2024

Autopathography Across Media: Trauma and Fluid Embodied Subjectivity

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Autopathography Across Media: Trauma and Fluid Embodied Subjectivity

An Honors Thesis

Presented to

The Faculty of the Department of Science, Technology, and Society

Colby College

In partial fulfillment of the requirements for the

Degree of Bachelor of Arts

By

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Waterville, Maine

May 19, 2024

Abstract

Illness memoirs with first-person point of view have gained more attention in recent years among medical sociologists and anthropologists. Different from traditional "case histories"written by doctors that are in danger of ignoring patients' voices, autopathograhical works delineate narrators' transformative experiences of persons to patients, emphasizing the importance of gaining social understanding of illness. Focusing on three works within the category of autopathography across genres and media forms in the late 1950s and contemporary periods, *the Cancer Journals* (1980) written by Audre Lorde, *the Collected Schizophrenias* (2019) written by Esmé Weijun Wang, and *the Diving Bell and the Butterfly (*2007) directed by Julian Schnabel, this project will explore the material and symbolic significance of integrating the experience of disease with self identities. The comparison of these three works in their use of thematic and generic elements will enrich the definition of autopathography as well as highlight its unique narrative form. Drawing connections to the clinical terminologies and treatments of different types of illness, this project attempts to gain a more comprehensive understanding of diseases considering suffer-survivors' experiences in regard to their interactions with social and cultural norms.

Keywords: autobiography; illness memoir; identity; selfhood; trauma; media specificity; disease

Acknowledgements

I would like to thank my advisor and seminar instructor Professor Ashton Wesner for her insights and guidance. She inspired me to pursue my passion for Science and Technology Studies and to be bold to explore new topics. I would also like to thank Professor Jay Sibara, the outside reader of this Honors Thesis. Besides all the helpful feedback they provided to help me revise this thesis, I enjoyed taking courses with them during my four years at Colby. Their passion and insights in interdisciplinary studies influenced and promoted me to conduct research combining multiple theoretical frameworks.

I am extremely grateful to Professor Aaron Hanlon, the chair of the STS department, for his support of my exploration in STS and my academic experience at Colby. I would also like to thank Professor Amrutha Kunapulli for her insights and help on my thesis revision.

I also appreciated suggestions and support from my friends and peers in the department of STS. I also enjoyed and felt inspired reading all your works during each workshop session.

Lastly, to my family, I would not be here without you, mom. It is your encouragement and patience that supports me throughout my whole life. Thank you for always being proud of me and supporting every decision I made to pursue my interests within and outside academic research.

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Introduction

Traditional “case history” written by medical practitioners, with its strict structure and reliance on “physician-centric” perspective (Morse 187), can omit patients’ experiences and comprehension of illness. In recent years scholars have highlighted case history’s danger of ignoring patients' voices, and instead recognized the importance of “autopathography” (Aronson 1) as an alternative form of medical narrative to study patients’ unstable selfhood interacting with disease. Formally defined by Campbell in *Psychiatric dictionary* as “the study of the effects of any illness on the artist’s life or art, or the effects of an artist's life and personality development on [their] creative work” (Aronson 1), autopathography recognizes artistic value in patients’ narration and highlights their fluid subjectivity due to their experience of suffering from illness. Nevertheless, this terminological definition also poses further questions such as the definition of “arts" and criteria of artistic qualities in relation to traditional aesthetic theory. Though written based on one’s personal experiences, autopathographical works with their narrative power can facilitate broader discussions regarding our understanding of illness since they consider the meaning of being ill comprehensively, intertwining scientific knowledge of disease with personal struggles. In other words, by recognizing various elements influencing one’s experience of being ill, autopathography as a genre sheds light on an interdisciplinary perception of disease and interrogates the notion of objectivity usually associated with medical science.

Theoretical Contributions & Research Questions

With more attention to illness narratives in recent years, different disciplines remain relatively siloed: medical fields discuss the use of autopathography as therapy, wherein researchers conduct empirical studies including quantitative analysis on evaluating positive clinical outcomes for patients after forming a more accurate "illness perception" (Petrie & Weinman). Comparatively, literary theorists and scholars in performative studies tend to approach the definition of therapy on a metaphysical level (Levine; Duggan), relating it to ancient tragic theory and Aristotle's concept of catharsis. The separate directions in works among clinical medicine, psychopathology, and literary studies not only endanger a definitional inconsistency regarding autopathography as a genre but may hinder us to recognize various factors influencing the experience of illness as most autopathographical works interrogate the notions of identity and normalcy in their narration of being ill during which their roles as patients in medical settings intertwine with those as social and political functioning persons in public spheres.

