Jasbir K. Puar argues, “transnational, postcolonial, and critical race theorists have pointed out, the centrality of the subject positioning of white women has been re-secured through the way in which intersectionality has been deployed” (“‘I would rather be a cyborg than a goddess’” 373). Puar calls for a queer assemblage framework to supplement the short-comings of intersectionality (“‘I would rather be a cyborg than a goddess’” 372). In some ways that intersectionality has been taken up, identity is positioned as a product of a gridlock where individual identities can be teased out and their impact analyzed in isolation. Assemblage theory centres the evolution of the identity, not as a collection of parts, but as an entanglement of relations that cannot be reduced to individualized identities. Assemblage theory accounts for how *things* inside and outside identity are, in fact, that identity as well. Assemblage theory, in this project, is an expansion not a rejection of intersectionality. As Puar argues, the two theories are not oppositional but "frictional" to each other ("'I would rather be a cyborg than a goddess'" 372). This friction is important in this project because although FNM is centred as the theoretical framework of this research, participants in this study used the term intersectionality to describe their experiences.

In fig. 51, Participant 4 discusses the frustration they feel about a perceived lack of equality or fairness for patients in the healthcare system. In our Closing Interview, Participant 4 expands on this moment by offering nuance to their experience. Participant 4 explains that as a Person of Colour, it was, in fact, surprising to them that their own experience in the healthcare system was brief and effective. This is because, as the participant explains: "with a bunch of news coming out about People of Colour and, you know, just different minorities being mistreated at the hands of healthcare professionals - it's - I've become acutely aware that I'm probably one of the luckier ones for sure." Participant 4 highlights the ways in which race intersects with illness to further perpetuate a risk of mistreatment in the healthcare system. This insight is reminiscent of the work of Pitts, INCITE!, and Sutphen and Andrews, as discussed in the Literature Review chapter. These authors collectively argue for an understanding of colonial medicine and its implications for Women of Colour today. In particular, the authors centre the dysfunction of the patient/physician encounter and argue that this moment is a microcosm of more widespread institutional prejudice born from the rejection of racial subjectivity. Participant 4 is aware of this and in their sobering reflection, they explain that they are surprised their experience in the healthcare system was not worse because the expectation for a Person of Colour is to be treated as a body void of subjectivity.



There is no doubt that I am one of the lucky ones who received treatment in a very simple, linear way.

It frustrates me that we are not all treated fairly or equitably, and that some receive sub-par treatment, or do not access treatment at all because of the fear of humiliation or rejection.

There is comfort knowing that we have a community, because talking about PCOS and Hyperandrogenism will eventually normalize it. May this be the start to more dialogue, more assistance, and a better understanding of this condition.

Fig. 51. Screenshot of Participant 4's Twine Story

Participant 7 similarly draws attention to moments of intersectionality when thinking about gender identity in relation to the healthcare system. In our Closing Interview, Participant 7 and I had a lengthy and nuanced conversation about the experience of being nonbinary and having hyperandrogenism. Participant 7 touched on insightful and complex factors that have made their illness experience different than a cisgender woman with the same disease. The participant reflected on the supremacy of the biomedical model and its perceived inability to make space for diverse gender identities. They explain that, in their experience, polycystic ovarian syndrome is a "female-dominated condition" where the specialists they have visited are "just looking at your biological parts" and have not been appropriately trained in gender diversity. Participant 7 concludes that: "it's a big assumption that if you have this, that you're female, and that's just like the world that it is." Ultimately, the participant points to not only a gap in the standard education of physicians but the impacts of larger sociocultural systems that lead to discrimination of gender-diverse people in the healthcare system.

A unique but significant theme detailed by one participant was the impacts of capitalism and the healthcare system. Participant 12 was an American resident, and their narrative touched on the impacts of healthcare costs and insurance in ways that other participants did not. It was apparent, as confirmed in our Closing Interview, that Participant 12 attended medical facilities that utilize a different healthcare model than other participants in the study, presumably the Canadian universal healthcare system. Participant 12, as an American, would be referencing encounters in medical facilities that may be operated by one of many distinct organizations or private-sector businesses, including non-profit organizations, government, or for-profit companies. Participant 12 shares a sobering anecdote about attending the hospital during a miscarriage. Before the author is able to see a physician, and while they are still actively bleeding from the miscarriage, they are directed to pay for the medical services. The participant explains: “We are directed to wait even longer, so that we can talk to someone at finance. I am still bleeding, waiting to see a doctor about a child that could be growing inside of me. They show us into an office where they explain all of the charges. We agree to the terms of paying them anything that we would owe. [[Then we go back to the waiting room]].”

Participant 12 goes on to describe being wheeled to a private room to receive an abdominal ultrasound where the healthcare provider asks the author if they are interested in receiving a transvaginal ultrasound as well. The participant explains: “I have no idea what it is and they tell me that I could opt out of it if I wanted to. I ask if it's going to cost more and if I would have to do it again in a few days anyhow. The answer to these questions are yes.” The participant notes that they decline the procedure, which they and their partner later regret. In our Closing Interview, Participant 12 expands on how they believe their experience with this hospital’s approach to receiving payment for services, and how they processed this, was impacted by their profession. The participant had worked as a Data-Analyst for a hospital in the past and described that they were constantly reminded of the organization's motto to make the hospital as much money as possible, despite that fact, as the participant explains: "this was a non-for-profit hospital." Although Participant 12 was the only participant to discuss the impacts of fee structures for medical services, this is a significant, additional barrier that patients with hyperandrogenism may face in differing healthcare systems.

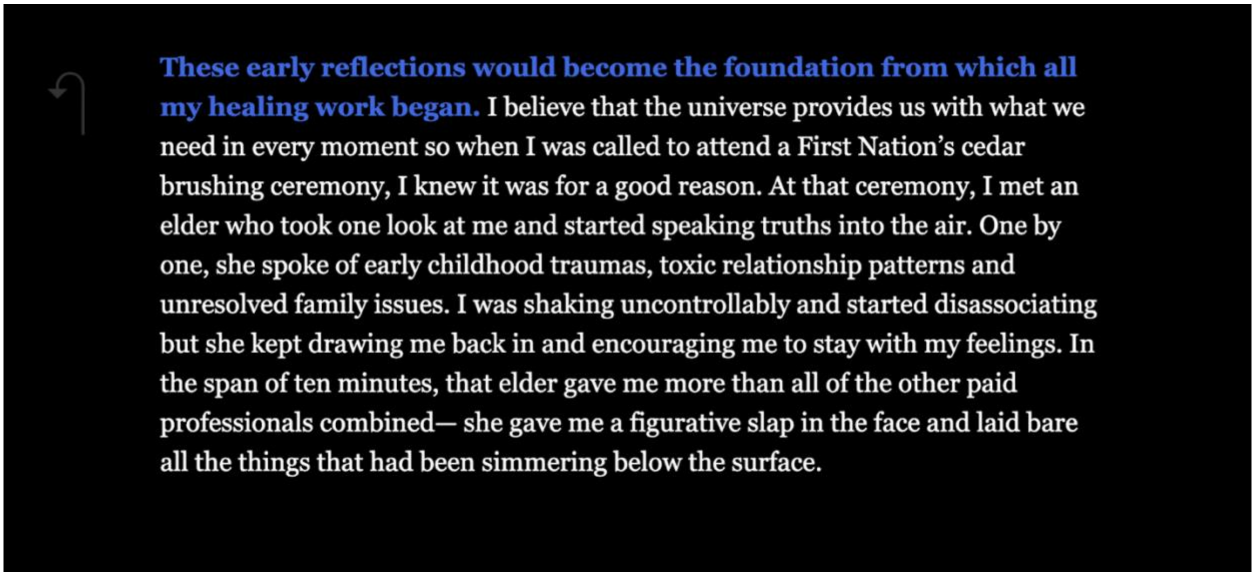
The dominant narrative theme of negative healthcare experiences is framed by participants in opposition to what they identified as positive experiences, mainly feeling validated, heard, and understood by physicians. Participant 11 sets up an effectively dizzying hypertext circuit where the reader/player must click through various hypertexts labelled as [[Dr. 1]], [[Dr. 2]], [[Dr. 3]] and [[Dr. 4]]. Selecting [[Dr. 1]] brings the reader/player to a passage that discusses the author visiting a physician with their mother at 16 years old. The physician tells the author to return when they plan to have children, reminiscent of Arthur Frank's concept of "remission society" that calls on the author to return to the healthcare system later, leaving them "well but not cured" (8). Selecting the [[Dr. 2]] hypertext brings the reader/player to a passage that reads: "He had never HEARD of PCOS and seemed like something that was over diagnosed. Refused me any help with it." This sentiment of dismissal is reflected again in the [[Dr. 4]] passage where the author describes how the physician ignored their diagnosis but offered options to remove the patient's "unsightly" skin tags. While the author establishes a sense of perpetual dismissal in their physician encounters, the cycle is broken when the reader/player selects the [[Dr. 3]] hypertext. Here, the author reverses the previous formula by describing a female physician who was akin to "sunshine". The author describes that this physician was empathetic and understanding of their illness and she progressed the author’s treatment by making referrals to specialists and facilitating regular blood work and medication refills.

Other participants use similar descriptive language to write about physicians who facilitate positive relationships. Participant 10 wrote that their physician “was patient and understood that my past trauma was going to make it difficult to insert the IUD but she was persistent yet gentle when booking me for another appointment to try again.” Participant 7 refers to their physician as “friendly, validating, and extremely comforting” in expressing to the author that they would address their illness. What is compelling about this thematic dichotomy created by the participants about what constitutes a negative versus a positive patient-physician encounter is that there was a distinct interpretation of gendered dynamics. A sustained belief from participants was that a male physician tended to be present in negative healthcare encounters whereas a female physician may facilitate positive experiences. This belief system was rarely articulated directly by participants, however, it was continually insinuated through various language choices. When participants chose to include or exclude the gender of the physician it created rich, generative meaning in the narrative context. It became apparent that when an author typically names a character as the “doctor” in their narrative, but suddenly makes a choice to include a sole reference to this same character as the “male doctor” or the “female doctor”, there was something intentional happening. The author is making a statement that the gender of the physician becomes important in the way they make meaning from their story. For example, in the Closing Interview, Participant 10 discusses “the other doctor that I found, like the female doctor” and “how she was so much more patient.” Participant 12 writes in their narrative how “The female doctor arrives and she tells me that the miscarriage was ‘complete’. I think she may be crying as she tells me.” Although assumptions can be drawn regarding why participants may have established this gendered dynamic, including perhaps a perception that female physicians may have lived experiences with gendered illness embodiment, the narratives in this study did not expand deep into this territory.

Finally, participants, in many ways, positioned alternative approaches to their illness in opposition to normative healthcare practices. Participant 12 creates this dichotomy in their Twine story by creating two separate hypertext links labelled [[Naturopathic Doctor]] and [[Western Medicine]]. Selecting the latter brings the reader/player through a narrative plot detailing the author's negative, dehumanizing experiences in the normative healthcare system. When the former hypertext is selected, a different story emerges. Here, Participant 12 writes a detailed narrative about feeling as if they had no path forward in the normative healthcare system. The author discusses feeling frustrated with being prescribed antibiotics every few months for a chronic condition that would not subside. The author's husband, on a flight back from China, met a flight attendant who suggested his wife see a naturopathic doctor. The author was skeptical about the validity of this practice. Their mother shamed them for considering this option and posed a series of questions to the author including: "What if it's a hoax?" and "Have you lost your mind?"

Participant 12 decides to visit a naturopathic doctor, whom they describe as "wearing busines casual underneath a lab coat and a stethoscope and does not look nearly as old as she is. Her hair is put up in a graceful way, something about her is different from anyone else I have met and it is a bit scary at first." The naturopathic doctor engages in consultation with the author and ultimately prescribes them a series of remedies the author has never considered before, including a food intolerance test, a bedtime routine, reflecting on their troubled relationship with their father, thoroughly chewing food, and a seed rotation that involves integrating various seeds in relation to the body’s hormonal cycle and the moon cycle. The naturopathic doctor also advises the author to take more time to enjoy life, where the author laments: “No doctors prescribe fun.” The author concludes their narrative with a strong endorsement of their experience with naturopathic medicine and discusses how they feel both physically and emotionally better. Ultimately, the author notes that the naturopathic doctor “asked me more questions that any other doctor had in my life. It was really wonderful to work with her as she knows the word ‘doctor’ means ‘teacher’... I trust her with my life.” In our Closing Interview, when reflecting on this narrative moment, Participant 12 explained that they are going to continue using naturopathic medicine to address their illness because: “I felt more. I felt loved.”

Participant 10 creates a similar dichotomy between normative healthcare practices and alternative approaches to illness, which for the participant is emotional healing work in relation to mind-body connections. In fig. 52, this participant details a compelling anecdote in their Twine narrative where, at the depth of their illness, they were invited to an Indigenous cedar brushing ceremony where they met an Elder who helped them start to make deep emotional connections. The author explains: “In the span of ten minutes, that elder gave me more than all of the other paid professionals combined— she gave me a figurative slap in the face and laid bare all the things that had been simmering below the surface.” This experience led the author to begin to reframe their illness and approach it in a different way - as an embodied emotional response to trauma where once the trauma is addressed the physical symptoms will resolve. There is an intriguing connection between Participant 12 and 10’s narrative construction of alternative illness response methods. Rather than centering if and how the physical methods alleviate symptoms of the body, it seems that the participants are highlighting the transformative potential of a connected relationality. Where the participants frame normative healthcare encounters as subjecting and dehumanizing, they position alternative approaches as empowering, generative and personally profound. Rather than interrogating if alternative responses to illness “work” in the sense that they produce a measurable reduction of physical symptoms, the participants seem to be highlighting that these practices “work” because they make them feel heard, understood and validated in their illness experience. Participant 12 explains their naturopathic doctor “told me that I was not ‘broken’ there's nothing ‘wrong’ with me,” and this validation that their body was not, in fact, abnormal, seems to be a strong source of the author’s support of an alternative approach to illness.



These early reflections would become the foundation from which all my healing work began. I believe that the universe provides us with what we need in every moment so when I was called to attend a First Nation’s cedar brushing ceremony, I knew it was for a good reason. At that ceremony, I met an elder who took one look at me and started speaking truths into the air. One by one, she spoke of early childhood traumas, toxic relationship patterns and unresolved family issues. I was shaking uncontrollably and started disassociating but she kept drawing me back in and encouraging me to stay with my feelings. In the span of ten minutes, that elder gave me more than all of the other paid professionals combined— she gave me a figurative slap in the face and laid bare all the things that had been simmering below the surface.

Fig. 52. Screenshot of Participant 4’s Twine Story

Empowerment

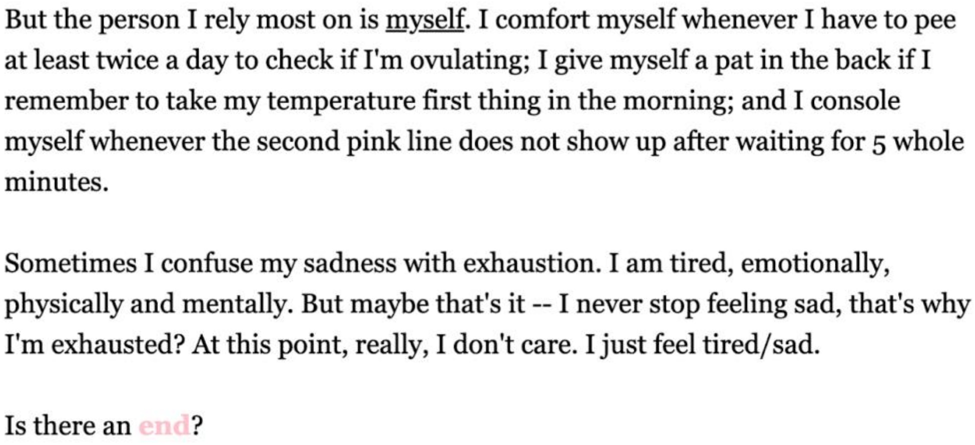
A common bookend theme in many of the participant narratives in this study was that of empowerment. Table 3 shows the theme of “Empowerment” was coded in the participant narratives twenty-three times, directly, however, this theme in various interpretations emerged in other codes as well. Participants discussed the theme of empowerment generally in three specific ways: knowledge and/or receiving a diagnosis, transformation, and community-building. The majority of the Twine narratives in this study explored themes of trauma, powerlessness or subjugation, however, there was a common literary strategy to pull the narrative conclusion into a moment of empowered summation. These conclusions focused on outlining strategies, approaches, and tactics that have allowed the author to feel more empowered in their illness journey.

A strong, recurring perspective perpetuated through multiple narratives was that acquiring knowledge on hyperandrogenism, or receiving a formal diagnosis of the disease, was an empowering experience for the author. Participant 3 describes a moment when their physician informs them of their diagnosis for the first time: "This body with all of its unexplained quirks and issues finally made more sense." The author explains, "In a way, it was relieving to finally know exactly what was wrong. The things I blamed myself for, that would fill me with guilt when I gazed upon the mirror, may not have been 100% my fault. My body was different. And it was relieving to finally be sure of that." This embracing of the potential of difference harkens back to Coleman et al.'s analysis of difference as FNM antiprejudice energy that is generative rather than inhibiting. The authors explain: "it takes us away from thinking difference only as binary separation or as opposed to sameness. It is entirely new and fresh thinking of difference: it affirms rather than negates." Difference, here builds up rather than divides as, according to FNM though, it is not concerned with separatism but multiplicity.

In one passage, Participant 3 offers three hypertext options to describe their newfound perception of themselves: [[Understanding]], [[Acceptance]], and [[Empowerment]]. Selecting the first hypertext brings the reader/player to a lengthy passage describing how a diagnosis helped the author understand themselves and their place in the world, including cultivating a sense of pride in being represented when learning about their illness in university courses. The second hypertext link, [[Acceptance]], explores how the author found acceptance within groups of people like them, and within themselves, including finding kinship in Facebook groups dedicated to the illness and within their own family with family members who also had the disease. Finally, selecting the [[Empowerment]] hyperlink brings the reader/player to a passage that describes the author's new sense of being emboldened to stand up for others marginalized by this disease. The author writes: "I am now more empowered than ever to use my voice to advocate for others like me. Those that are lost, that are trying to accept themselves, that feel ostracized for the way their bodies look or behave, I can advocate for. I want to build a future where those who are struggling with themselves can live as they wish." Being empowered in their illness experience, for this participant, is political. It not only allows the author to feel an elevation of individualized power, but it calls them to extend that power to those around them, experiencing oppression, as well.

Many participants mirrored a perspective of finding strength in a diagnosis. For example, Participant 4 explains in their narrative that they were seeking a name for their illness because, for them, "knowledge is [[power]]." The author writes: "PCOS...it finally had a name! I booked an appointment at the doctor immediately. I was DONE with not knowing. It was the best decision I could have made." However, other participants complicated a linear belief that a diagnosis was an inherent resolution, as it may afford clarity in some aspects, but, as a result, further questions emerge. Participant 7 writes that while they were exploring their gender identity, they underwent an exam that indicated ovarian cysts. The author notes: "This doesn't change my diagnosis or treatment plan but it did provide me with both a sense of validation that PCOS was an accurate diagnosis for me and also an increased sense of uncertainty. How long have I had cysts? When did they develop? Are they stable or growing?" Ultimately, the author questions: “[[Where does this leave me now?]]” In our Closing Interview, Participant 7 elaborated on this narrative moment and explained that receiving a diagnosis was emotionally complex. This is similar to Butler’s argument of how a gender identity disorder (GID) diagnosis (later renamed in the Diagnostic and Statistical Manual of Mental Disorders as gender dysphoria) can impact individuals in expansive ways. For some, a formal diagnosis could legitimate their health status for access to surgeries, hormonal therapy, and insurance coverage. However, naming a disease holds meaning. For some this asserts the body as abnormal which may have dehumanizing implications including calling into question one’s gender identity (Butler, *Undoing Gender* 77). The reality is that both experiences might be simultaneously true for most. While Participant 7 believes a formal diagnosis can aid a patient in navigating the healthcare system, particularly when seeking referrals to a specialist, diagnostic labels may also be “quite harmful.” This harm stems from dynamics of diverse identity intersecting with noninclusive medical diagnostic language, as the participant mentions a dissonance created as a nonbinary individual receiving an “assigned female diagnosis” like hyperandrogenism.