Medical humanities or medical sociology provide possibilities for bridging the gap between epidemiological and humanistic understanding of illness. While there are a few examples of interdisciplinary scholarship at the intersection of these, most of them tend to focus on a particular form of illness narrative such as non-fictional essays by professional writers (Nettelbeck) and graphical novels by visual artists (Williams).

My project recognizes the necessity of enriching the study of autopathography. As such, I employ diverse frameworks in STS in general with a particular focus on medical humanities. I attempt to reconcile the medical definitions of illness and trauma with their symbolic interpretations under the social and cultural contexts. Rather than focusing only on the usual

non-fiction essays on illness I turn to works across genres of personal memoir and film as well, and use frameworks from multiple disciplinary traditions, like literary criticism, media studies, and STS studies. By comparing and contrasting these works, I explore how their commonalities contribute to the generic definition of autopathography while bearing in mind how the representation of illness varies because of different types of diseases and medium specificity.

Methods

In my research, I investigate the generic definition of autopathography and include analysis of scholarly articles in the fields of clinical medicine, psychopathology, literature, and critical theory. My review is both thematic and chronological. Importantly, though some scholars may not explicitly use the phrase "autopathography" or "illness memoir", I find that their theoretical frameworks and studies are pertinent to first-person narration about illness in that they seek to represent trauma in expressive arts therapy and interrogate medical terminologies by encouraging the integration of personal experiences. Recognizing these connections, my project also takes these theoretical essays and autobiographical narrations into account, which extends the previous definition of autopathography.

My thesis also conducts primary analysis of three works, *The Cancer Journals*, *The Collected Schizophrenias,* and the film *The Diving Bell and the Butterfly* (2007). I stage a conversation among these authors and adopt theoretical frameworks in various disciplines such as literary theory, gender studies, disability studies and media studies. Concepts such as intersectionality, technoscientific constructs, and gaze would be particularly relevant. Comparing and contrasting themes and forms among three primary sources, I explore how the narrators reconstruct their self-images in nuanced ways. I focus on how their experiences reflect on wider public issues, such as the social construction of "normalcy," gender norms imposed on women, inequalities experienced by intersectional identities. In general, this section attempts to explore autopathography's emphasis on patients' subjectivity and their transformed construction of selfhood vis a vis diagnosed diseases. I will also analyze how works with autopathographical nature have the power to use narrators' private stories to critique social norms and hegemony.

After an analysis of how serious diseases alter narrators' self-perception and their response to the transformation, the project then explores how the use of different media forms (prose, journal, and film) complicate the narrations with two major themes included: first, how the narrative forms with symbolic implications interact with and destabilize narrators' self-perceptions. And second, how certain strategies associated with particular narratives forms shape a collective understanding of illness among communities tackling serious health issues.

Frameworks and concepts**:**

- Science and Technological Studies Related
    - critical medical humanities (social understanding of illness; transformative experiences of persons to patients)
    - disability studies (technoscience and discriminative design; invisibility)
- Others
    - critical theory (tragic/trauma theory; apparatus theory; semiotics, feminism, psychoanalysis)
    - literature and film (close reading; formal analysis)

Close-reading strategies:

- Track key themes and concepts such as confusion and selfhood; locate specific sections of works including these ideas; and gather them in one document for a horizontal comparison.
- Film specifically: keep a viewing journal including time stamps and screenshots of key scenes (xx:xx:xx form)

Primary Sources: The three works below range from non-fiction essays to films in which the narrators themselves focus on their experiences with diseases and how illness impacts their self-construction.

- *The Cancer Journals* by Audre Lorde:

In this 1980 non-fiction book, Lorde discusses her struggle with breast cancer and its relation to her multiple identities with a combination of journal entries and recollection. The form of this work also echoes the aim of autopathography as it unsettles the assumed coherent selfhood by combining different narrative forms such as journal entries, first-person narration, and theoretical argument to complicate the embodied self-perception. In her work, Lorde discusses the unequal and biased treatments she encountered in the hospital due to her marginalized identities. In addition, she discusses the lack of breast cancer narratives as a symptom of the societal oppression of women. For example, Lorde problematizes the way medical professionals in hospital and recovery centers advocate for the use of breast prostheses post-mastectomy. In the last chapter, she criticizes the artificiality of prosthetic breasts and emphasizes the danger of imposing a notion of normal physical appearance on women in detail.