Participants discussed the concept of empowerment in relation to an internal, emotional transformation. While the Twine stories in this study tended to swell to an empowered narrative conclusion, this ending typically centred a transformative mindset in order to ultimately accept living with the disease. Participant 10 writes: “At this point in the story, you may be wondering what all these life changes have to do with PCOS. You may think that PCOS is simply a medical issue but for me, it was rooted in this journey of healing and self-discovery. [[As I began to live in my truth, my symptoms started to ease.]]” The Participant goes on to describe the most difficult moments of their experience with PCOS, referred to by the author as their personal “dark ages”, and concludes that despite the suffering the disease caused them, they believe it was a necessary experience to give them “fuel to figure out what I needed to begin the healing process.” Ultimately, for the author, their experience with the illness has become more bearable because of the lessons they have learned in the process. This is a similar sentiment found in various narratives in this study. In fig. 53, Participant 9 writes about finding strength in themselves during their fertility journey, explaining: “the person I rely most on is <u>myself</u>.” They describe various laborious efforts required when someone is trying to get pregnant, including urinating on ovulation tests and morning temperature checks, ultimately concluding that they are the stable comfort for themselves in difficult times. The author wonders: “Is there an [[end]]?” The following passage explains that there may not be an end to the disease, but there is an end to the author’s struggles. The author’s belief that they have come to an emotional place of accepting the disease was articulated in various narratives in different ways, however, they tend to merge through the concept of transformation.



But the person I rely most on is myself. I comfort myself whenever I have to pee at least twice a day to check if I'm ovulating; I give myself a pat in the back if I remember to take my temperature first thing in the morning; and I console myself whenever the second pink line does not show up after waiting for 5 whole minutes.

Sometimes I confuse my sadness with exhaustion. I am tired, emotionally, physically and mentally. But maybe that's it -- I never stop feeling sad, that's why I'm exhausted? At this point, really, I don't care. I just feel tired/sad.

Is there an end?

Fig. 53. Screenshot of Participant 9’s Twine Story

Finally, Twine narratives in this study explored a theme of empowerment through community-building. In particular, participants wrote about the internal power that stems from finding kinship with other women and individuals with hyperandrogenism as well as through support from loved ones. Participant 3 writes about the support they found through various Facebook groups for individuals with similar illnesses, where they “encountered role models, peers, and mentors with a diverse wealth of different experiences, backgrounds, and lifestyles.” Social media engagement as a method of grappling with hyperandrogenism was a topic discussed by Participant 4 as well. In Participant 4’s narrative, a passage discusses how a Facebook post outlining various symptoms, such as “[[Adult acne]], [[Irregular periods]], and [[Sporadic fluctuations in weight]]”, led the author to seek out an official diagnosis. In the previous passage, the author wonders: “Who knew that [[Facebook]] would start getting me to think otherwise?”

Participant 3 discusses how social media movements, such as “body positivity or fat acceptance”, helped them to develop acceptance for their body as it is. The author notes, through the process of being more open about their hyperandrogenism experience, they discovered that their cousin also has the disease. This bond with their family member has helped the author process how common the disease is and how important it is to reduce the stigma of the diagnosis. Finding empowerment through familial and community bonds was a theme shared by Participant 3, as well. In the author’s narrative, they consider how cultivating vulnerability by sharing their feelings with loved ones might help the author to cope more effectively with the illness. Ultimately, the author hopes this vulnerability will allow them to “get to the point where I'm not an occasional spectator of the beautiful sunshine on this [[planet...]]...but rather, someone who basks in the sun at any given opportunity.” The narrative of transformation, here, is about reframing an internalized belief system, informed through lived experience, that illness impedes living one’s life fully and that community support can challenge this.

Part III: Situating Narrative Themes

Narrative Perspective

Every Twine written in this study formed the same subject position of the narrator through the first-person point of view. In every participant's story, the author wrote about their illness experience utilizing the *I* pronoun. As discussed in the Methodology chapter, the textual *you* in digital fiction has been extensively theorized by scholars Alice Bell and Astrid Ensslin. The authors argue that the use of the textual, ambiguous *you* in digital fiction is a highly mediated process between the intentions of the author, the interactivity of the technology and the agency and choices of the reader. Because of this matrix of factors, the use of the textual *you* has the potential to generate complex, distinct outcomes regarding identification with the protagonist of the story. For example, Bell and Ensslin found in a 2019 study that "readers' negotiation of the various identity positions offered by ambiguous forms of address displayed their tendency to adopt positive identity positions of 'you' but resist negative identity positions by reframing the 'you' as an optional identity that they were expected to psychologically project into" ("A Reader Response Method not Just for 'You'" 262). *You*, then, becomes a contentious space for the reader/player to make decisions about where they fit into the story world, in a nonuniform way.

There is a prevalent tradition in Twine writing to use the second-person point of view, where the reader/player becomes a character in the narrative navigating hypertexts that tend to include the *you* pronoun. This convention stems from the common ancestors of Twine storytelling: "game books (choose-your-own-adventure stories), parser-based text adventures (interactive fictions), and hypertext fictions" (Salter and Moulthrop 139). For example, in Ana Anthropy's *Queers in Love at the End of the World*, the reader/player becomes the protagonist of the story: "it's just the two of you together. You have ten seconds, but there's so much you want to do: [[kiss]] her, [[hold]] her, [[take]] her hand, [[tell]] her." When the participants in this study centre the first-person perspective, it could be argued that they foreground the experience of themselves as the author rather than that of the reader/player. This breaks with the interactive fiction tradition that tends to explore the choices and beliefs of the reader/player, designed by the author. A simplistic analysis of this phenomenon might suggest that participants in this study overwhelmingly chose to build a Twine that embodied a narrative story rather than a game-like structure.

This phenomenon is inserting itself into a larger, relatively unresolved scholarly debate around formalism and the game-ness of literary hypertext. Salter and Moulthrop argue that "At a certain point in the early history of digital fiction, it was fashionable to accuse them of debasing literature (see most notoriously Birkerts). Nonetheless, figures associated with hypertext, such as Joyce, Shelley Jackson, and John McDaid, have identified mainly as fiction writers" (140). However, as Astrid Ensslin argues in *Literary Gaming* (2014), game and story are not distinct categories, and the boundaries of one may seep into the other. Ultimately, this is what Twine is. Twine is self-aware of this inability to pin it down. Chapbook, one of Twine's built-in story formats, has an official GitHub guide that includes the following note: "Keeping in the spirit of vexing formalists who prefer clear boundaries, this guide calls the things you'll create with Chapbook stories and the people who you share them with players, but you shouldn't infer anything from this usage. Please make strange things with Twine and Chapbook." This tradition of using Twine to make strange is embodied in the stories of this study.

Perhaps some participants may view their first-person narrative as a game, while others see theirs as a piece of literature. Others may identify with both or neither. As Salter and Moulthrop argue, "Twine inherits this contradiction. It is structurally familiar and formally suggests so many antecedents that it does not at first glance appear transgressive—and yet it transgresses and transforms." Rather than assert the extent of the game-ness or narrative-ness the participants' Twines embody because of the first-person perspective, it may be more productive to grapple with why this style was popular. An obvious reason would be an expectation the participants interpreted from the writing prompt to explore their subjective experience. Although participants did spend time in the module reading other example Twine games for inspiration, all of which were written in the second-person point of view. This, theoretically, would also have the potential to sway writing style. There is not enough information to analyze why participants in this study chose the first-person perspective in their writing, however, there may be a similar impact from this choice. Where conventional Twine games appear to foreground the choices of the reader through the second-person point of view, participants in this study used Twine to centre their own subjectivity.

One participant, Participant 9, while still using the first-person perspective, creates a metalepsis, or the transgression of narrative levels, by acknowledging the reader/player. A passage of this author's story reads: "If you chose to click this link, then hello, I want to tell you something more than my *PCOS-related problems*." This is the sole narrative in the study that includes the use of a "you" pronoun, however, the author still employs a first-person perspective. The second-person pronoun is employed in a self-reflexive way to draw attention to both the reader reading and the author writing the story. A later passage reads: "I hope you also find a way to deal with your own struggles, no matter how big or small they are; *don't be so hard on yourself*, we all have issues." Empathy, particularly empathy for the reader/player, has sat at the crux of the game-ness/narrative-ness Twine debate for years. Salter and Moulthrop explain how, in response to critics of Twine who challenge a lack of game-like objectives, authors such as

Leigh Alexander and Raph Koster raise the question of empathy. Alexander wonders how understanding another human is not considered a challenge and Koster argues that games conveying empathy for the reader/player rather than the other way around are much more difficult to design (Salter and Moulthrop 23). Although Participant 9's narrative deviates from the others in the study by including reference to the reader/player, the narrative creates a similar impact where the reader/player is hailed as an audience, solely to hear the experience of the author.

The narrative subject positions formed in this study enact and restrict moments for action in different ways. However, all the Twines build a formulaic trajectory for the author's agency. The stories begin with a setting a scene for a lack of agency for the author and, as the narrative processes, the author is granted or restricted agency through their narrative encounter with other subjects, objects, and forces. The subject position of the author is framed initially as powerless, with oppositional forces enacting oppression onto the body. These oppositional forces are vast but include puberty as violence onto the body, the author's own body as a character, fatphobic physicians, the opinions of the mother, the labour of fertility, or the physical pain of hair removal practices. All these forces work together to restrict the agency of the author. However, the Twines in this study collectively shift the narrative tone, through encounters with other forces, to grant moments of action for the author as the story progresses. For example, narratives facilitate agency for the author through encounters with alternative medicine practices, talk therapy, formal diagnosis, or knowledge accumulation. This becomes significant as the authors in this study did not frame the inherent embodiment of hyperandrogenism as restricting agency but as how the illness is taken up culturally. Logically, it follows, that moments granting action for the author did not come from alleviating symptoms of the illness but through encounters with cultural forces that pushed back against illness stigma.

Narrative Affirmation and Erasure

Reflecting on the analysis of narrative themes in this study, insight emerges around what is generally affirmed and erased in the discursive framing of the participant's Twines. Collectively, narratives in this study affirm that a female body that experiences masculinizing symptoms is abnormal. This abnormality renders the body in need of control, deciphering and strenuous maintenance. The default in the abnormal body runs the risk of seeping into the author's psyche as well, ultimately rooting the abnormal body in emotional bankruptcy. In turn, narratives affirm that bodily abnormality is undesirable because of its relationality with outside agents rather than an inherent undesirability. It is in the author's encounters with other people, institutions and social systems that make their bodies undesirable, not the neutral embodiment of symptoms. This turning to the cultural take-up of disease as the culprit of facilitating suffering, rather than embodied symptoms, is reminiscent of Couser's novel category of a counterhegemonic and postcolonial challenging narrative style known as the rhetoric of emancipation. These narratives are inherently political in nature, according to Couser, where the rhetoric of emancipation is attuned to the political struggle of identity for disabled people. These narratives focus less on eradicating symptoms and more on institutional recognition of the humanity and rights of those with disabilities (Couser, *Signifying Bodies* 47). In this study, moments of Couser's notion of emancipation looked like reflection on dehumanizing experiences in the healthcare system and naming moments of body-based injustice.

Narratives in this study affirm that illness is a personal journey of growth where, in order to heal therapeutically, the patient must resolve a perception of emotional bankruptcy, gain knowledge, receive a formal diagnosis, and locate a community of support. Finally, the Twines in this study affirm the belief that encounters in the normative healthcare system are generally dehumanizing, subjugating, or violating. Female physicians, for many participants, generally acted as characters who challenged this trend by making authors feel validated, heard, and understood. Overall, participants affirmed alternative methods as an effective response to their illness, not because of a measured reduction of symptoms, but because of producing a greater sense of well-being.

The centering of alternative approaches to illness is reminiscent of Anne Hunsaker Hawkins final narrative classification in her 1993 book *Reconstructing Illness: Studies in Pathography.* As discussed in the Literature Review chapter, Hawkins argues that one of the major themes of pathographies include limitless healing capabilities of the mind and attitude, belief in the results of holistic treatments, and coveting notions of an inner spirit (Hawkins 9). Pathographies, or illness narratives, that embody these themes tend to also reject a Cartesian notion of the mind-body split, and instead reinforce a belief of the self as the body. This framing of the mind as expansively bound to the body beyond the physical was reproduced by authors in this study as well. The authors wrote about emotional trauma stimulating physical symptoms and inner healing as a path toward physical healing. I want to avoid reinforcing the narrative classification systems offered by early scholars of illness narratives, such as Hawkins, Frank and Couser, in this study. The value produced from these structuralist categories is not assumed in this context, and the emerging arguments against these genre classifications as made by authors such as de Bie and Teare, discussed in the Literature Review, are strong. However, what this mirroring back to Hawkins' genre classification of alternative medicine does is highlight a response to illness subjugation that appears evergreen.

An argument can be made that the Twines in this study may fit into Frank's genre classifications of restitution, quest, or chaos, but that claim will not be made here. Frank notes "In the remission society the foreground and background of sickness and health constantly shade into each other. Instead of a static picture on the page where light is separated from dark, the image is like a computer graphic where one shape is constantly in process of becoming the other" (9). Frank's use of the term *shade* is a remarkably generative tool, especially in the active verb form to *shade*. Rather than think about the corpus of my research as narrative moments that can be slotted into structural typologies, I value Frank's sentiment of the centering of lived experience in conjunction with an appreciation of narrative as *shading*. Narrative accounts of illness, in this sense, cannot be sliced into pieces, but rather, must be looked at as a comprehensive experience. This comprehension takes into account the life of the author in relation to the story of illness, the ways the author's identity intersects with their illness experience and the way these factors *shade* into each other. As discussed in depth in the Methodology chapter, in my research I turn to a methodological approach to considering *shade* rather than typology by conducting both screening and exit interviews with participants. The Screening Interview asks extensive questions to mark identity characteristics in order to better understand how different experiences of identity can come to shape and be shaped by hyperandrogenism. The Closing Interview asks open-ended questions of participants to explore their experience using literary hypertext to write an illness narrative. Rather than analyzing participant narratives in isolation, this project attempts to examine them in relation to the data obtained by the Screening and Closing Interviews which explore narrative themes, technical experiences, identity, history and more.

By reinforcing particular belief systems, narratives in this study work to erase various counter-discourses. Most notably, upholding traditional biomedical approaches, a sense of contentment with the abnormal, and questioning the category of abnormality was erased. While the Twine stories in this study tended to challenge the omnipotence of the normative healthcare system, this led to an erasure of upholding a biomedical model of illness that, some argue, rejects a holistic approach to treatment. Generally, Twines in this study did not approach the concept of the abnormal body as positive or even neutral. In the same vein, there were few narrative moments when authors explicitly question abnormality as a category or challenged dichotomies of healthy and ill or normal and pathological. It is important to mention this outcome without value judgment. These findings do not lend to an analytical interpretation that questioning these dichotomies would be good or bad. This was an expected outcome as participants in this study were invited to share their stories of illness. Explored in depth in previous chapters of this work, the ways in which illness and pathology intersect with gender identity are highly complex and produce significant, meaningful impacts on the lives and well-being of individuals.

Narrative Interaction with Outside Agents

The authors in this study chose distinct and meaningful ways to intersect their narratives with external texts, authors, and readers. Most notably, this was done through choices participants made around considering differing reader/player experiences and foregrounding traditionally authoritative informational resources versus less authoritative sources. In one narrative, written by Participant 12, the author takes into consideration how various reader/players may experience their story by including a content warning. The opening passage of this participant's story includes a line that reads: "*Note: My story comes with a warning because they all include themes, which may cause a strong reaction in women with similar experiences." The author, in this disclaimer, is grappling with how the experience of some readers, namely women with hyperandrogenism, may be different than others because of the potential of a strong emotional reaction to the narrative content. This content warning, written by the author, speaks to how narrative meaning becomes altered through the text's dialectic with other agents, including reader/players. It becomes important for this participant to convey the complexity of the reader experience and how the intended meaning, in their story, may shift with each unique reader experience.

While the narratives in this study, in many ways, undermined the authority of traditional pillars of knowledge, namely the normative healthcare system, simultaneously these same narratives upheld other forms of authoritative knowledge. For example, Participant 10 incorporates a statistic from The World Health Organization that describes how often PCOS is diagnosed across the world. Participant 12 includes an external URL link to a diet challenge. The author writes: "I am now more determined than ever to get PCOS out of my life. I did the 30 Day PCOS Diet Challenge with Kym Cambell, her website is https://www.smartfertilitychoices.com/." These choices made by the authors to incorporate external texts into their narrative is a productive action that further shapes the meaning of their story. For example, In Participant 11's narrative, the author shares the Oxford English Dictionary definition of the term shame as "noun a painful feeling of humiliation or distress caused by the consciousness of wrong or foolish behaviour. verb (of a person, action, or situation) make (someone) feel ashamed." This dialectic with an external text generates additional, complex meaning in the narrative of the participant.

The definition of shame Participant 11 chooses to include reinforces the belief that the origin of shame is the fault of the individual. The definition situates the root of the emotion as “the consciousness of wrong or foolish behaviour” rather than a consciousness of how the world treats individuals based on social stigma. This interpretation of the term alters the meaning, or rather, makes shame mean the fault of the author. This paints the meaning of the author’s narrative in various ways. The definition of shame is the opening passage in this narrative. Once the reader/player moves on from this passage, they are confronted with anecdotes from the author that centre the abnormal body, symptoms and feelings of inadequacy. Most of these passages loop back to the opening passage about shame. For example, in a subsequent passage the author describes how infertility affects their relationship, “I know the suffering is not just my own. My spouse, excited as he was at the first positive also feels the pain of each negative test as well. Sometimes I think he blames me. And I don't fault him on that. I blame [[me]] too. When the reader/player selects the [[me]] hypertext, they are looped back to the definition of shame. Not only does the author create a literal and figurative link between their illness experiences and the emotion of shame, but, reinforced by this textual understanding of shame, blame is situated with the author. This is an example of how external texts intersecting with the participant narratives expanded, stretched, shifted and deconstructed narrative meaning.

While most external texts that authors engaged within their narratives could be considered traditionally authoritative, one participant challenged this pattern. Participant 7 built a Twine narrative that centred knowledge dissemination where, before the author wrote about their experience with a particular issue, they chose to define and contextualize the issue with external links to information sources. In some cases, the author chooses to link to traditionally authoritative sources such as the Mayo Clinic or the Migraine Institute. The author includes descriptions of various symptoms and informs the reader/player that “Hyperandrogenism should be considered for anyone who presents with hirsutism, menstrual disturbance, or central obesity during puberty." The author provides a definition of hirsutism including the phenetic pronunciation and a URL to a page about the condition on the Mayo Clinic's website. While the participant upholds traditionally authoritative knowledge in some ways, they also make stark decisions to challenge it by incorporating alternative sources.

For example, the author writes about their experience as a nonbinary individual. In this discussion, they define and explain to the reader/player the differences between the terms sex, gender and gender identity. The author notes: "It's common for people to confuse sex, gender, and gender identity. But they're actually all different things." In a later passage, the author includes the following line of code: <img src="https://www.genderbread.org/resource/genderbread-person-v4-0" width="600" height="800" alt="Use it Online">. This line produces an infographic of The Gender Bread Person, a popular teaching resource created by Hues, a global justice collective of artists, educators, and activists co-created in 2017 by Sam Killermann. This teaching resource is less mainstream than, say, the Mayo Clinic, and it produces the sentiment that the author is committed to teaching the reader/player about not only their illness experience but the political ideologies that intersect with their story. In our Closing Interview, Participant 7 reflected on incorporating concept definitions into literary hypertext, noting: "I think in storytelling, we often struggle with needing to give like background or definitions and things like that. So that tool just allows you to kind of incorporate those without, I think, taking away from like the narrative of the story." The participant is highlighting Twine's ability to compartmentalize narrative pieces into separate passages, which, by creating a system of hypertextual division, ironically for the author, allowed for increased narrative flow. This is because informative resources and definitions related to the narrative could supplement the story without creating a stark intervention.

Part IV: Technology

Using Twine

In Closing Interviews, Participants overwhelmingly spoke to the accessibility of the Twine software in various ways. Most notably, Participants discussed Twine as user-friendly and straightforward to learn when following the steps outlined in the module. Participant 11, for example, explained how the module gave them all the information they required to build their story, although, they chose to Google additional information to expand the scope of their project. Participant 4 noted: “I thought it was very, very easy to use. And that tutorial was awesome. So that is all I needed. And then I was on my way.” However, the accessibility of Twine was predicated on the assumption of time. Participants explained that although Twine was eventually straightforward to use, it took them some time to get to a place where they were prepared to write. Being appropriately prepared for participants looked like having the time to concentrate on the module instructions and the emotional or mental capacity to write about difficult experiences. Participant 11 explained that they initially were struggling to start the module, “But I was also like, at work and I was distracted. So the second time I attempted it was, it was much easier to grasp, I guess, when I didn't have the same distractions.” Similarly, Participant 9 discussed how they attempted the module once before and could not complete it as they were “too distracted at that time.” The Participant explained, “I stopped because I was like, ‘No, this is not gonna work. I'm not gonna give 100%.’ And then, for my second attempt, that's when it really like, okay, this is how it's being done.”

Beyond distractions and mental capacity, some participants explained that Twine initially felt too daunting. Participant 5 mentioned that they felt nervous to start the tutorial because of a reference to coding I made in the Screening Interview. They were pleasantly surprised at how user-friendly the software was after they did begin the module. Participant 9 shared that engaging in the module's storyboarding exercise, which asked participants to free write among other tasks on a physical sheet of paper, was imperative to their success in completing their Twine story. They explained that having a physical outline of their story before they started to engage with the more complex software of Twine allowed them to focus on learning the program without being overwhelmed with brainstorming a narrative topic at the same time. Another participant explained that the inherent structure of Twine was actually less overwhelming than sitting down to write a narrative on a physical sheet of paper. Participant 5 explains:

> I've written about my experience in the past, and I found it was a lot less intimidating. Because when you go like write a piece, you just see like big bulk text. That's kind of what you visualize, but using the hypertext, instead, it's just like, there's lots of steps to it, I found. So it was easier to just like, take a break, and then move on to the next step. And then kind of see how everything flows together when you kept like, testing it. That's what I liked about it, and just a lot less intimidating.

For this author, the structure of literary hypertext is more inviting because it breaks down the mass bulk of text into smaller, more digestible sections. This is a compelling comment because it speaks to an issue that many writers discuss of feeling paralyzed at the start of the writing process because a blank, white screen or paper reflects a sense of absence that needs to be filled. Twine, on the other hand, allows the author to build the narrative in smaller, progressive steps.

One participant found the software too complex. I ended up working with this participant to build their narrative into the software for them. In our Closing Interview, they explained “I'm old, right? [laughs] So, for me to learn, like new stuff, I have to do it all the time for my job. So when it came to this, I was a little bit like, overwhelmed with the like program.” This participant shares that despite not completing the literary hypertext design portion of the study independently, they still felt the experience of writing their illness narrative was impactful. The participant believed they would have been successful if they were able to learn Twine in an in-person session. Although this was one participant’s experience, this is a critical finding of this research. While some individuals may feel empowered through online pedagogy, others may be more successful through an in-person environment.

Although there was a strong and clear consensus amongst participants that Twine was easy to use and learn, there was discussion of various minor technical issues. One participant noted that accessing Twine on their phone made some text unreadable and switching to a laptop fixed the issue. A couple of participants shared frustrations they had with publishing their stories to file, a built-in feature of Twine’s that allows authors to publish their stories to an HTML file on their desktop. While the module outlines the steps of this process, it fails to offer troubleshooting techniques to account for different computer settings. Further, various, beginner CSS and HTML codes were available for participants including codes to alter text alignment, size and style, but most participants either chose not to include any code or simply alter text colours.

Participant 11 explained in our Closing Interview that after they played the example Twine games in the module, they wanted to replicate some of the stylistic features in their own story. However, the participant notes, “I was trying to figure that out. But in the interest of my time too like, I just didn't have time, but it would have been cool to kind of customize it a little more." Participant 16 explained that by manipulating the colour codes of the text and background, they were not able to find a way to make their narrative "look pretty" and ultimately the story "looked ugly" to the author. The participant does not expand on their intention, but this raises questions about expectations of aesthetics in relation to art. Mainly, there is an assumption, at times, that the art we create should be beautiful, however, why is beauty in art important to us? What would it mean if this participant's story was, in fact, visually "ugly"? This is an important inquiry to examine in future research along with barriers to access around computer programing, especially for marginalized people living with illness.

How Code Makes Meaning

In her 2004 "Print is Flat, Code is Deep", N. Katherine Hayles argues "We can no longer afford to pretend that texts are immaterial or that text on screen is the same as text in print. The immateriality of the text has ceased to be a useful or even a viable fiction" ("Print is Flat" 86-87). Hayles' work in hypertext theory highlights the significance of accounting for the embodied materiality of code and how this materiality makes meaning. Meaning in literary hypertext is formed through a matrix of factors including the relationality of physical artifacts of the digital text, discourse and content, and the encounters between readers and authors. In this study, participants chose to incorporate CSS and HTML codes, for example, in various ways that contributed to the meaning-making of their Twine stories. In particular, participants used colour, alignment, size, and text style codes to design the look of their narratives.

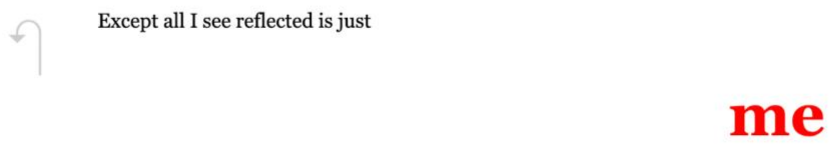
At the time of the study, participants used the Twine 2.3.8 release in the Harlowe 3.1.0 story format. This story format sets default colours. The background of a Twine story is black, the text is white, and the hyperlinks are blue. These default colours can be altered through colour codes that target the HTML, a process that the module explains to participants. While text colour can be altered through manipulating RGB values, HSL values or hexadecimal codes, the module outlines the most simplistic, yet limited, option of inserting the colour name into pre-existing CSS. CSS specifies basic colour names that attribute to what is known as keywords. In turn, properties in CSS can take these keywords and ultimately set the text and background colours. Participants were given a snippet of CSS to insert into their Story Stylesheet and shown how to replace the colour of the Twine's text, background and hyperlinks. Out of the five participants who changed the default background colour of their Twines, most (three) changed the default black background to white with black text. This was an interesting finding because the participants actively incorporated colour codes into their stories in order to reproduce a rather familiar digital appearance. White background with black text is a standard colour combination used for various websites, applications and digital writing documents. Rather than choose to challenge assumed expectations around how a digital narrative document should look, participants chose to reproduce this.

This choice may have been made for various reasons, including the fact that a white background with black text may be presumed as the most readable combination. Richardson et al. conducted a review of the literature on colour and contrast in e-learning and found that luminance contrast, which measures the difference between the brightness of foreground elements relative to the background, was the most critical factor in determining the legibility of text and symbols (658). The authors note that in a seminal study conducted, Murch (1987) found that black text on a white background was widely deemed by participants as a legible contrast. However, this study found alternative colour combinations as more legible including black text on a green background and blue text on a white background (Richardson et al. 659). In addition, this study finds that Harlowe's default colours (white text, blue hyperlinks and black background) were found to be equally as legible as black text and a white background (Richardson et al. 659). Following a review of the literature, Richardson et al. ultimately conclude that accessibility in relation to digital reading is highly complex and goes beyond colour contrast including text size and font. The authors note that "These findings indicate that visually impaired users have different needs. For all users, the interplay of text style and background color can have other effects—beyond readability—which can influence learning" (Richardson et al. 660). There is perhaps a path emerging to argue that the participants' choice to replicate the colours of a standard digital writing document, rather than the expansive colour palettes typically found in video games, speaks to perceptions around favouring narrative-ness over game-ness. However, this argument would be too simplistic and not informed by the findings. It is beyond the scope of this research to study how colour choices were made by participants, however, understanding why a standard colour contrast was popular would be important for future research.

Ensslin argues in *Canonizing Hypertext* (2007) that "With respect to hypermedia, authors employ images, animation, film and sound to create additional layers of meaning, which correlate to textual meaning in various ways" (21). Several participants chose to include images in their Twines, including selfies, memes, infographics and a motivational quote set on an image of a summiting mountaineer. One participant chose to include images of themself in their Twine, showing what they call a "before" and "after" picture. Subverting the typical tradition through which content is labelled with this language, mainly for marking weight loss images, this participant merely captures their smiling face in both images. The alt attribute, which specifies an alternate text for an image if the image cannot be displayed, is labelled by the author as:

<alt="Before picture of seeing a Naturopathic">. The author describes exploring multiple healthcare avenues to address their illness, to no avail. They finally decide to visit a naturopathic doctor and feel a sense of hope. Sitting in the waiting room for this initial consultation, the author writes "my husband pulls out my Iphone and I tell him to take a [[before picture]]." Later in the narrative, after the author has experienced positive results from their naturopathic treatment, they write: "[[Here is a current picture of me]] shows that I am feeling better than I did when I was taking birth control at the begining of this very wild journey." For me, there is little difference between the person in the images. Their hair is longer in the after shot and they are standing presumably outdoors as the background is washed out from sunlight. Perhaps the lack of a stark visual difference indicates that the transformation for the author was beyond the body.

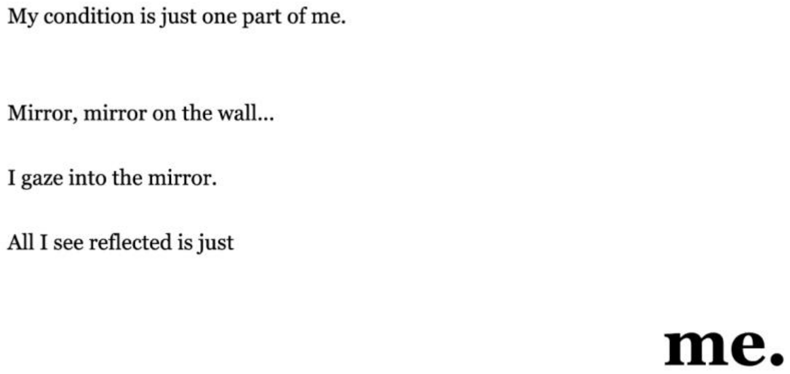
Style and colour codes were used by participants in diverse ways. Mainly, when participants did choose to incorporate style codes, they employed them in ways that transformed their narratives into a visual experience where the colour, size, style and spacing of the text produced narrative meaning. For example, Participant 3 describes a scene where they are looking at themselves in the mirror. Fig. 54 shows the following passage that reads: "Except all I see reflected is just me." The word "me", however, is set apart from the rest of the phrase. It sits alone on a lower line, right-aligned, enlarged, and in bold red colour. This is a simple, yet striking, use of basic stylistic codes used by the author to generate an embodied representation of the self as exiled, alone, or, perhaps, obtrusive. The author ends their narrative by describing the methods of "acceptance", "understanding" and "empowerment" that allowed them to come to a place of contentment with their body. The last passage replays the moment of the opening scene, however, this time "me" looks different. In fig. 55, the text is still enlarged and right-aligned, however, it is no longer in bold red, but the familiar black that is uniform throughout the textual narrative. This stylistic choice made by the author creates a neat bookend that captures a sentiment that the author still may struggle with their illness, but they have found small ways to accept themselves. Participant 16 creates a similar visual in their closing passage. The author writes several phrases that ponder the possibility of an illness cure or relief for the symptoms of the body, such as "Maybe next month the number will budge," or "Maybe the skin will get lighter." Each of these statements begin with the word "maybe". The final line of the narrative is a single "maybe" standing alone and emboldened. This simple design effectively creates a sentiment for the reader/player that the author is suspended in the maybe, not here nor there, but the unknown.



Except all I see reflected is just

me

Fig. 54. Screenshot of Participant 3's Twine Story



My condition is just one part of me.

Mirror, mirror on the wall...

I gaze into the mirror.

All I see reflected is just

me.

Fig. 55. Screenshot of Participant 3's Twine Story

Using style codes to organize texts and hyperlinks into a visual experience was a common strategy by participants. In fig. 56, Participant 4 is listing the symptoms of their illness and the emotions these symptoms produce. Rather than list the symptoms in a typical way with uniform size, on a single line and left-align, the author plays with these elements to create a visual scene. Each symptom is aligned in a different column and on a separate line. As the reader/player moves along the symptoms, the text becomes larger and more menacing. For me, this passage resembled the motion of descending a staircase where you are led deeper into the depths of the illness. Similarly, Participant 3 centres the uncomfortable experience of hair removal in their narrative. In one passage, the author describes the painful sensation of removing facial hair by a threading method, noting: "The taut thread grates across my skin, taking small hairs at a slow, painful one strand at a time." The latter five words of the statement, however, are set apart. The author sets each word on a single line. Double spacing encloses each word in isolation. As the reader/player you are forced to halt, searing in each word as if a single strand of hair is ripped in sequence from your skin as well.

Infrequent and often non-existent periods.

Painful cystic acne.

A fat body.

Shame, anger, confusion.

Fig. 56. Screenshot of Participant 4's Twine Story

Designing Hypertext

Participants, in Closing Interviews, discussed the significance of the hyperlink word or phrase choice in their narratives. They explained that the text that they decided to be the hyperlink(s) in each passage was significant because they felt the hyperlink was set apart from the bulk of the other text and embodied emphasis. Participant 4 describes that they choose the hyperlink text in order to cultivate a specific tone for their narrative: "it was almost like I was able to remove myself out of the situation, but also write about myself, but kind of almost like, on a different plane, because then I was sort of looking back to see how was I feeling. And how are those feelings [are] important to the story and, and the tone. And then which words then would be the best to hyperlink to the next…the next page." Ultimately, the hyperlink text that participants in this study created shaped the meaning produced by their stories.

Hyperlink text choice marks, for the reader/player, the text as meaningful to the narrative by inherently signalling the progression of the plot. The hypertext is a door that leads the reader/player to the next passage and therefore embodies meaning beyond textual discourse. For example, in Participant 16's narrative, they discuss the emotional impacts of culturally negotiating a body perceived as abnormal. The participant writes: "But how does anyone look past the weight?" The next passage reads: "Because I don't know if I can sometimes. [[Well]]." The final word is set apart from the other text on a different line. The hyperlink function renders the word blue, in contrast to the white colouring of the additional text. This choice made by the author to emphasize the word [[Well]], through spacing and hyperlinking, swells the meaning of this simple passage in expansive ways. The word "well" is an unassuming, ambiguous word that holds enormous potential for interpretation. "Well" encompasses a range of emotions such as exasperation, exhaustion, dismay, and hopelessness. It is a slippery term that is difficult to pin down. It can be an exclamation of surprise, anger, resignation, or relief. But it can also mean the absence of illness. There is an expectation, in the context of literary hypertext, that if the reader/player clicks on [[Well]], they will be brought to a passage that connects physically and thematically to the hyperlink text. The linked passage in Participant 16's story signals defeat, resignation and a loss of hope: "I guess this isn't the moment. Maybe next month it will be." In the case of Participant 16, when a simple word is chosen as the hyperlink, it works to propel meaning beyond the boundaries of a linear story.

As discussed in the Methods and Protocol chapter, participants were introduced to three Twine story structures in the module of the study: a *forward path*, a *weaving path*, and *multiple paths*. A *forward path* is when the story moves the reader/player through a linear plot progression. There is only a single hypertext option in each passage for the reader/player in this scenario, however, this structure is useful for designing a uniform reading experience. A *weaving path* branches the narrative into two or multiple hypertext passages but ultimately comes back to a single path. The final narrative structure, *multiple paths*, incorporates a multitude of hypertext paths for the reader/player to follow. In this structure, each path may describe a different plot and narrative conclusion. The module explains that *multiple paths* may be more complex and time-consuming to build, but they have the potential to be a generative method to "play through" different scenarios or dream up alternative ways things could have been in relation to the illness experience. As depicted in fig. 57, each story structure was ultimately built by a participant in this study, but a *weaving path* was the dominant choice. There are many possible reasons why this path may have been popular for participants, including the time constraints of the workshop.

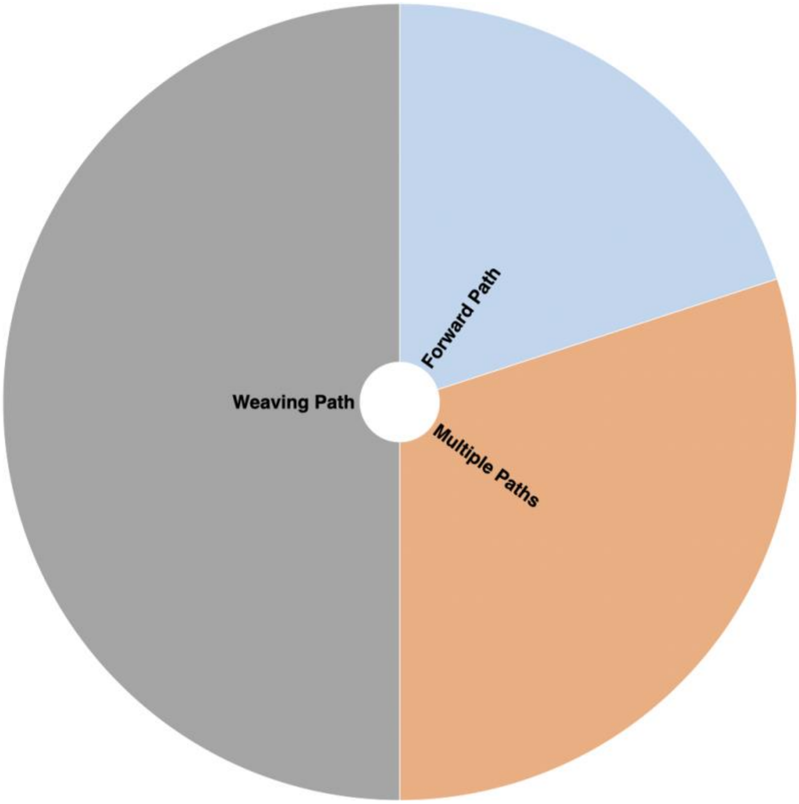


Fig. 57. Hierarchy Sunburst Chart of Path Choice Found in Participant Narratives

Participants tended to utilize a *weaving path*, and at times *multiple paths*, to design a narrative loop within their stories. Narrative loops built into the participants' stories included hyperlinks that bring the reader/player back to engage with a previous passage. The cyclical loop was discussed by participants in Closing Interviews as an effective method to personify the experience of their illness. Some participants used the cyclical loop to covey the labour of maintaining the normality of the body. Through various hair removal practices, for example, one participant designed a loop where the reader/player becomes stuck in a continuous cycle of hair growth and removal. Other participants discussed negative mental health circuits they were able to build into their Twine narrative. Participant 11 explained that they built a loop centred around returning to the feeling of shame in their narrative to mirror their illness experience. They explain: “there's times where it's like, yeah, like things are finally going, it's good to be hopeful. And then you just, it all goes back to the beginning.” Participant 16 discussed their illness journey as dominated by a feeling of being enclosed within a loop where they would make efforts to change their body only to be met with stagnation. This bodily stasis would trigger a cycle of harmful thoughts. This participant was able to map this circuit in their Twine story. The opening passage notes the amount of work the author has put in to “get this weight off” followed by several hypertext options of actions the reader/player can take. Each option you click will loop you back to the opening passage with a single hypertext that reads: “[[So why won't the scale move?]]”. The author contextualizes the cyclical loop they designed, explaining: “this really does affect your mental health… if I'm doing all these things and my body isn't allowing me to love it the way I need to, to be healthy then like, how am I supposed to love it? And I think that was the whole purpose is like, no matter what I was doing, it was still like the same end result, as sad as it was.” This design structure effectively plays with the idea of choice for the reader/player. While it appears the narrative offers hyperlink options to move the story through a chosen plot, ultimately, the reader/player is always looped back to the beginning. This reinforces an oppressive feeling of an illness that has power over the life of the author.

Using a *weaving path* to play with the idea of reader choice was a popular strategy for participants in different ways. While some participants, like Participant 12, designed an illusion of choice, other participants foregrounded the agency of the reader/player in the narrative. This juxtaposition was most clearly marked in the stories of Participants 5 and 9. In one passage of Participant 5's narrative, the story splits into a weaving path. This is a stark deviation from the precedent of a forward path established in previous passages of the narrative. The author writes: "It's a tough feeling. But on others days, I feel [[empowered]] [[strong]] [[resilient]]." This narrative split seemingly offers the reader/player a moment of choice. Which adjective will they select? Whichever path is taken, if the reader/player decides to move backward in the narrative via the undo arrow, they will see the sentiment of agency crumble. All three options yield the same passage that reads: "And those are the days that push me to go outside and see the [[light]]." This strategy to create an illusion of choice is countered by other participants. For example, in Participant 9's narrative, the author gives the reader/player the ultimate choice in the opening passage. The reader/player can choose to embark on the lengthy and emotional path described by the author as: "a [[story]] about PCOS-induced infertility." There is a different option, however, sitting beneath the initial line of text. This path, described as [[different topic]], will bring the reader/player to the end of the narrative. Without experiencing any of the passages throughout the Twine, the reader/player moves to the end of the story where the author writes: "If you chose to click this link, then hello, I want to tell you something more than my *PCOS-related problems*." In this final passage, the author outlines what they are grateful for in their life. This is the ultimate design for hypertext choice because it allows the reader/player to decide to not read through the author's illness experience at all.