- *The Collected Schizophrenias* by Esmé Weijun Wang:

This collection of essays, published in 2019, has a common theme on how mental health problems alter her social identities. The author explores her difficulties in integrating mental illness (schizophrenia) as a part of her personality associating with her identities as a prolific writer, an Ivy-league student, an East Asian descent . Similar to Lorde's *Journals,* Wang discusses racial and gender inequality while offering a nuanced view of how chronic disease shapes a person's identity in similar yet different ways than other severe but sudden forms of

illness. Wang explores the particularities of how the definition and diagnosis of mental disease affect one's understanding of body/mind duality.

Here, I analyze three chapters in which Wang discusses different aspects of her experiences with schizophrenia. In contrast with a popular assumption that people tend to avoid being diagnosed of serious mental health issues because of social stigmatization, Wang supports diagnosis and emphasizes that the accurate diagnosis can not only help a person understand themselves better but also form a community with similar struggles. This sense of community and healing through diagnosis echoes Lorde's emphasis on using her work to promote more breast cancer narratives to form collective voices and increase the visibility of women's physical and psychological struggles. Taken together, I show how these private stories relate to and reflect larger social problems by citing scholarly articles focusing on critical race studies and gender studies. In the other two chapters, Wang questions the definitions of "normalcy" and "high-functioning" by interrogating the complex relationship between mental problems and the construction of self. I connect her argument with Lorde who also criticizes the statement of "being normal" in accordance with social norms and comments on how illness integrates into a part of her identities.

- *The Diving Bell and the Butterfly* directed by Julian Schnabel:

This 2007 film is based on the French journalist Jean-Dominique Bauby's memoir[1] of the same name. Similar to the memoir, the film focuses on Bauby's life after a massive stroke that

[1] It is also worth mentioning that the original memoir was written in the 1950s (same period with Lorde's work) and that the film was produced during the same time as Wang's work (2005). Thus, these works not only share thematic similarities but offer us a view regarding how illness is perceived in the contemporary world.

left him with a complex medical condition called locked-in syndrome (a rare and serious neurological disorder). Since Bauby is almost completely physically paralyzed, but remains mentally normal, the film explores his changing understanding towards the disease and his attempt to redefine his identities. The film mixes elements in art cinema with a focus on practical issues related to illness. Locking inside the "diving bell", which is his own body, prompts Bauby to reexamine his previous experiences and to dive into his imagination as free as a "butterfly". Considering his condition is more extreme compared to Wang and Lorde's and his social identity as a white male in Europe, I use this film to compare and contrast with works by Lorde and Wang. In particular, I show how illness destructs one's self-construction while providing the three narrators peculiar positions for contemplation and reexamination of social norms.

Significance

With cross-genre analysis, my project explores the representation of illness in different forms of media. The emphasis on medium specificity expands current interpretations of concepts such as "gaze" and "representation" in the context of illness and trauma. Additionally, my project furthers an exploration of autopathography as a genre uniquely poised to combine medical and social models of understanding together and emphasize how illness can unsettle one's constructed selfhood. Connecting frameworks in multiple disciplines such as psychology, literary, media, disability, and STS, this research aims to deconstruct the binary between "objective" scientific accounts and personal stories with certain degrees of fictionality. Rather than placing autopathography in a secondary position or as supplementary to medical case studies, I emphasize that autopathographical works are of equal social value to medical journals.

In part, this is because autopathographical works carry artistic, social and clinical significance to patients, medical practitioners, and general readers/viewers[2].

[2] This understanding of illness memoir is co-constitutive with my personal engagement in medical communications. During my internship at Dana-Farber Cancer Institute, I was trained to pay particular attention to word choices and omit the word "cancer" as much as possible when conducting interviews with previous patients as it could make them recall unpleasant experiences. This practical work experience affirms the value in advocating autopathographical works considering the lingering, traumatic experiences of suffering and surviving serious illness as well as the importance of not keeping these experiences invisible.