Returning to Salter and Moulthrop's analysis, they offer three terms to describe the linking strategies of a literary hypertext author. As discussed in the Methodology chapter, *navigational* linking identifies the movement of a character or point of view through a story world space, *procedural* linking uses described action as an anchor, and *conversational* linking relies on responsive speech as the anchor of the hypertext (Salter and Moulthrop 69). These terms categorize the narrative text that authors choose to become hypertext links. In this study, all three linking strategies were utilized by participants in their narratives, including a fourth and fifth category, coded as *other* linking and *dead-end* linking. *Other* linking was an additional category included to capture hypertexts that failed to fit neatly into Salter and Moulthrop's analysis. For example, the hypertext link "[[I've been giving myself the time and space to create healing modalities]]" was coded as *other* linking. Although perhaps this hypertext link fits most closely to *procedural* linking because it details an action of the persona, it fails to embody the definition offered by Salter and Moulthrop. The authors describe *procedural* linking as "where the anchoring text describes an action involving the persona: 'You shut the door'; 'The ostrich says nothing'; 'The Twinebot emits another burst of story'" (Salter and Moulthrop 69). The difference in the action detailed by the example hypertext and the definition is that the former fails to offer the reader/player a sense of choice. The reader/player, in this example, is not choosing a hypertext action of the persona to further the plot, this was the only hypertext link in the passage that describes a reflection on the action by the author.

Dead-end linking was a category included in the coding of the narratives to capture a path that has no further links. Most stories included at least one *dead end* link, to produce the "final" passage of their narratives, however, *dead-end* linking was utilized by participants in additional ways. Most notably, participants used *dead-end* linking in various passages of their story to create a sense of a lack of options where the only path forward is to move backwards. For example, Participant 4 includes a passage detailing the various symptoms of hyperandrogenism. They write: "Do you have the following symptoms? [[Adult acne]] [[Irregular periods]] [[Sporadic fluctuations in weight]]." The reader/player must select one of these symptoms to move forward in the Twine, however, the first two symptoms are a *dead-end* link. Once the reader/player is taken to the next passage, they are confronted with a single word: Yes. This word that confirms your character's experience of the symptoms is not hyperlinked. There is no way to move on in the Twine without selecting the undo arrow that is built into the Harlowe story format. Eventually, to continue the narrative plot, the reader/player must select the final symptom, which includes a hyperlink to a subsequent passage.

While this was a seemingly calculated and effective strategy used by the author to create a sense of regression, other participants used *dead-end* linking in ways that appeared unintentional. *Dead-end* links were coded 21 times in Participant 12's story. While some of these links may have been by design to create a particular reader/player experience, the intention of others was less clear. For example, the author devotes many *dead-end* links to passages about their relationship with various family members, including their mother, father, sister and cousin. When the reader/player selects the passage, they are taken to a description of the author's relationship with that person or a description of a significant moment in their shared lives. Two family member passages, the mother and step-brother, are left blank by the author. It is unclear if the black passages are meant to create meaning around a lack of a relationship with these people, perhaps, or if the participant simply forgot to include the text. Fig. 58 shows an image of the back end of the Twine structure in the software's interface. The structure of hyperlinks utilized in this Twine reveals that the passage devoted to the mother is actually the only passage that is linked to the larger story structure. The additional family-themed passages include links to one another, but not to the larger story structure. The effect this design creates is that none of the family-themed passages, except the mother, can be accessed when the Twine is published. In other words, these passages only truly "exist" in the Twine interface, but not in the published form of the HTML file because there are no hyperlinks that lead to them.

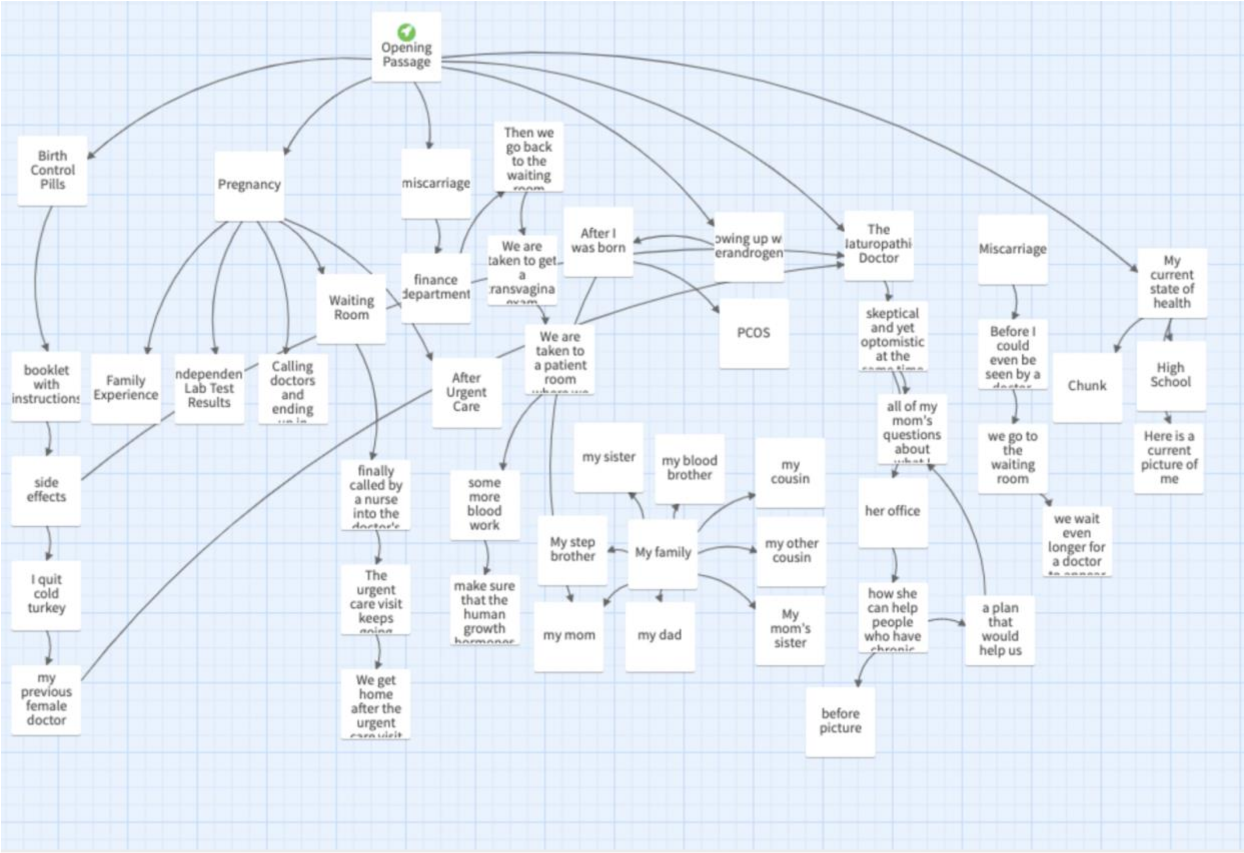


Fig. 58. Screenshot of Participant 12's Twine Structure

Perhaps this was a mistake by the author. Or, if it was designed purposefully, there is much to be said about the discursive meaning produced by this choice. It creates a salient image of the author seeking, through endless winding paths, familial relationships to no avail. This strategy, or accident, of a passage with no hyperlink access, was found in one other participant's story. In the back-end structure of Participant 4's Twine, there is a single passage with no hyperlink to the larger story structure. This passage is titled "Normal" and includes no text. The passage cannot be accessed in the published HTML file, but it exists in the interface. This likely was an error made by the participant when building their story, however, an inaccessible passage dedicated to the theme of normality produces an added layer of meaning. Normality is just under the surface, in the bones, but the author is unable to reach it.

As depicted in fig. 59, *navigational* linking was the dominant linking strategy used by participants in this study. The reasons why participants relied on *navigational* linking in this study require more research, however, the conceptual impact on the narratives is clear. The dominant use of *navigational* linking, for the narratives in this study, produced a feeling that the reader/player is navigating the story as if it were a space. As Brian Teare argues, in line with the scholarly criticism of narrative medicine's assumptions of the narrative self, the illness experience may feel less like a textual story. For Teare, illness is a place. He writes:

> The woods of illness were wordless, though they burgeoned with sound, texture, sensation, atmosphere. The somatic experience of illness wasn't narrative: it was place. It was a place my body made out of its chronic disequilibrium, its migraines and nauseas, its gastrointestinal distress and joint pain. There was no story and no map, either. I didn't know how to bring anybody there. (Teare)

Reimaging the possibilities of space in relation to other material-discursive phenomena is also a core project of FNM. Karen Barad writes in *Meeting the Universe Halfway* that "With the click of a mouse, space, time, and matter are mutually reconfigured in this cyborg 'trans-action' that transgresses and reworks the boundaries between human and machine, nature and culture, and economic and discursive practices" (223). Barad offers a generative way into looking at how time, space, matter, and discourse become entangled in an affective way. In the case of this study, the reader/player is able to tour various narrative moments that are important to the author's illness story. These moments depicted in various passages, through *navigational* linking, become tableaus or vignettes that the reader/player can visit, experience, leave, and perhaps return to.

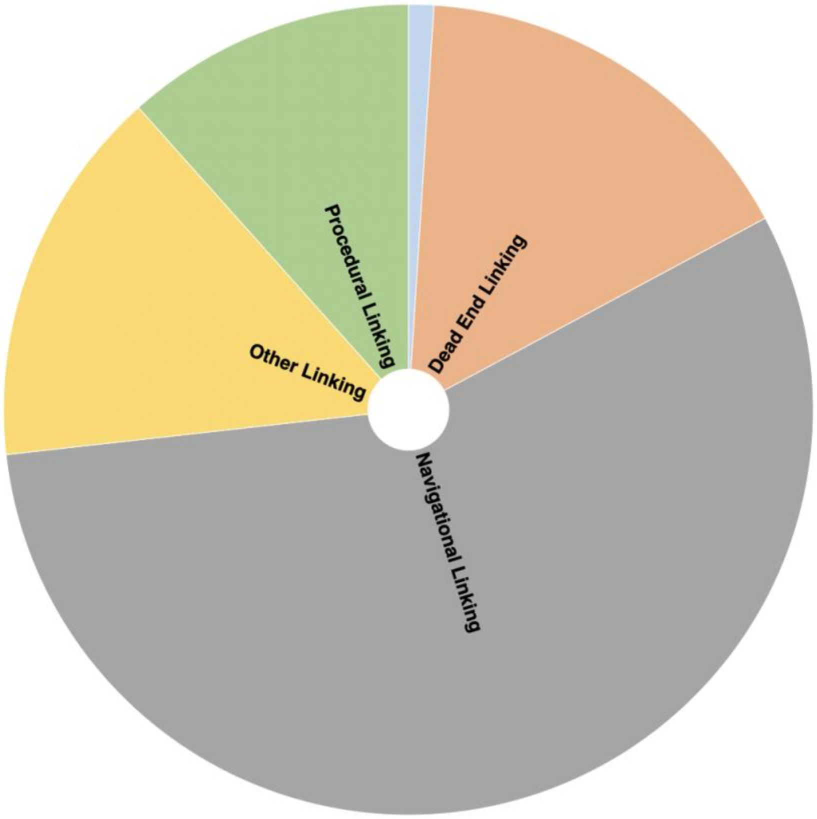


Fig. 59. Hierarchy Sunburst Chart of Linking Strategies Found in Participant Narratives

Navigational linking, in the stories of participants, was used in diverging and converging ways to create a sense of spatial touring. Some participants used *navigational* linking to explore past memories as narrative scenes. Participant 11, for example, hyperlinked the names of people in their life that are important to their illness journey, including physicians and family members. While, on the surface, this hyperlinking strategy may not appear as navigational, it was coded as such. This is because the author designs the narrative to produce a sense of spatial navigation where, when the reader/player clicks on the name of a person, they are brought to a space dedicated to telling the story of their relationship with this character. Rather than explicitly advance the narrative plot in a linear way by detailing a subsequent action, the passage will pull the reader/player back into a memory of the author with this person in their life. The author will explore their relationship and the impact this person has on their illness experience. For example, in the opening passage, the reader/player is grappling with the concept of shame. By selecting the hyperlink option [[Dr. 1]], they are brought to a scene of the author at sixteen years old sitting in a physician's office learning of their diagnosis for the first time. The narrative then loops back to the opening passage about shame. Selecting [[Sister]], this time, will bring the reader/player to a scene from later in the author’s life when they are dealing with infertility amidst their sister’s pregnancy. Ultimately, *navigational* linking in this Twine centres a narrative that explores emotions around relationships that define moments of an illness, rather than a series of events that play out in order.

Other participants used *navigational* linking for knowledge dissemination. For example, Participant 7 designs a Twine that acts as a spatial database of information. The reader/player has hyperlink options to tour the database and learn about the illness of hyperandrogenism, gender identity, and the personal experiences of the author. The author writes: “Before I begin sharing my story, it's important for you to understand [[Hyperandrogenism]] is.” When the hyperlink is selected, the reader/player is taken to a passage that outlines the definition of the disease, what symptoms accompany it, and the prevalence of its diagnosis in relation to other hormonal disorders. The Twine continues this pedagogical strategy by bringing the reader/player through passages that describe [[polycystic ovary syndrome (PCOS)]], [[What is Gender vs Sex]], and [[hirsutism]]. Through *navigational* linking, this author’s Twine acts as both an illness narrative and an interactive tool for the reader/player to learn about various embodiments. In this sense, the Twine is intended to be toured as a definitional database, with added lived experience for context, where there is no “correct” path to take.

While *navigational* linking was used by participants to create a sense of a narrative space, a single spatial location was most commonly described: the waiting room. It might be assumed that other healthcare spaces, such as a physician's office, would be the central, formative space in the story of the illness experience, however, for participants in this study the waiting room was the dominant thematic space depicted. Several participants used *navigational* linking in their stories to explore the space of a waiting room to depict anxiety around the healthcare encounter as well as feeling intentionally kept in the dark regarding the nature of the illness. For example, Participant 12 designed a dynamic Twine narrative that uses *navigational* linking to explore the feeling of being charted through a maze of rooms and left to wait. In the story, the author is experiencing a miscarriage after a period of infertility. The author and their partner rush to visit an urgent care clinic. The author writes:

> we are waiting in the cold waiting room playing soft romantic music from the 80's, which don't sound too romantic now, 6 feet away from each other due to COVID-19 restrictions. My head hangs, I want to cry. I need to cry as I feel like I already know how things will play out. I don't cry, but I feel as though if I could, everything would go away. The physical and emotional pain of everything. I have the feeling that I let everyone down for some reason. I go into the maze when my name is called.

What follows is a series of passages that circle the reader/player through seemingly endless rooms of the clinic, including the finance department to provide health insurance information, a bathroom for a urine sample, and a patient room to complete a lifestyle choices questionnaire.

Finally, the author sees a physician that informs the couple that the miscarriage was “complete.” The author explains: “There's a knock at the door even before my husband and I can embrace and cry together in privacy.” A nurse returns to explain additional tests that are required for the near future. In Closing Interviews, the participant summarizes this experience as being made to feel like they are merely a number in the system.

Salter and Moulthrop further categorize the structure of a Twine passage as either *bifold construction* or *unified construction*. A *bifold construction*, according to the authors, splits the texts of the passage into two distinct parts. The upper section is described as diegetic text that reports the events of the narrative world. The lower section is hypothetical text, consisting of “language still in play” (Salter and Moulthrop 69). This language still in play, according to the authors typically includes hypertext options for the reader/player to advance the narrative. A unified construction, in contrast, merges the hypertext and the diegetic text into a single section. As the authors explain, in a unified construction “There are link anchors, but they fit into the diegesis instead of pulling away from it, as is often the case in the bifold scheme” (Salter and Moulthrop 70). Ultimately Salter and Moulthrop outline these two categories to organize the scholarly trajectory of narrative-ness versus game-ness in literary hypertext. A simplistic analysis would conclude that a “bifold construction accentuates the gamelike qualities of Twine stories, while the unified approach plays to literary interests” however “this distinction can never be absolute” (Salter and Moulthrop 70). Passages in this study were coded, individually, as either *unified*, *bifold*, or *bi-uni construction*. The latter category captured passages that incorporated aspects of both *bifold* and *unified construction* where hypertexts would be littered throughout the diegetic upper section, as well as in options for plot advancement in the lower section. As depicted in fig. 60, the Twines in the study overwhelmingly included passages of *unified* *construction*. In line with Salter and Moulthrop's call to resist the urge to filter Twines into a binary of game versus narrative, it may be more valuable to "explore the spaces between those alternatives, refining a new art form as we go" (71). Therefore, no claim will be made regarding the game-ness or narrative-ness of this finding.

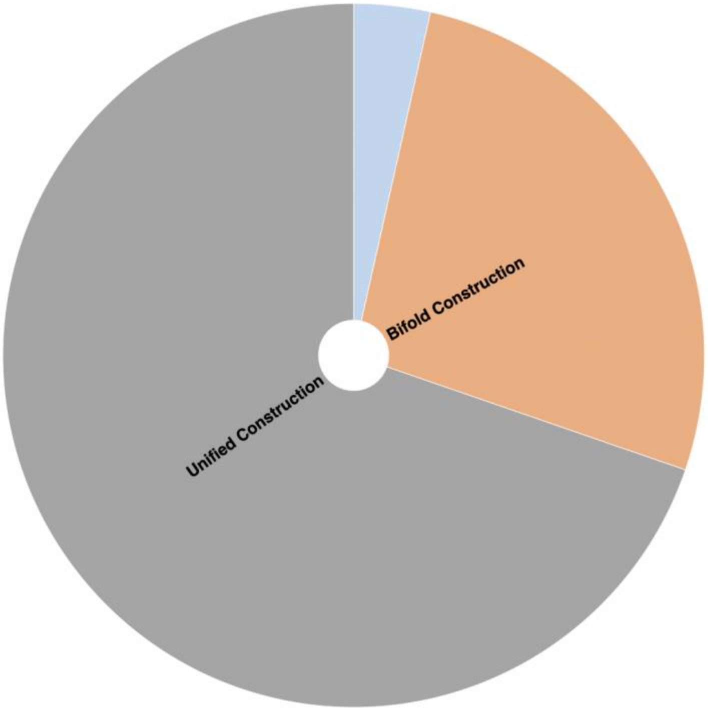


Fig. 60. Hierarchy Sunburst Chart of Passage Construction Strategies Found in Participant Narratives

Mapping the Illness Narrative

The most compelling finding of this research was how the participants spoke about the therapeutic potential of using literary hypertext technology to write illness narratives. Participants, in different ways, explored the concept of using the digital features of Twine to visually map out their experiences, and manually organize them by hyperlinking passages, to find a structure that the participant felt was best suited for personal reflection. Participants used language such as constructing an experiential chart, a map, a planner, a puzzle, or a web, to convey this phenomenon. Collectively, participants described how the ability to physically and spatially organize their illness narrative into passages, that can be linked in various ways and situated in a linear/nonlinear path, created a unique and effective resource for the participant to design an individualized therapeutic resource for reflecting on experience. Participant 1 explains: "I think it made me think more about like how things like fit in together and how certain parts of like my experience might be related…that was really interesting using like, the flow chart style kind of in that way." Similarly, Participant 16 notes: "It was almost like a choose-your-own-adventure, except in this way, it was just more so all of the decisions that I was creating, was still leading to the end result, which was very relatable to my life." This shared sentiment of the therapeutic value of mapping the illness narrative through hypertext and passages was discussed by participants in four different ways: a belief that writing with Twine mirrors the human thought process, matches the experience of an illness diagnosis, conveys the feeling of a negative mental health circuit, and facilitates personal discoveries through the practice of hyperlinking.

Some participants made claims that the rhizomatic structure of Twine "mirrored" how they perceived the brain engages in thought process, and therefore the software is well suited to build personal narratives. Participant 4 describes their belief that mapping out their illness narrative in Twine, through branching hypertexts, "mirrors the way that we think." The participant explains: "Sometimes your memories will trigger other, other things that have happened, you know? And so by, by planning it out this way, I was able to kind of channel some of that, like, yeah, there was this event, oh, and then and then this happened, or these are the kinds of things that were going through my mind. And I think it actually better captures how we think in general." In contrast, Participant 1 discussed how they believed their "brain worked" in a more linear fashion where they felt more genuine designing a forward path in their Twine, rather than multiple paths. The participant explains: "I think the platform still like worked really well for that [linear storytelling] and I liked that it was like, there was like a heading, and you could travel between like different… because it was kind of broken up into little topics, I guess. And I used like one hyperlink to like jump forward reading about another part." Participant 1 explained that, although Twine may be traditionally used to create nonlinear narratives, building a forward path with thematic passages still had a therapeutic impact. Rather than reinforce any claims about inherent processes of the brain, what is significant, here, is a belief system that participants cultivate around how literary hypertext facilitates their writing effectively. They are arguing that the technology, in different ways, offers a useful method to brainstorm their thoughts, organize their narrative structure and build their stories. This may be through utilizing branching narrative paths or creating a linear story with thematic passages.

Participants made claims about how the Twine software cultivated emotional breakthroughs via the hyperlink feature. Participant 5 describes how they wrote about different life experiences in multiple passages. Initially, they believed that these anecdotes were emotionally distinct moments. The participant incidentally chose the same thematic word to be a hyperlink in each passage. It was when the participant saw two passages physically link to each other in the Twine interface, via the use of the same hyperlink thematic word, that they recognized the two experiences as emotionally bound. The participant explained: "there was a point where I made it more like a bulk text, but I was able to actually break it down. And then like, see the links between them." This author is describing a concept of a physical link in the software cultivating a cognitive link that becomes important to the therapeutic process. This is compelling insight because it speaks to how Twine might facilitate therapeutic reflection through digital features, rather than the act of writing an illness narrative alone.

Participants shared a common belief, reflected on in Closing Interviews, that the rhizomatic capabilities of literary hypertext embody the feeling of an illness diagnosis. Participant 12 discussed their belief that writing in Twine matches the feeling one experiences when one receives an illness diagnosis. They explain:

> I think in like in the sense of writing a nonlinear story where I can just kind of go all over the place with kind of the narrative and what I wanted to get across. I think that's really helpful. Because with hyperandrogenism and PCOS - these conditions just kind of make your brain just kind of scattered all over the place. So it is kind of nice to know that I don't have to start at the beginning that I can go to different places, and be like, 'oh, yeah, that is connected. That does make sense'.

Participant 4 discussed similar insight, explaining that in the aftermath of an illness diagnosis, a patient is forced to consider an influx of questions and anxieties: "You're, you're going through so much, and you're thinking about so much and like, what are the implications? What is the diagnosis mean? How do I have to change my lifestyle?" Akin to Arthur Frank's argument that illness disrupts this planned destination of our life, illness diagnoses mushrooms our projection of a linear life path into a web of endless possibilities, or in other words, the unknown. For these participants, the inherent structure of Twine helped them capture this feeling.

Ultimately, the belief systems that emerged for participants from mapping their illness narratives in Twine can be summarized by the astute reflection of Participant 7 who refers to this phenomenon as the intersectional "web of our identity." The participant notes: "I think specifically in using Twine where you can link everything I think it really just talked to like the web of our identity and how everything kind of comes together. Versus if it was, you know, a video making a video or writing a story, I think it just gives more space to kind of link and ties different parts of like who I am together." For this participant, and others, the web of identity is rooted in experiences of intersectionality. Participant 7 explains how writing their illness narrative in Twine "highlighted for me my intersectionality of like, this is one piece." They go on to explain that their illness, along with their gender and many other elements of who they are, are single pieces of their experience that all intersect to create their identity. The participant reflects: "I think that to me, [Twine] kind of just gave space, I think for like, kind of some of the intersectionality of the experience and as much as it's like, all one part of identity, it is different aspects of it." The digital features of Twine, in this sense, both deconstructed and reconstructed this identity web in ways that allowed some participants to gain a more comprehensive understanding and therapeutic reflection of their illness experience.

Returning to FNM theory outlined in the Literature Review, mapping the illness narrative comes to represent the relationality between parts, or intra-action. Karen Barad wrote in *Meeting the Universe Halfway* that intra-action is a response to interaction. Barad argues that intra-action is a signifier for mutually constituted agents that are in an entanglement with each other (*Meeting the Universe Halfway* 33). Truman explains that "rather than the term interaction (which suggests ontologically distinct individual agencies preceding interaction), phenomena are produced through intra-actions (specific material configurations of human, nonhuman, animal, material that do not preexist their relations)." The process of intra-action is present in mapping the experience of illness through a technological software to find that the pieces are, in fact, always already in relation to generating the whole. Intra-action was coded in the research several times, including a moment in Participant 12's Closing Interview where they explain the effect of the writing process. They note: “with writing the story it is more of kind of zeroing in on that and saying, okay, you've ignored this part of the puzzle and identity for so long, you've got to confront it…This is what you need to figure out, you know…To be a whole person. To come together.” This process of pulling pieces apart, to ultimately come together, is a compelling image of the entanglement of all the matter that makes up the self.

Twine, Resistance and Capacity

As of June 2022, Chris Klimas hosts a Patreon account to fund periodic software releases related to the Twine project where he notes that he maintains a full-time job in addition to his contribution to Twine. Patreon is a platform that facilitates membership funding for creative projects, in exchange for access to exclusive content, community, and insight. Alternatively, Twine suggests supporting the maintenance of its infrastructure through donations to The Interactive Technology Foundation, a nonprofit organization that provides support for the interactive fiction community. In keeping with Twine’s spirit of collective contribution, the site encourages non-financial support as well including drafting answers to Twine user questions, contributing to the official Cookbook, fixing software bugs, or translating the Twine user interface to another language.

According to the GitHub source code, Twine 2 was written using various programming languages including HTML5 and JavaScript. The Twine software is open-source and, as of December 2022, is maintained by a collective of individuals on several different repositories through GitHub and other development platforms. GitHub, and its culture of supporting collaborative version control of, typically, open-source projects speaks to Twine’s identity as an inclusive space of collective contribution and creation. As Salter and Moulthrop argue, Twine can stand as an equalizer in a classroom where students hold differing experiences with programming, technology and digital literacy because, at its core, the software is a tool to make the personal political. The authors argue:

> At a time when our technology is increasingly complex, sealed in tiny boxes and inscrutable to most of its users, Twine is transparent and open. At a time when our software is produced by large teams, with most of the production members hyperfocused on a project part, Twine allows a single person to develop an interactive experience holistically, without relying on any external specialist's knowledge. Twine is a tool for resisting the dominant interactive storytelling of our times and, as such, tends to be a tool for chronicling resistance and struggle. (Salter and Moulthrop 2)

This is a lot to live up to, I think. I was compelled in this research to highlight how literary hypertext embodied this vehicle for accessible personalized resistance. I found it did, in many ways. Akin to Couser's arguments that certain illnesses or disabilities can limit how a person is able to write or publish their story. Couser was referring to more traditional writing and publishing practices in relation to partnerships such as assisting authors, transcribers, translators and ghostwriters and the kinds of ethical issues that can emerge. Despite Twine standing as a poster child for accessible, anti-establishment game development, it is still inaccessible in many ways for those living with particular illnesses or disabilities. For example, Twine stories may be compatible with screen readers, but this feature requires technical skill from the author. It is vital to have experience incorporating sets of roles and attributes that define ways to make web content more accessible to people with disabilities, a practice referred to as Accessible Rich Internet Applications (ARIA). The choice of Story Format is also a central decision for facilitating accessibility. Further, Twine today is multifaceted; it is haunted by the aftermath of Gamergate and increased misogyny in the gaming community, the COVID-19 pandemic and disruptions to the supply chain, the sky-rocketing cost of living due to inflation, global climate change-induced natural disasters, and increased risk of the loss of human rights. What I learned from my participants in this study was that you can have the most technologically accessible tool to create narratives aimed at elevating emotional well-being, however, capacity, in all its forms including physical, mental, financial, and temporal, to sit down and learn a new technology is a privilege. In addition to outlining the sociohistorical legacy of Twine as a tool of resistance for those pushed to the margins of game development, it is important in this study to note the real-life ways in which power relations monopolize capacity.

Part V: Therapeutic Value of Literary Hypertext Illness Narratives

In Closing Interviews, participants were asked to describe their feelings toward their body, identity, or ideas about where they fit in the world after writing about their illness. This question included further prompts that aimed to identify if participants believed writing their literary hypertext illness narrative was an impactful experience, in various ways. Overwhelmingly, participants reiterated the same belief: that writing a single illness narrative, in any format, cannot (and is not intended to) "cure" or "fix" the self. After writing a single Twine narrative, one will not suddenly develop an encompassing positive body image or resolve past illness trauma. This finding is aligned with the second-wave scholars of hypertext, emerging in the 2000s, who cautioned against overenthusiastic declarations of literary hypertext's emancipatory capabilities. Scholars such as Ensslin, Pope, Miall and Mangen argue that the liberatory value of literary hypertext can be cultivated through careful and strategic adoption of immersive, adaptable and user-friendly practices (Ensslin and Skains 8). At the core, however, is the centring of co-creation modalities. Second-wave hypertext scholars conclude that the transformative potential of the medium is found through collaborative methods that empower the reader’s contribution to the text’s creation and actively deconstruct binaries between the author and reader/player. In this study there are no reader/players. Or, alternatively, I as the researcher have become a reader, as well as the participants who have read each other’s stories. This study, though, resists a stark dichotomy of author/reader by eliminating the subject position of reader all together. The focus is on the author and the experience of writing the narrative, which is a method of challenging subject positions.

The consensus from participants was that engaging in writing a literary hypertext illness narrative was impactful and beneficial because it facilitated reflection on past experiences. This process of reflection, for participants, ultimately led to new vantage points to better understand emotions, the establishment of a connection to the self, and validation of experiences of injustice. Participants agreed that their writing of a literary hypertext illness narrative did not produce a purely transformative, curative outcome. What the authors noted was an impactful opportunity to reflect on past experiences and gain a new, productive perspective. For example, Participant 16 explains: “I don't want to say that there was like this crazy positive impact after writing it, but I do think it kind of, for me, it was more so like a looking back as to like, where I was first where I am now.” The participant goes on to explain their personal growth in overcoming a sense of hopelessness to ultimately embrace “self-love” regardless of what their body looks like. This transformation took place before the participant wrote their narrative, however, the writing process allowed them to reflect on it. They note: “This is, this is really where I was at my lowest. But it was good to write that and know that that's not where I am now.” Participant 1 described using the writing process as a tool of reflection through a method of juxtaposing positive and negative experiences. They explain: “I think that going through the writing process allowed me to do that and like, think about all of the negative interactions I'd had and like, kind of add those up. And then all of the positive interactions I'd had and like compare them to each other. which I'd never really done before.” This sentiment was mirrored in the answer of Participant 5 who notes: “I don't know if you can ever really have an experience that like automatically shifts everything that you think of yourself.” They go on to explain that the writing process allowed them to bring past illness experiences to the forefront of their attention, which they typically resist. Finding this time to centre and reflect on their illness experience, for this participant, emboldened them to connect with the healthcare system again. The participant explains that they made an appointment with their physician for the following day. They note: “I think ever since like, I decided that I wanted to participate in this study, I realized I needed to reach out to my family doctor. It was almost like a cue in my mind, because I need to like go and see a specialist specifically for hyperandrogenism.” For this participant, reflecting on their experience of illness through writing emboldened them to revisit a treatment plan in the normative healthcare system.

There was a recurring theme, in Closing Interviews, of the writing process allowing for a novel vantage point to reflect on the illness experience from a removed space. Participant 10, for example, shared that it took them a long time to write their narrative. They recall putting the module off because it felt “triggering’” and “overwhelming” to dig up the emotional experiences they have had over the past several years. It was “serendipitous”, according to the participant, that I eventually sent them a follow-up email, inquiring if they were still interested in participating in the study because they finally felt ready to write. The participant explained: “so that weekend like I took a whole Sunday and I just sat with everything that whole Sunday, it was a very, very quiet day. And I just wrote down everything.” Ultimately, the author notes, “it felt really good to actually just write it out and get it out. And yeah, kind of put it into perspective. It was like me not being part of it anymore, but kind of being out of it and looking at it from out here.” Participant 9 shared a similar sentiment, describing the convention of writing something down that you want to remember. They explained that “you can't really shrug something off because it's already written. It's there, it's there for the world to see.” In writing, the hardship of the experience becomes immortalized, and this allowed them to recognize their courage in navigating the pain. Ultimately, the participant believes the writing process to be different from sharing their experience in person. In the past when living in a different country, the participant felt unsafe sharing their experience of infertility with others. The participant explains: “The thing that I'm trying to avoid is people, like, people…pitying me because I'm going through that stuff. So when I was writing, I was like, no one's gonna know, or no one's gonna judge me or no one's gonna feel bad for me or feel sorry for me… it relieved me of the burden that I've been carrying for years.” In the end, this participant concludes that sharing their experiences, in any capacity, is important to them but it is difficult to talk about their past and easier to write about.

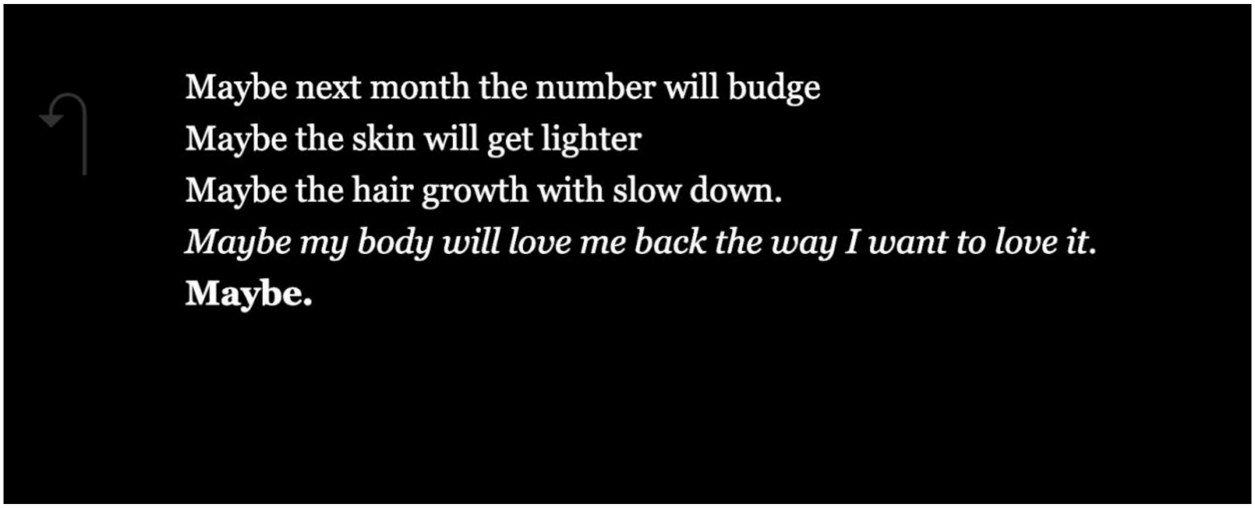
Participants described that the writing process helped them understand themselves better. This outcome was discussed by participants in different ways including finding a resolution for past emotions or discovering a sense of identity. Participant 11 shared that they wrote about a negative emotional reaction they had when they heard the news that their sister was pregnant. Writing about this time helped the author process a sense of shame around infertility. The participant explained: “I'm realizing that it was the shame that was actually causing that, like, the fact that I've been working so hard and couldn't get something that's so easy for other people. I think it gave me a better understanding of the emotions attached to it.” This reflective process had real-world impacts on the life of the participant. They discussed: “That was a really big moment because she actually just found out she's pregnant again. We reacted much differently this time. And we've talked about that.” This participant was able to use the writing process as a way to understand their responses better to ultimately address the relationships in their life. Participant 12 discussed a similar reckoning with the self in relation to gender embodiment through writing. They describe:

> before the study, I just, I have just a lot of confusion and a lot of just anger towards my body…But now it was more of like, just trying to more identify who, who I really am. And trying to figure out, you know, how, how I'm in between two different worlds, or multiple worlds, if that makes sense. And then by being kind of processing this, and writing things down. I came to a place where I was like, at the end of the day, it's just, I'm just me. I'm just myself.

The author comes to the conclusion that despite the feeling of existing between multiple worlds, they can remain grounded in themselves. It is poetic to think about the relationship between Twine and the self as inverse. In the software, the author starts at a central passage and branches outward into multiple paths. But for this participant, their "multitude of worlds" was honed in through their writing experience to a central point of self.

One of the main outcomes discussed by participants in the Closing Interviews was that writing their illness narratives in literary hypertext facilitated a sense of validation of the injustice they experienced. While some participants believed they were not able to feel validation in the moment, seeing their experience written out in the interface legitimized for them that what they experienced was, in fact, unjust. For example, Participant 10 reflected on their experience with a "fatphobic" physician who coldly advised the author to lose weight without acknowledging the myriad of factors contributing to their embodied experience. The participant wrote about wanting to "spit in his face" at that moment but ultimately did nothing. Although the author could not stand up to this act of perceived discrimination at the time, writing about the experience affirmed, for the participant, that they experienced injustice. This sense of not only contending with the injustice of the past but actively imagining a new future world is the bones of FNM.

The concepts of situated feminisms and speculative fabulation were both coded in the Twines of this study. These are FNM concepts, described by Truman as mirrored energy. Situated feminisms is concerned with an ethical inhabitation that recognizes the self as deeply intertwined with a network of matter, both human and non. This situated knowledge, according to Truman, is a FNM "project toward a different world." This different world is found through speculative fabulation or imagining how the world can be. Truman brings in the theories of Elizabeth Grosz in her 2004 book *The Nick of Time: Politics, Evolution, and the Untimely*, to fortify "how political and cultural struggles focus on a both reconfiguring the past to rectify injustices" as well as a process of limitless, ongoing world-building by imagining what the future can be and past could have been (7). This FNM exercise emerged in the narratives of this study. Participants wrote about past injustices and how the material realities of prejudice and pathology come to be in their lives. What was less stark, but budding, in these narratives was a feminist imagining of a more just world. For example, speculative fabulation is embodied in the final passage of Participant 16's narrative as shown in fig. 61. It is the final two lines, set apart from the rest of the text by different styling, where a future world is imagined: maybe.



Maybe next month the number will budge
Maybe the skin will get lighter
Maybe the hair growth with slow down.
Maybe my body will love me back the way I want to love it.
Maybe.

Fig. 61. Screenshot of Participant 16's Twine Story

Literary Hypertext Illness Narratives as a Teaching Tool

The previous section details how participants reiterated a common belief that writing an illness narrative in literary hypertext does not have a curative effect on the self but can offer a valuable opportunity to reflect on past experiences. Participants, however, also came to an additional conclusion. This additional conclusion, I believe, truly pushes this research beyond the scope of individualized therapeutic solutions to implicate power relations at play within institutional structures. Ultimately, I began this research by pulling illness narratives as a method out of narrative medicine as a practice. However, participants in this study seem to refortify this connection by calling for an integration of patient narratives in clinical practice, research, and education. This is the basis of a narrative medicine approach and akin to Martinez and Fleck-Henderson's notion of health liberation. Participants explained that the distress that accompanies hyperandrogenism is rooted in the way the disease is taken up culturally. Therefore, for literary hypertext illness narratives about hyperandrogenism to cultivate true therapeutic value, they should be a tool, for not only the author to reflect on the experience, but for the wider community to read and learn about the experience of hyperandrogenism.

Participants spoke about the desire to share illness narratives in various ways, including formally in a healthcare education setting or informally through social media platforms such as TikTok. Participant 11 explains: “I thought about sharing my, my Twine, like somewhere. I don't know where.” The participant goes on to explain that they wanted to share their story in a place that would cultivate awareness of the experience of hyperandrogenism amongst people in their community. They note: “I don't think like even people…understand like, like the teacher that told me like, oh, that it's fake. Or the doctor that only wanted to deal with my skin tags and nothing else.” Participant 10 dives deeper into this belief by acknowledging that literary hypertext illness narratives would be a beneficial method in a formal therapy session. The benefit of this tool, according to the participant, would be amplified by its accessibility to healthcare professionals who deal with hyperandrogenism so they can gain an understanding of the lived experience of the disease. The participant astutely notes:

> it would be even cooler if it [Twine illness narratives] was actually like a medical tool as well, right? Like, if doctors and health care providers could also be on board that it's not just a therapy thing, but like, it's a it's - it's funny because it is an illness and is a narrative, but it's also like a very real thing that needs like, there, there's very real care that needs to happen, right? Like, either medicine needs to be prescribed or things need to happen and change. Right. So it'd be so cool if it was also used by healthcare professionals, like doctors, not just therapists.

This sentiment was mirrored by other participants as well. Participant 3, for example, explained that they felt that for a PCOS patient, there were institutionalized issues in the healthcare system that acted as a barrier to humanized treatment. The participant wonders if they had access to a “collection of, like, people’s stories like this” if they would be able to map a pattern that points to the reasons that underpin systemic injustice in the healthcare system. Ultimately, for participants in this study, the therapeutic value of literary hypertext illness narratives is supported by expanding access to the stories in the community to target the institutional dehumanization of the illness experience.

Chapter Review

This chapter outlines the analysis and discussion of the research project and discusses these findings in relation to the theoretical framework. The chapter begins with a discussion of how matter is centred in the research of this project, mainly through the use of embodied, sensorial-focused writing prompts. In line with a FNM framework, the methods through which I foreground implicating myself as the researcher into the research are explained. The ways through which the narratives in the study build a discursive object are explored. The discursive object is mainly framed as the abnormal body. Collectively, the Twines in this study centre the belief that a female body that experiences masculinizing symptoms is abnormal. The abnormal body is discussed by participants as uncontrollable, requiring strenuous labour to maintain a normative femininity, in need of a cure, and a mystery to be deciphered. Further, participants affirmed common themes of recognizing the body as abnormal during the first menstruation in adolescence as well as dualized abnormality, both of the body and the mind. The deficiency in the abnormal body, according to the narratives, has the potential to filter out of the boundaries of the abject to corrupt the author’s psyche as well, ultimately rooting the abnormal body in emotional bankruptcy. The Twines in the study collective position this bodily abnormality as undesirable. However, this undesirability is rooted in its relationality with outside agents rather than an inherent undesirability. When the illness of the body encounters other people, systems and institutions it becomes undesirable, according to participants, not because of an inherent bodily undesirability. Participants affirm beliefs that illness is a moral or transformative journey of growth where healing the body is facilitated through healing the mind through resolving a perception of emotional bankruptcy, gaining knowledge, receiving a formal diagnosis, or locating a community of support.

Healthcare experiences were written about by participants as, generally, negative. Participants discussed feeling subjugated, dehumanized, or dismissed by their physicians or perceiving the physician to lack knowledge on the topic of polycystic ovarian syndrome. There was a common theme of a sense of violation during particular medical procedures, mainly transvaginal ultrasounds. Ultimately, conceptualizations of intersectionality by participants were framed as understanding how identity impacts negative healthcare outcomes (including fat bodies, race, and gender identity). Several narratives intersected with the topic of health and capitalism, particularly through exploring experiences in a private healthcare system. Positive healthcare experiences were underpinned by feeling validated, heard, and understood by physicians, mainly through a gendered dynamic. There was a sustained belief from participants that a male physician tended to be present in negative healthcare encounters whereas a female physician may facilitate positive experiences. Finally, participants upheld a belief system that affirmed alternative approaches to illness. Rather than interrogating if alternative responses to illness "work" in the sense that they produce a measurable reduction of physical symptoms, the participants seem to be highlighting that these practices "work" because they make them feel heard, understood and validated in their illness experience. By reinforcing particular belief systems discussed above, the Twines in this study work to erase various counter-discourses such as upholding traditional biomedical approaches, a sense of contentment with the abnormal, and questioning the category of abnormality.

Participants ultimately found that Twine was impactful as a tool to visually map out their experiences, and manually organize them by hyperlinking passages, to find a structure that was best suited for therapeutic reflection. While Twine has a sociohistorical legacy as a tool of resistance, the participants in this study highlighted that accessibility is complex. Power relations, according to participants, can monopolize capacity, particularly the capacity to sit down and learn a new technology for writing. Ultimately, participants reinforced that engaging in authoring a single hypertext narrative cannot, and is not intended to, have purely curative outcomes in relation to emotional wellbeing. However, what was beneficial for participants in the writing process was reflecting on past experiences, which led to new vantage points to better understand emotions, the establishment of a connection to the self, and validation of experiences of injustice. Participants concluded by affirming that the true transformative potential for literary hypertext illness narratives about hyperandrogenism would be as a teaching tool for healthcare providers and the wider community to learn about the experience of hyperandrogenism. The summarized finding of this research, in response to the research question is as follows: individuals with hyperandrogenism can use literary hypertext to write illness narratives that build positive relationships between themselves and the world by engaging with various themes and software features to visually map and organize experiences into a structure best suited for reflection, both for individual therapy and institutional pedagogy.

Chapter VI: Conclusion

Introduction

This chapter will conclude the presentation of this research and its findings. First, there will be a summary of the key findings of the research in relation to the research question. Next, a discussion of the main contributions of this research will be presented, including application beyond the academic literature. As discussed throughout this project, the Twine illness narratives in this study are intended to be accessible for individuals to write in isolation. This research is intended to stand as one response to illness that may be taken outside, within or alongside the normative healthcare system, including formal psychological therapy. The nuances of mediating this application will be detailed in this section. The application discussion will be followed by an outline of the research limitations of this project, including an analysis of the effectiveness of the methodology. As detailed throughout this paper, a novel and targeted methodology called critical discourse analysis for digital-born narratives (CDADN) was built specifically for analyzing this research. This section will review the pros and cons of this methodology in relation to the corpus of this research. In particular, there will be a focus on how this methodology is or is not primed to cultivate analysis that responds to the research question. Finally, recommendations for future research will be discussed in relation to emerging technologies.

Summary of Key Findings

The methodology of this research was designed in a way to engage with both the technical aspects of the literary hypertext software and the thematic choices made in the story world that contribute to positive relationship building for the participant. The research question asks how women and nonbinary individuals with hyperandrogenism can use literary hypertext technology to write illness narratives that construct positive relationships between their identities and the world. The intention of turning to the value of literary hypertext for this goal opens space to consider the maladaptive aspects of the technology or the counter-productive mechanisms that may have hindered, or made complex, positive relationship building. Therefore, the key findings of this project were structured into three general categories through the process of conducting the methodology: the meaning made from narrative themes, how technology was used, and reflexive considerations of the research project. The Analysis and Discussion chapter is divided into five sections: Matter, Narrative Themes, Situating Narrative Themes, Technology, and Therapeutic Value of Literary Hypertext Illness Narratives. The following section will outline the general findings of these categories.

The methodology of this research, which incorporates a feminist new materialism (FNM) theoretical framework, calls on the researcher to consider their responsibility in the generated networks, relations, and worlds that emerge from the research. As described in the Methodology chapter, a part of this responsibility includes ensuring research serves the interests and well-being of marginalized individuals, and a clear implication of the researcher in the research conducted. The outcomes of this research are in service to women and nonbinary individuals with gendered illness to respond to their disease in a new way. As a researcher who lives with the illness being studied, I intentionally designed the methods to include moments of personal intervention. In the Screening and Closing Interviews, I took time to share small amounts of my own illness experience with participants by sharing personal anecdotes and mirroring emotional responses if these perspectives were authentic to my experience.

To further consider how FNM came to act as a reflexive tool in this research, the methodology calls for the research to consider how materiality is centred in the project. As detailed in the Analysis and Discussion chapter, materiality was at the core of this research through the technological writing tool but also through the narratives that were produced. Materiality was positioned in the forefront through the writing prompts offered to participants in the Twine module. Both the free writing prompt and the final illness narrative prompt intentionally call on participants to centre their embodied, rather than conceptual, experience of the disease and to think about sensory perception. These prompts ask the participants to write about how it feels to live in a body that is ill by turning to the sensorial experiences of the material body. Narratives produced in this study, as described in the Analysis and Discussion chapter, tended to foreground the materiality of the body through narrative as a result.

Narrative themes of the Twine stories were analyzed by the methodology through several different prompts. The first prompt calls on the researcher to consider how the narrative builds the discursive object. This research found a single, common discursive object built into every participant's narrative: the abnormal body. Considering the centering of the material body in the writing prompt, body-focused narratives were expected. However, the theme of abnormality of the body was widespread. The abnormal body was written about by participants in both explicit and abstract ways. First, participants wrote about the abnormal body as uncontrollable and requiring control. These narrative framings included the body as uncomfortable and as not adhering to a standard of femininity. The illness of the body was written about as the source of the abnormality but in contrasting ways. Some narratives framed abnormality as inherently a part of the self while others positioned it as an external force acting on the body. Second, participants wrote about the abnormal body in relation to the labour of maintaining normative femininity. These narratives included a sense of being trapped in this circuit of maintaining femininity through tedious, relentless rituals on the body.

Third, narratives in this study wrote about the abnormal body as requiring a cure. This cure, for participants, was framed as an objective that they are attempting every path to meet. Fourth, participants wrote about first discovering the abnormality of the body through a similar narrative scene: the first menstruation. Participants discussed recognizing their first period as not behaving the way they believed it should, and therefore making a discovery that their body was abnormal. This moment in adolescence was tied to a theme of childhood sexuality as well. Narratives framed childhood sexuality as something that can be imposed by adults but cannot be discovered by the child on their own. Fifth, participants wrote about a dualized abnormality where the abnormality of the body is linked to either emotional bankruptcy or a Queer identity. Finally, narratives in this study framed the abnormal body as a mystery that requires deciphering. To unravel the mystery of the abnormal body, for participants, ultimately relinquishes guilt where the abnormality is not the fault of the author but the fault of the illness.

Considering how larger discourses came to shape and layer onto the narratives pulled out several distinct narrative themes including relationality, healthcare experience and empowerment. Relationships written about by participants in their narratives tended to fall into specific categories: the mother, the sister and romantic relationships. The mother was the most frequently coded relationship in this study. Participants wrote about the mother in distinct ways. First, there was a common theme of shame in revealing the abnormality of the body to the mother. This shame was linked, at times, to the first menstruation scene discussed above where participants wrote about both a fear and an inevitable duty to disclose the abnormal menstruation to the mother. Second, some narratives in this study constructed a belief system that it is the mother’s role to monitor/intervene/maintain the normality of the daughter's body. Third, narratives included ample discussion around the fear of becoming your mother. Fourth, and similarly, participants discussed fears about not becoming a mother at all. The Analysis and Discussion chapter considers the construction of the mother in the narratives of this study and considers implications for the potential of internalized misogyny through the ways in which the mother is culturally positioned to be at fault for a “dysfunction” the child’s body in ways other parents may not be.

Other relationships that were strongly coded in this research include the sister and the romantic partner. The sister was narratively framed as a symbolic concept, rather than a literal sibling, of a feminine ideal that the illness of hyperandrogenism prevents the author from achieving. Romantic relationships were written about by participants in varying ways. Participants discussed feeling as if the disease of hyperandrogenism strips them of femininity and therefore renders them undesirable to romantic partners. In longer-term heterosexual relationships, participants wrote about feeling as if they are failing in their role of womanhood, a role that is required of them in a romantic partnership. Finally, there was ample discussion in the Twines of moments of unsupportive actions from a romantic partner in contrast to the partner acting as the sole, safe companion to discuss anxieties and fears regarding the illness.

The ways in which larger discourses came to layer onto the narrative of this study emerged through the framing of the healthcare experience as well. Participants, overwhelmingly, framed their experiences in the healthcare system as negative, mainly through feeling subjugated, dehumanized, or dismissed by their physicians or perceiving the physician to lack knowledge on the topic of polycystic ovarian syndrome or hyperandrogenism. Narratives shared a theme of experiences of violation during particular medical procedures, mainly transvaginal ultrasounds. Participants wrote about either perceiving the procedure as invasive or else not being adequately informed of the various steps. Negative healthcare experiences were positioned by some participants through a lens of intersectionality and discussions of how identity impacts negative healthcare outcomes (specifically discussions around fat bodies, race, and gender identity). Finally, some participants discussed unique experiences in a privatized healthcare system through navigating the impacts of capitalism and insurance. Negative healthcare experiences were juxtaposed by participants with what they deemed as positive experiences.

Positive healthcare encounters, for authors, were indicated by feeling validated, heard, and understood by physicians. Finally, the authors constructed a level of gender dynamics in their stories. There was a sustained belief from participants that a male physician tended to be present in negative healthcare encounters whereas a female physician may facilitate positive experiences. Positive healthcare encounters were expanded by participants to include the realm of alternative medicine and alternative approaches to illness. Narratives that framed alternative approaches to illness as beneficial tended to resist grappling with quantitative results. Rather than consider if alternative responses to illness “work” in the sense that they produce a measurable reduction of physical symptoms, these stories tended to assert that alternative practices “work” because they allow the author to feel heard, understood and validated.

The final narrative category identified in the Twines of this study was empowerment. Participants wrote about empowerment in various ways including knowledge/diagnosis/insight as empowering, transformation, and community building. First, the narratives in this study position a formal diagnosis of a disease as political. Increased knowledge of the disease was discussed as empowering the author in a way that emboldens them to extend that power to those around them experiencing similar oppression. Other participants complicated the idea that a formal diagnosis was an inherent resolution. These stories suggest that diagnosis may afford clarity in some respects, but, as a result, further questions emerge. For example, having a formal diagnosis may assist a patient in receiving treatment or navigating the healthcare system, however, participants noted a sense of harm in diagnostic labels as well. Second, the Twine stories in this study tended to conclude on an uplifting note. This narrative ending typically looked like the author undergoing a mindset transformation in order to ultimately accept living with the disease, rather than receiving a cure. Third, empowerment was written about by participants as community building. The narratives in this study, supported by insight from Closing Interviews, validated a sense of power that stems from finding kinship with other women and individuals with hyperandrogenism and through support from loved ones.

The methodology of this study works to situate the narrative themes by considering the subject positions formed and how these positions enact or restrict moments for action. All narratives in this study used a first-person point of view. The Analysis and Discussion chapter discussed how the literature on literary hypertext considers how conventional Twine games appear to foreground the choices of the reader through the second-person point of view. The narratives in this research, by contrast, centre the subjectivity of the author. This does not, however, make claims regarding the game-ness or narrative-ness of the Twines because of the first-person perspective. As the literature on literary hypertext suggests, making structuralist assumptions of game versus narrative erases the complex nuance of writing in hypertext.

Further, the narratives in this study build a formulaic trajectory for the author’s agency where the story begins with a lack of agency for the author and, as the narrative progresses, the author is granted or restricted agency through their narrative encounters with other subjects, objects, and forces. This phenomenon was found to be important because the participants did not frame the inherent embodiment of hyperandrogenism as restricting agency but as the ways in which illness is taken up culturally. Narratives resisted cultivating moments of granting action for the author through alleviating symptoms of the illness and embraced this action through encounters with cultural forces that pushed back against illness stigma.

The process of situating the narrative themes was concluded by an analysis of what is affirmed and erased by the stories in this research and why. What is affirmed through the analysis of the discursive framing of the narratives is a collective assumption that a female body that experiences masculinizing symptoms is abnormal. This abnormality renders the body in need of control, deciphering and strenuous labour. The dysfunction of the body has the potential to infect the author's psyche as well, resulting in emotional bankruptcy. This belief was present in the inverse as well where emotional bankruptcy is present first and leads to the disruption of the normal functioning of the body. Narratives affirm that bodily abnormality is undesirable because of its relationality with outside agents rather than an inherent undesirability. It is in the author's encounters with other people, institutions and social systems that render their bodies undesirable, rather than the neutral embodiment of symptoms. Narratives in this study, then, position disease as a personal journey. This journey centres the concept of growth where healing is rooted in resolving emotional bankruptcy, gaining knowledge, receiving a formal diagnosis, and locating a community of support. Finally, the narratives in this study collectively assert that encounters in the normative healthcare system are generally dehumanizing, subjugating, or violating. The development of gender dynamics is relevant in this belief system where narratives position females over male physicians as more inclined to produce positive healthcare experiences. Ultimately, participants affirm alternative medicine and alternative approaches to illness as effective responses to illness, not because of a measured reduction of symptoms, but because of producing a greater sense of well-being. The collective affirmation of particular beliefs in the narratives of this study is in line with the erasure of counter-discourses including traditional biomedical approaches, a sense of contentment with the abnormal, and questioning the category of abnormality.

The ways in which participants employed the digital features of the Twine software to build their narratives were coded by power relations. Overwhelmingly, participants believed that the Twine software was user-friendly and straightforward to learn when following the steps outlined in the module. However, this accessibility of the technology was predicated on the assumption of time to concentrate on the module instructions and the emotional or mental capacity to write about difficult experiences. Participants discussed this notion of capacity in different ways. For example, some participants noted that Twine initially felt daunting to learn before they began the module. One participant noted that the Twine module was important because it allowed them to complete the storyboard outline before starting the Twine tutorial. This allowed the participant to focus on learning the program without being overwhelmed with brainstorming a narrative topic at the same time. Another participant explained that the structure of building a Twine story was less overwhelming than writing a narrative on a physical sheet of paper because it breaks the writing process down into manageable sections. While most participants felt prepared to complete the study through online pedagogy, one participant felt they would be more successful learning the program in person.

The Analysis and Discussion chapter of the paper details how the digital features of the narratives, including code, have been impacted by and responded to larger social factors. Generally, participants chose to incorporate colour, alignment, size, and text style codes that contributed to the meaning-making of their Twine stories, in different ways. When the default background colour of the Twines was altered, it was most commonly changed to a standard white background with black text, suggesting that rather than choose to challenge assumed expectations around how a digital narrative document should look, participants chose to reproduce this. Several participants chose to include images in their Twines, that generated different meaning. Finally, style codes transformed narratives into a visual experience where the colour, size, style and spacing of the text produced narrative meaning. The meaning generated from the manipulation of style codes in these narratives cannot be summarised into a general theme or pattern. Each of the narratives in the study incorporated, or chose not to include, style codes that worked to build on the specific meaning of their individual story. This meaning-making process for each narrative, is of course, highly subjective.

Multimodality, specifically choices made to construct the hypertext links, shaped the narrative meaning in various ways. The text chosen to hyperlink in the stories of this study is significant because the hyperlink is set apart from the bulk of the other text and embodies emphasis. A weaving path was the dominant story structure choice in this study. Participants tended to utilize a weaving path, and at times multiple paths, to design a narrative loop, that brings the reader/player back to engage with a previous passage in order to personify the experience of their illness. Using a weaving path to play with the idea of reader choice was a popular strategy for participants in different ways. Some participants designed an illusion of choice while other participants foregrounded the agency of the reader/player. In general, participants employed dead-end linking in various passages of their narrative to create a sense of a lack of options where the only path forward is to move backwards. A strategy, or accident, of a passage with no hyperlink access, added an additional layer of meaning to several stories. For example, a passage with no hyperlink that does not appear to be the "true" end of the narrative created a sense of stagnation or lack of options to move forward.

The narratives in this study most commonly utilized navigational linking. The use of this linking strategy produced a feeling that the reader/player is navigating the story as if it were a space. Navigational linking was also used for knowledge dissemination by designing a Twine that acts as a spatial database of information. The waiting room was the dominant thematic space depicted, and through navigational linking, this room explored themes of anxiety around the healthcare encounter as well as feeling intentionally kept in the dark regarding the nature of the illness. Finally, passages in this study were predominately a unified construction, which suggests an affinity with narrative-ness over game-ness, however, literary hypertext scholars such as Salter and Moulthrop argue against this essentialism.

This research found that participants used the digital features of the literary hypertext software to structurally chart the narrative of their illness in ways that the author perceived as most conducive to personal reflection. Participants explored the concept of using Twine to visually map out their experiences, and manually organize them by hyperlinking passages, to find a structure that was best suited for therapeutic reflection. This visual map was discussed in different ways by participants including mirroring the human thought process, matching the experience of an illness diagnosis, conveying the feeling of a negative mental health circuit, or facilitating personal discoveries through the practice of hyperlinking. Ultimately, participants reflected on the capabilities of Twine through the lens of intersectionality. Participants spoke about the software allowing for the deconstruction and reconstruction of the "web of our identity," or in other words, a way to visually contend with the array of identities that produce the self. Twine has a sociohistorical legacy as a tool of resistance for those pushed to the margins of game development, but the participants in this study highlight the real-life ways in which power relations monopolize capacity, particularly the capacity to sit down and learn a new technology for writing.

The key findings discussed above come to a pivotal moment at the central question of the effectiveness of literary hypertext as a tool for women and nonbinary individuals to write illness narratives that construct positive relationships between themselves and the world. Participants reiterated the same belief that writing a single illness narrative, in any format, cannot "cure" or "fix" the self. The value, for participants, in engaging in writing a literary hypertext illness narrative was found through the facilitation of reflection on past experiences. This reflection was discussed by participants in various ways including leading to new vantage points to better understand emotions, establishing a deeper connection to the self, and validating past experiences of injustice. Ultimately, participants come to a conclusion that reintroduces the value of narrative medicine. For literary hypertext illness narratives to cultivate true therapeutic value, according to participants, they should be used as a tool, not only by the author to reflect on experience, but for the wider, social and medical community to read and learn about the experience of hyperandrogenism.

Main Contributions of Research

The research conducted in this study is a critical piece of a larger, complex puzzle of research taking place at the intersection of medical/health humanities, digital humanities and gender studies. This research responds to a query in these fields that is grappling with novel, innovative approaches to responding to gendered illness. This research extends the literature on the benefits of illness narrative writing into the digital space for a particular illness for marginalized identities. These findings are important for a cultural moment that is embracing digital connectivity while calling awareness to the limitations of normative approaches to illness.

The findings of this project are aligned with the second-wave scholarship on literary hypertext that cautions against an over-enthusiastic proclamation of the revolutionary capabilities of the medium. In response to the scholarship that challenges the claims of the inherent narrative self, this research assumes literary hypertext illness narratives as one potentially beneficial approach to responding to illness rather than the only path. Significantly, the research conducted in this study brings to the forefront a specific corpus and research topic that is fresh to the academic literature. There is no research published on the effectiveness of literary hypertext as a tool to write illness narratives for marginalized people. Further, representation of the experiences of women and nonbinary individuals with hyperandrogenism in academic literature is scarce. This project is intended to be a first step to aid subsequent research on the topic of literary hypertext illness narratives and the lived experience of hyperandrogenism, both in their intersection and independently.

The research conducted in this study has contributed to the development of impactful outputs. In 2019, near the beginning of my research on this topic, I published "Conversations with Buer" in *Families, Systems, and Health*. This publication is a personal illness narrative contributed to the journal's special issue on illness experience. It was important to me to initiate this project by practicing my own writing about illness. I wrote about seeking therapy for an anxiety disorder and the conversations I would have with the personification of my illness. Over the course of the research design, implementation and writing of this project, I presented this research at twenty-six various conferences (as of December 2022) which have contributed to the dissemination of the findings. At the completion of this dissertation, I intend to develop this work into a monograph proposal to further contribute to the distribution of the research.

Like Twine, the impact of this research is branching and forging multiple paths. First, this project has outlined a novel approach to theorizing the experience of hyperandrogenism. The theorizing of the construction of the abnormal body through the narratives of individuals with hyperandrogenism is a completely novel and critical contribution to the literature. This new approach to theorizing the experience of hyperandrogenism is an extension of the work I published in the 2020 article “Illness of the Gendered Body, Freud's *The Uncanny*, and ‘being-in-the-world’” in the *Canadian Review of Comparative Literature*. This article was a critical initial step into my final dissertation topic because it allowed me to organize my theoretical understanding of hyperandrogenism and the abnormal body outside of the world of literary hypertext.

Second, the findings of this research innovate the practice of therapeutic illness narratives for marginalized individuals. This study contributes to a larger discussion around access to alternative methods for responding to illness, particularly for marginalized identities. The information in this project can support individuals in accessing literary hypertext software and writing illness narratives online. Organizations can utilize the findings in this project to develop literary hypertext modules of their own to facilitate illness narrative writing for their communities. These organizations may look like illness advocacy groups, schools, or illness support communities.

Third, this research develops a new method for conducting literature reviews through building literary hypertext databases. The Literature Review chapter details the development of the literary hypertext database I built for the purpose of constructing a literature review for this project. The online, open-access journal *Interdisciplinary Digital Engagement in Arts & Humanities* has accepted my article outlining the development of this project entitled “Building

Hypertext Literature Reviews for Qualitative Research." This is an important new method for conducting qualitative literature reviews that can be utilized in interdisciplinary projects.

Forth, this project outlines the unique development of a Twine module design informed by a political narrative therapy framework. The Methods and Protocol chapter outlines the design process of the interactive Twine module used by participants in this project. This insight will be shared in a forthcoming chapter in the forthcoming book *EnTwine: A Critical and Creative Companion to Teaching with Twine* edited by Anastasia Salter and Stuart Moulthrop and published by Amherst College Press. This chapter will detail pedagogical approaches to developing literary hypertext modules for writing illness narratives which can be utilized by individuals, clinicians and organizations.

Fifth, this research develops a novel methodology for analyzing digital-born narratives through critical discourse analysis. The Methodology chapter outlines a new methodology for studying literary hypertext illness narratives that I designed for this research, called critical discourse analysis for digital-born narratives (CDADN). I found that there was a gap in the literature for a methodology that could comprehensively grasp all the intricate parts of my corpus including a feminist new materialist centering of matter, digital technology, software elements, code, textual narratives, and participant interviews. I intend to develop this chapter into a publication that introduces this methodology for use in projects researching digital-born narratives.

Sixth, this research presents an innovative proposal to address the sociopolitical marginalization of hyperandrogenism in the treatment of the illness, through the application of narrative medicine. This proposal calls for educating healthcare providers and the public about the political experience of hyperandrogenism. In considering this call, I wonder what it would look like to prescribe a Twine illness narrative in the treatment of hyperandrogenism. Or, how could Twine illness narratives be incorporated into patient digital files for clinicians to learn from? There is a clear path for this research to be applicable to psychological therapy and clinical use. Healthcare providers who practice narrative therapy, narrative medicine, or utilize illness narratives in their approach, can benefit from the findings of this research and implement the strategies outlined.

Research Limitations

This study, like all research, was bound to particular restrictions, errors and oversights. The limitations of this project include the legacy of previous research, workings of the methodology, participant pool, world events, and software considerations. There is no foundational research that could be drawn on in this project related to literary hypertext illness narratives and marginalized identities. This was a barrier to the development of integral parts of the project, including the literature review and methodology. Many sections of this research, because it is interdisciplinary, required a Frankenstein approach to design that pulled pieces of different frameworks and meshed them together. While in some areas this became an advantage because it facilitates a curated and individualized approach to the development of the project, it was a limitation to the literature review. It would have been beneficial to have a set of previous studies and articles more closely related to my research topic to build on.

Designing and implementing a new methodology for this project was an extensive task to take on. This task, though, felt necessary as other established methodologies were not curated to capture my corpus. I have no previous experience designing a new methodology and this is a glaring limitation. CDADN is essentially an amalgamation of several different functioning methodologies and works by pulling out the relevant aspects of each. Because I sidestepped truly creating a novel original framework, I believe I was able to prevent a lot of the cracks that had the potential of emerging in this approach. I found the methodology generally effective in providing me with the adequate analysis required to answer the research question. However, there were moments in the analysis process where I saw various gaps in the approach. For example, the methodology is designed to do a lot and capture a lot of various kinds of data. In this ambitious approach, important nuance fell through the cracks. In the analysis, I found there were interesting coding choices being made by participants including specific style codes or linking strategies. While the methodology has mechanisms to analyze these digital features in the context of the narrative, I did not have a way into analyzing why these choices were made by the participants. In retrospect, it would have been useful to evaluate these choices in the methods of the research, mainly in Closing Interviews.

The demographic makeup of the participants of this study was generally diverse. I believe there was important representation among individuals who embodied various identities related to race, ability, health, gender, body size, and sexuality. Representation lacked, or failed to be measured, in class and age. There was no reporting of socioeconomic class identity in the Screening Interview of this study. This was an intentional decision. There was ample consideration of how to include a self-reported question in the interview regarding class, but the nuances of this were complex. Class identity is a contentious space between and outside of education, income, employment status, residence, life history, etc. The risk of getting this identity marker wrong outweighed the benefit of including this data in the study. Age was a question included in the Screening Interview and this data revealed that participants in this study were relatively young (all participants were in their 20s or 30s). There is more to be analyzed in the recruitment methods of this project that appears to have been exclusionary to older individuals. This may be due to the online recruitment methods and the online nature of the study. Additional factors may be contributing as well including understanding who is more inclined to be seeking alternative ways to respond to hyperandrogenism and why.

Many would consider the participant pool as an evident limitation of this study. There were ten participants who completed the module and submitted their narratives in this research. This is a small number of participants which prevents the research from being able to make any sort of broad claims about the findings. The findings of this study are relevant to the nuanced and detailed experiences of a small number of people. However, there are benefits to the pool size as well. Because of the embodied and experiential nature of this research, I was able to produce a mass amount of data from a small number of participants. I spent time with each participant, listened to their story and shared my own. They gave hours of their life as well. This sort of deep reciprocal bond is rare in research conducted on large participant pools and was imperative for this project.

The participant research of this study began at the start of the COVID-19 pandemic, which led to unexpected disruptions in the design of this project. I was debating conducting the participant research as an in-person workshop, but this idea was quickly discarded after March 2020. To protect participants, adhere to local and national guidelines, and to accommodate distance, the study was designed to take place entirely online. The pandemic mandating the online nature of the research, in fact, was less of a limitation to this study than the mental and emotional toll isolation inflicted on participants and myself. As discussed in the Analysis and Discussion chapter, technology can be unmatched in its accessibility, however, this access can only go so far. It does not respond to the capacity required to sit down and learn a new software and spend time reflecting on emotional experiences.

Finally, there were technical limitations of the software used in this research. NVivo, the data analysis tool employed in this study, was generally effective at coding the data. This software, though, is limited in its capability of accommodating hypertext data, code and HTML files. This was a large hurdle. As described in the Analysis and Discussion chapter, NVivo mainly supports textual, auditory and visual data files. To circumvent this limitation, I had to get creative with the ways I analyzed the corpus of this research. Twine stories were coded in the software as Word documents in order to capture the textual data. The obvious limitation to coding stories through a Word document file in NVivo is that the rhizomatic design of the Twine story is erased. Additional screenshots of the story in the Twine interface were included to capture the hypertext structure. Further software limitations came alongside Twine's periodic version updates that made some instructions in the module outdated. This occurred after all participants completed the module, but points to the ever-evolving nature of these digital tools.

Recommendations for Future Research

Understanding the research limitations of this study allows for targeted recommendations for future research to fill important gaps. Critical research to build on this project would consider studying the benefits of literary hypertext illness narratives for people with hyperandrogenism with a larger participant pool. A project like this would require ample funding. Similarly, altering the facilitation design method of this study in future related research would produce helpful data. This may look like incorporating in-person Twine workshops to teach literary hypertext illness narratives instead of, or to supplement, the module. Additionally, researching various application methods and environments would contribute to relevant data on the topic, including the facilitation of literary hypertext illness narrative workshops in therapy settings, schools, or the clinical context. Finally, limitations of the methodology, including turning to frameworks that can capture the decision-making process for code and digital design choices made by participants would supplement this research.

Branching expansively from this project would see a two-fold scholarly focus: research on other digital technologies for writing literary hypertext illness narratives and centering other pathologized identities. This research centres hyperandrogenism, however, the study of this disease in particular opened up paths to consider an array of varying embodiments and pathologized identities in relation to illness narratives including identities of disability, biological sex diversity, and neurodiversity. There is a mountain of progress required to understand the experiences of these embodiments in the academic literature. Further, this research resists valorizing a particular technology like Twine, or even a genre of writing like literary hypertext, as the only/best method for illness narratives. I am interested in expanding conceptualizations of what coping with illness can look like and how the digital space is opening new doors for healing, resisting, and finding community. Subsequent research to build on this project, then, would consider centring telling the story of illness through other digital practices such as social media, comment sections, games, code, film, video conferencing, etc. For example, in 2022, Astrid Ensslin and I published "The Possibilities of Illness Narratives in Virtual Reality for Bodies at the Margins" in the journal of *Digital Creativity*. In this article, we look at how virtual reality technology may be utilized as a method for illness narrative creation for pathologized identities. Pushing the research in a direction curious of what else can be discovered in the digital space is the intention of this project.

Chapter Review

This chapter began with an outline of the key findings of this research project related to matter and feminist new materialism, narrative themes, contextualization of themes, and technological findings. The following sections outline the main contributions of the research, the limitations of this research project, and the recommendations for future research. Ultimately, this chapter responds to the research question of how literary hypertext can be used as a tool for women and nonbinary individuals to write illness narratives that construct positive relationships between themselves and the world. This project found that participants in this study used literary hypertext software to structurally chart the narrative of their illness in ways most conducive to personal reflection. Participants used the Twine program to visually map out their experiences, and manually organize them by hyperlinking passages, to find a structure that was perceived as best suited for therapeutic reflection. Ultimately, participants believed that writing a single illness narrative, in any format, cannot "cure" or "fix" the self. The value, for participants, in engaging in writing a Twine illness narrative was found through the unique process of reflection on past experiences. Ultimately, the findings of this research return to the framework of narrative medicine. Participants believed that for literary hypertext illness narratives to cultivate true therapeutic value, they would be tools, not only by the author to reflect on experience, but for the wider social and medical community to read and learn about the experience of hyperandrogenism.

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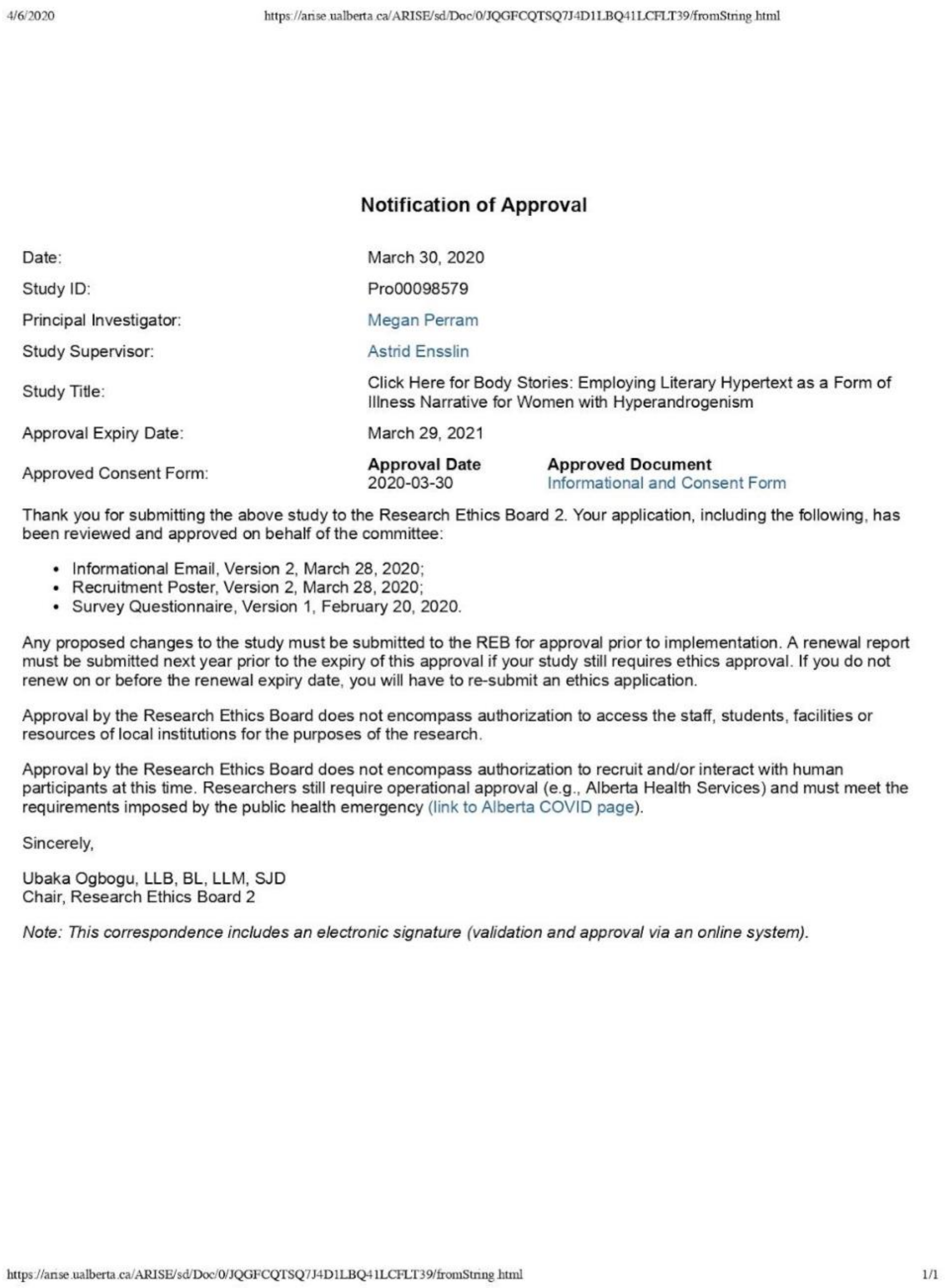
Appendices

Appendix A: Study Ethics Approval



4/6/2020 https://arise.ualberta.ca/ARISE/sd/Doc/0/JQGFCQTSQ7J4D1LBQ41LCFLT39/fromString.html

Notification of Approval

Date:	March 30, 2020	
Study ID:	Pro00098579	
Principal Investigator:	Megan Perram	
Study Supervisor:	Astrid Ensslin	
Study Title:	Click Here for Body Stories: Employing Literary Hypertext as a Form of Illness Narrative for Women with Hyperandrogenism	
Approval Expiry Date:	March 29, 2021	
Approved Consent Form:	**Approval Date** 2020-03-30	**Approved Document** Informational and Consent Form

Thank you for submitting the above study to the Research Ethics Board 2. Your application, including the following, has been reviewed and approved on behalf of the committee:

- Informational Email, Version 2, March 28, 2020;
- Recruitment Poster, Version 2, March 28, 2020;
- Survey Questionnaire, Version 1, February 20, 2020.

Any proposed changes to the study must be submitted to the REB for approval prior to implementation. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Approval by the Research Ethics Board does not encompass authorization to recruit and/or interact with human participants at this time. Researchers still require operational approval (e.g., Alberta Health Services) and must meet the requirements imposed by the public health emergency (link to Alberta COVID page).

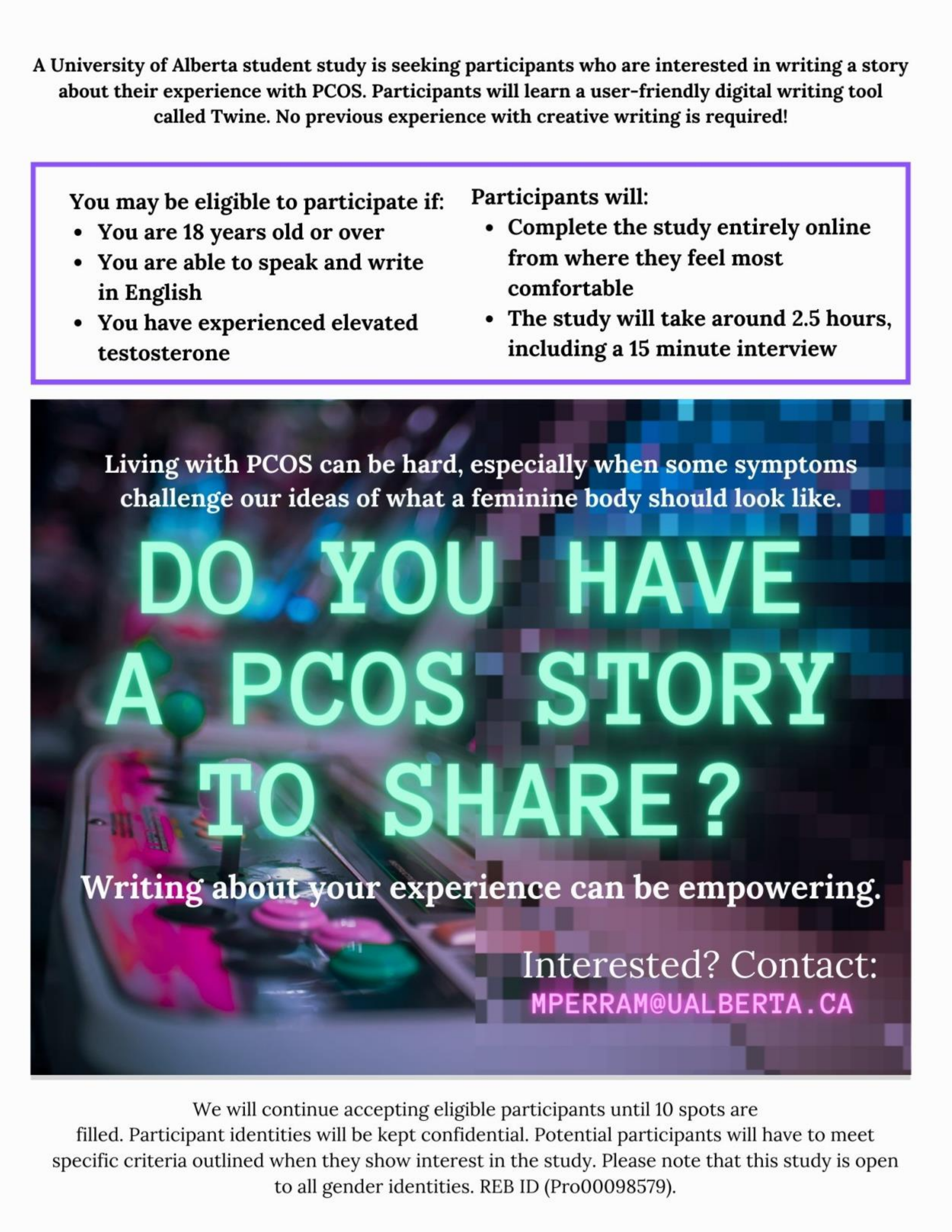
Sincerely,

Ubaka Ogbogu, LLB, BL, LLM, SJD
Chair, Research Ethics Board 2

Note: This correspondence includes an electronic signature (validation and approval via an online system).

https://arise.ualberta.ca/ARISE/sd/Doc/0/JQGFCQTSQ7J4D1LBQ41LCFLT39/fromString.html 1/1

Appendix B: Study Recruitment Poster



A University of Alberta student study is seeking participants who are interested in writing a story about their experience with PCOS. Participants will learn a user-friendly digital writing tool called Twine. No previous experience with creative writing is required!

You may be eligible to participate if:

- **You are 18 years old or over**
- **You are able to speak and write in English**
- **You have experienced elevated testosterone**

Participants will:

- **Complete the study entirely online from where they feel most comfortable**
- **The study will take around 2.5 hours, including a 15 minute interview**

Living with PCOS can be hard, especially when some symptoms challenge our ideas of what a feminine body should look like.

DO YOU HAVE A PCOS STORY TO SHARE?

Writing about your experience can be empowering.

Interested? Contact:
MPERRAM@UALBERTA.CA

We will continue accepting eligible participants until 10 spots are filled. Participant identities will be kept confidential. Potential participants will have to meet specific criteria outlined when they show interest in the study. Please note that this study is open to all gender identities. REB ID (Pro00098579).

Appendix C: Informational Email

Dear [Name of Inquiring Participant],

Thank you so much for reaching out and expressing interest in participating in my study.

What is this study called?
Employing Literary Hypertext as a Form of Illness Narrative for Women with Hyperandrogenism

What is this study about?
I'm interested in understanding how digital tools can be used to write about the experience of hyperandrogenism - a term used to describe elevated testosterone, frequently found in women with Polycystic Ovarian Syndrome (PCOS).

I want to know how digital writing might be empowering for women. I became interested in this topic after I was diagnosed with PCOS myself and began writing about my own experiences online.

What will I be asked to do?
To participate in this study, you will be asked to complete an online module that teaches you how to use a user-friendly and accessible software called Twine. Twine (Twinery.org) is a freely accessible, open-source tool for writing stories online. It can be accessed through an internet browser. Twine is used to write stories in a nonlinear way by using hypertext – words that become digitally linked by clicking or tapping on them. You will use Twine to write a story about your experience with hyperandrogenism. You don't need any previous experience with hypertext tools or creative writing to participate!

This module will be completed entirely online in a location where you feel most comfortable and can be completed in around 2 hours. You can space this time out if you wish as well. Once you finish writing your story, you will be asked to complete a 15-minute, open-ended interview reflecting on your experience using Twine to write your story.

I will continue accepting eligible participants until 10 spots are filled.

Who can participate?

This study is open to all gender identities who have experience with hyperandrogenism.

To be eligible for the study, you must:

1. have the ability to speak and write in English
2. be 18 years old or over
3. self-identify as having hyperandrogenism, and
4. have experienced **two** or more of the symptoms listed below
   Please note that this means you **do not need to have had a formal diagnosis** from a doctor.

To be eligible, you must have experienced **one** symptom from List A.

List A:

- Hirsutism (excess facial or body hair)
- Alopecia (male-pattern-baldness or female-pattern baldness)
- Irregular, absent and/or painful periods
- Enlarged clitoris with virilization (increased libido)
- Deepening voice with prominent larynx
- Increased muscle mass and decreased breast size
- Infertility

You must **also** have experienced **at least one other** symptom from List B which is not the same symptom you selected above.

List B:

- Hirsutism (excess facial or body hair)
- Severe acne
- Seborrhoea (oily skin)
- Alopecia (male-pattern-baldness or female-pattern baldness)
- Hidradenitis suppurativa (inflammatory skin condition)
- Insulin resistance
- Associated type 2 diabetes due to insulin resistance
- Acanthosis nigricans (rough, darkly pigmented areas of skin)
- High blood pressure
- Low HDL cholesterol and high LDL cholesterol
- Obesity
- Irregular, absent and/or painful periods
- Enlarged clitoris with virilization (increased libido)
- Deepening voice with prominent larynx
- Increased muscle mass and decreased breast size
- Infertility

Thanks so much for taking the time to reach out. If you are eligible and interested in participating, let me know. We can set up a time to do the screening interview over the phone or Zoom. From there, I can share with you our information and consent form that will have a more detailed description of this study, participation requirements, and notes on confidentiality.

If you have any questions about this study, participation or eligibility, please don't hesitate to reach out.

All the best,

Appendix D: Screening Interview Script

ID#:
Screening Date:
Interviewer: Megan Perram
Selected for Workshop: TBD

Reminders:

- You can end this interview at any time
- If there's a question you don't want to answer, just say "pass"
- Our audio and video are not being recorded - I am typing out your answers by filling in a survey form

What are your pronouns?

____

Part I: Eligibility

1. How would you assess your ability to speak and write in English?

   Please indicate on a scale of 1-5 (1 being no ability and 5 being fluent or native-speaking).

   ☐1 ☐2 ☐3 ☐4 ☐5

0. Are you 18 years old or over?
☐Yes ☐No

0. Do you <u>self-identify</u> as having hyperandrogenism, and have you experienced <u>two</u> or more of the symptoms listed below?
☐Yes ☐No

Have you experienced <u>one</u> symptom from List A?

List A:

- Hirsutism (excess facial or body hair)
- Alopecia (male-pattern-baldness or female-pattern baldness)
- Irregular, absent and/or painful periods
- Enlarged clitoris with virilization (increased libido)

- Deepening voice with prominent larynx
- Increased muscle mass and decreased breast size
- Infertility

Have you experienced at least one other symptom from List B which is not the same symptom you selected above?

List B:

- Hirsutism (excess facial or body hair)
- Severe acne
- Seborrhoea (oily skin)
- Alopecia (male-pattern-baldness or female-pattern baldness)
- Hidradenitis suppurativa (inflammatory skin condition)
- Insulin resistance
- Associated type 2 diabetes due to insulin resistance
- Acanthosis nigricans (rough, darkly pigmented areas of skin)
- High blood pressure
- Low HDL cholesterol and high LDL cholesterol
- Obesity
- Irregular, absent and/or painful periods
- Enlarged clitoris with virilization (increased libido)
- Deepening voice with prominent larynx
- Increased muscle mass and decreased breast size
- Infertility

[For ineligible participants]: Thank you very much for your interest in this study. Unfortunately, our criteria for inclusion does not allow for us to proceed any further. We will discard the information and answers you have provided, and we will not include this in our analysis with the exception of noting how many potential participants were interested in our study.

Part II: Diversity

Now I'm going to ask you some questions about how you identify. The personal data collected from these questions will not be linked back to you in any way. It may be linked to your anonymous Twine story you create in this module. It will be used to better understand how different experiences of identity can come to shape and be shaped by hyperandrogenism. You have the choice to answer all, some, or none of the following questions and this will not affect your eligibility in this study. If a question is asked that you do not want to answer, simply say "pass" and we will continue to the next question. If you feel uncomfortable or would like to stop at any time, please let me know.

Do you have any questions before we begin?

1. Where are you a current resident of?

2. What is your age?

3. Do you consider yourself to be:

A. Do you consider yourself to be a person of colour, a racialized person, or mixed race?

☐Yes ☐No

[Probe] If yes, how would you describe yourself?

Notes:

B. Do you consider yourself to be an Aboriginal, First Nations, Metis, Inuit or Indigenous Person?
☐Yes ☐No

Notes:

C. Do you consider yourself to be a disabled person or person with a disability?
☐Yes ☐No (If yes, how do you describe your disability?)

Notes:

4. Check all that apply:

D. Do you consider yourself to be:

☐A plus-size person
☐An average size person
☐A thin person
☐Do you describe your size in another way?

Notes:

E. Have you ever experienced any kind of body image concerns around not feeling feminine enough?

☐Yes ☐No

[Follow up] If yes, how would you describe these concerns?

Notes:

F. To describe your gender, do you consider yourself to be (Check all that apply):

☐Trans*
☐Genderqueer
☐Non-binary
☐Two-Spirit
☐Cis
☐Female
☐Woman
☐Man
☐Male

None of these describe my gender. I identify as ___________________________

G. To describe your sexual orientation, do you consider yourself to be (Check all that apply):

☐Heterosexual/Straight
☐Unsure/Questioning
☐Lesbian
☐Gay
☐Queer
☐Bisexual
☐Asexual
☐Two Spirited
☐Pansexual

None of these describe my sexual orientation. I think of myself as:

H. Have you received healthcare treatment or visited a healthcare facility for your symptoms of hyperandrogenism?

☐Yes ☐No

[Follow up]: If yes, how would you describe your experience with the healthcare system?

Notes:

I. Are you a person that identifies as having a psychiatric disability or mental health issues?
☐Yes ☐No

Notes:

J. Have you ever written about your experience with hyperandrogenism, either for a public audience or privately (this includes writing about your illness in online posts, forums, or communities)?
☐Yes ☐No

[Follow up]: If yes, how would you describe the experience of writing about your illness?

Notes:

K. One final question:

If you participate in this study, you will complete an online module teaching you an easy-to-use program called Twine. Twine is used to write stories in a nonlinear way by using hypertext – words that become digitally linked by clicking or tapping on them. You will be using Twine to write a story about your experience with hyperandrogenism.

The module:

- Can be completed entirely online in a place where you feel most comfortable.
- is designed to take around 2 hours. You can pause the module and begin again and can save your work.
- Will encourage you to write about your experiences with hyperandrogenism, including experiences in the healthcare system.

Are you willing to participate in this module?

☐Yes ☐No

Notes:

Thank you for answering my questions. I'll be in touch shortly to let you know if you have been selected to participate in this module.

Appendix E: Information Consent Letter and Form

Study Title: Click Here for Body Stories: Employing Literary Hypertext as a Form of Illness Narrative for Women with Hyperandrogenism

Research Investigator:
Megan Perram
442-A Old Arts Building
University of Alberta
Edmonton, AB, T6G 2H4
mperram@ualberta.ca
780-240-7462

Supervisor:
Dr. Astrid Ensslin
241C Old Arts (office)
University of Alberta
Edmonton, AB, T6G 2E6
ensslin@ualberta.ca
780-492-492

Background

- You are being asked to be in this study because you are at least 18 years old, are an English-speaker, and have experienced at least two clinical symptoms of hyperandrogenism - a term used to describe elevated testosterone, frequently found in women with Polycystic Ovarian Syndrome (PCOS).
- You will be asked to write a story about your experiences with hyperandrogenism, using a digital tool called Twine. You will also have the opportunity to read the stories of fellow participants.
- This study is being conducted to understand how women with hyperandrogenism can use technology to help create positive relationships between their identities and the world.
- Please note that use of the term "female" and "woman" is only to reflect the language of clinical diagnosis. Other gender identities who may have personal experience with hyperandrogenism are eligible and encouraged to participate.
- The results of this study will be used in support of my dissertation.
- Before you make a decision, one of the researchers will go over this form with you. Please feel free to ask any questions you may have about the project or if anything on this form is not clear. You will be given a copy of this form for your records.

Purpose

- Women with hyperandrogenism can be made to feel that they are not “normal”. To help cope with this, some women with hyperandrogenism turn to writing stories about their experience of illness.
- These stories have typically been studied as text written on a piece of paper, books, etc. This leaves out other ways of telling stories. Digital tools offer us new ways to tell our stories, including in a nonlinear way.
- This study will research the experiences of women with hyperandrogenism who use literary hypertext technology as a tool for telling their stories.
- The data being collected is for a graduate dissertation.

Study Procedures

- You will complete an online module teaching you an easy-to-use program called Twine. Twine (Twinery.org) is a freely accessible, open-source tool for writing stories in a nonlinear way. Twine is used to write stories in a nonlinear way by using hypertext – words that become digitally linked by clicking or tapping on them. You will be using Twine to write a story about your experience with hyperandrogenism.
- This module will be completed entirely online in a place where you feel most comfortable. You are encouraged to meet with the Research Investigator prior to starting the module in order to go over any questions you may have. We can meet over Skype, Facetime, or telephone depending on what works for you.
- You can complete the module at your own pace. The module is designed to take around 2 hours. You can pause the module and begin again and can save your work.
- When you are finished the module, the Research Investigator will contact you to complete a 15-minute interview reflecting on your experience with the module.
- Once all Twine stories have been completed, you will have the option to share your story in a secure shared Google Drive folder that all participants will have access to. This is completely optional, but speaks to the idea of building community which is an important part of online narrative forums and a part of why Twine was created. You can still participate in this study and **not** share your story with other participants if you choose.

Module Breakdown:

The module is housed on a website (https://itch.io/) and can be completed in your browser.

. **Part I** *Hyperandrogenism:* This section of the module provides a brief introduction to hyperandrogenism and some issues people face with it.

. **Part II** *Twinery.org:* In this section, you will be introduced to the Twine website and nonlinear writing. You will also be given web links to access several public Twine stories and will be encouraged to read at least two. This is to introduce you to examples of what Twine narratives can look like.

. **Part III** *Storyboarding:* You will go through a brief storyboarding exercise that will help you map out the main components, themes, or events you want to include in your story.

. **Part IV** *Twine Tutorial:* You will have access to a comprehensive step-by-step guide on how to create a basic Twine story. This guide will include an outline for basic Twine features and instructions on how to save stories.

. **Part V** *Writing your Twine Story:* You will be asked to write your own story in Twine. You will be encouraged to build a story as basic or as complex as you wish.

. *Open-ended Interview*: Once you complete the Twine writing stage, the RI will set a Zoom meeting with you to complete a short interview on your experiences with the module. The Zoom interview will use two forms of recording - one through the Zoom meeting recording feature, and the other through an iPhone audio recording as a backup. The recording files will immediately be uploaded to a secure Google Drive folder, and the secure password-protected local desktop of the RI as a backup. The files will then be deleted from their original source.

. *Final Twine Sharing:* Once all Twine stories have been completed, you will be invited to share your stories in a secure shared Google Drive folder that all participants will have access to. This is not a requirement of the study but speaks to a sense of community-building.

Risks

- Participation includes writing about your experiences of illness, which could be psychologically or emotionally stressful for you. Thinking about and writing about your experiences in the healthcare system, or reflecting on your body can be potentially trauma-inducing.
- You may also not want others in your life to know that you live with hyperandrogenism if you feel like you do not have access to a private space to complete the module.
- You should also be aware of the potential for slight mental fatigue from learning Twine and creating your story.

Benefits

- The practice of writing about the experience of illness, has been shown to be a beneficial exercise that can empower you as the author. This project will give you a chance to reflect and discuss, in a safe environment, your experience with illness, and to think of new ways of understanding, supporting, and writing about what it means to have a body seen by some as “sick” or “abnormal”. Writing about experiences of illness has also been linked to helping authors process trauma associated with the healthcare experience.
- You will be able to access the study wherever or whenever is most comfortable and appropriate for you and complete the study at your own pace.
- Please note that some participants may not get any direct benefits from participating.
- The information we get from this study will help us better understand how women with hyperandrogenism can experience empowerment through writing about their illness, and could help improve the experiences of people with hyperandrogenism in the future.

Voluntary Participation

- Your participation and consent in this study is voluntary and can be withdrawn at any time throughout module completion, survey participation, and data collection/analysis by informing the Research Investigator.

- You are not obligated to answer any specific questions even if participating in the study.
- If you agree to be in the study you can change your mind and withdraw at any time.
- If you withdraw from the study, you will have the option of your data being destroyed or retained.
- If you wish to withdraw after data collection has been completed, you can do so up until the results will be disseminated (1 month after you finish the interview).

Confidentiality & Anonymity

- Your information and identity will be kept in a secure, password protected and encrypted Google Drive folder, including the ID legend, as to eliminate associating participant names with any data.
- If you lose your ID, please contact the Research Investigator.
- The module will be published online at iotch.io and accessible in an internet browser. You will be given a link to the module to access when you are ready.
- You can withdraw at any time by closing the web browser and informing the RI. You will be given a unique identification number (ID) at the start of the study to identify your work. The list of participant IDs will be kept secure and only accessible by the Research Investigator. Only the RI will be able to link you to your Twine story and your interview answers.
- The data collected from this study will be used in a dissertation, research articles, and conference presentations.
- **We may use the data we get from this study in future research, but if we do this it will have to be approved by a Research Ethics Board.**

Contact Information

If you have questions regarding this study, please do not hesitate to contact the Research Investigator:

Megan Perram
mperram@ualberta.ca
780-240-7462

If you want to provide your consent to participate in this study, please electronically sign this document and email it to the Research Investigator at mperram@ualberta.ca.

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can call (780) 492-2615. This office is independent of the researchers.

If you need help:
If you need immediate mental health resources you can visit Check Point or Mind Your Mind. These two websites offer extensive resources that can help, including emergency mental health hotlines. Please know that you can also contact the Research Investigator for additional support.

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

Participant's Name (printed) and Signature	Date
Name (printed) and Signature of Person Obtaining Consent	Date

Appendix F: Closing Interview Script

I wanted to start by thanking you for participating in my study on hypertext illness narratives for individuals with hyperandrogenism. It was wonderful to have you and your valuable contribution to this work.

As detailed in the information letter, the final step for your participation is this short interview where I will ask you about your experiences writing about your illness with Twine. I also want to remind you that you may revoke your consent and/or participation in this study at any stage before data analysis (around 1 month after this interview).

I would like to know a little more about your experience using literary hypertext to write an illness narrative. Mainly, I am curious to what extent using a nonlinear digital writing tool to write about your illness was a beneficial experience for you. How did it help you change the way you view your body or how you view your body in relation to the world? The information you provide will help me understand if and how nonlinear digital writing is a valuable tool for women with hyperandrogenism to write their experiences of illness.

Before we start I want to let you know that I am taking an audio recording of this interview. The audio recording will later be transcribed by myself and the transcript will be analyzed with your Twine story. Your name or any other identifying features will never be associated with your data.

Do you have any questions?

Q1: What was your experience using Twine to write about hyperandrogenism?

[Probe] To what extent did you find the software enjoyable, frustrating, user-friendly, complicated, etc.?

Q2: How would you describe your feelings toward your body, your identity, or your ideas about where you fit in the world after writing about your illness? (i.e., this may look like having a new, positive perspective on how your body is perceived in the world or developing a kinder evaluation of your body)?

[Probe]If yes, how have your perspectives improved? In what aspects of your life do you notice these improvements? What was it about the experience of writing about your illness that was the most beneficial?

[Probe]If no, have you noticed no change to your perspectives or a negative impact?

Q3: How did writing about your illness shape or reflect on your experience with hyperandrogenism in the healthcare system?

[Probe] Has the way you feel about your experience in the healthcare system changed? How?