Literature Review

> "Sometimes in a moment of déjà vu
> I forget where I am and my hands bleed
> into the bed and the bed bleeds into the wall. There are colors becoming other colors
> and it doesn't mean anything.
> This is always happening and we never notice."

(Espinoza)

In her poem "Sometimes in a Moment of Déjà Vu", Joshua Jennifer Espinoza reflects on her experience of having mental illness and recognizing her identity as a transgender woman. Combining poetic language with theoretical thoughts, Espinoza's writing can be used as both primary source for close-reading analysis and secondary source which helps us understand the traumatic experience caused by illness. Just as the French term "déjà vu" describes the feeling that one has lived through the current situation before, Espinoza prompts us to think about how one's physical fragility due to certain illness can be transformed to long term psychological trauma intertwining with one's identities. In this literature review, I examine how trauma caused by disease is understood by scholars across disciplines, and why first-person narration regarding trauma and is indispensable.

According to the National Institute of Mental Health, "Post-traumatic stress disorder (PTSD) is a disorder that develops in some people who have experienced a shocking, scary, or dangerous event." The use of the word "post" combined with the present perfect tense regards trauma as suffering in the past. In other words, though it has a consistent impact on one's current

life, the traumatic event itself is seen as an experience one suffered previously. This clear separation between past and present contrasts with Espinoza's writing that indicates bleeding is "always happening." I think the differences regarding how trauma is defined on an authoritative scientific website and how it is interpreted as a personal experience suggests the inadequacy of medical accounts.

As Esmé Weijun Wang notes in her book *The Collected Schizophrenias*, medicine is "an inexact science" (10) involving many factors that are not quantifiable. Yet the field of medicine involves not only the doctors but also patients themselves, whose bodily and psychological experiences should be valued. In other words, when communicating with patients, medical practitioners should consider them as holistic persons instead of patients defined by illness. The comprehensive understanding of an individual's experience with disease could enlarge the scope of medicine beyond its emphasis on the material aspects of patients' suffering.

This viewpoint is supported by the clinical pharmacologist Jeffrey Aronson. In his article "Autopathography: the patient's tale", Aronson points out case studies conducted by medical practitioners are "straitjacketed" by their "artificiality" (1) for their negligence of patients' perspective. To avoid simply relying on this mode of narration, Aronson promotes autobiographical narratives written by patients themselves. The term "autopathography" defined by Aronson not only establishes a contrast with "pathography", which has a clear reference to traditional medical accounts (1), but also emphasizes patients' subjectivity considering they are the narrators of the story.

The importance of using autopathographical works to foreground patients' autonomy resonates with Amanda Nettelbeck's argument, in her article "The Transfigured Body and the

Ethical Turn in Australian Illness Memoir". Nettlebeck draws on the "literal and symbolic" meanings of a medical waiting room in order to points out that an individual loses their control to the body as their identity transforms from a "person" to a "patient" (164). In other words, lying on the hospital bed, one is in danger of becoming objects to be operated on and to be carried by. Therefore, authopathography offers them a place to claim their subjectivity by narrating their personal experiences in dealing with illness.

Mindful readers may question the necessity of defining autopathography as a unique genre since its emphasis on first-person narration may also fit into autobiographical works. However, autobiography usually following a chronological order assumes a coherent form of selfhood throughout the entire work. In regard to the experience of illness, the transformation from being a "person" to a "patient" is significant in the narration. As Nettelbeck explains, unexpected illness has the power to disrupt one's "fixed" definition of "self" (164). In particular, severe disease challenges traditional binaries between normal and abnormal, abled and disabled. being ill makes an individual reconsider these "social assumptions" (164) and try to redefine their identities. Therefore, the definition of "autopathography" as a genre highlights disease's transformative power on one's identity construction. The distinction from autobiography suggests a challenge to linear narrative tradition and to the assumed coherent selfhood.

The struggle of re-creating one's identities and finding potential reconciliation between one's old self and the new "illed" body is a common theme in many autopathographical works (Nettelbeck 164). Though one may be physically recovered from illness, as the metaphor of "wound" suggests in Espinoza's poem, the experience of illness is traumatic and acts as a constant present that creates disturbance to suffer-survivors. Considering the inadequacy of trauma's scientific definition that suggests a chronological relation between trauma and its

impacts, I think introducing scholars from other disciplines can enlarge the concept of trauma and facilitate a comprehensive understanding of traumatic experience. The viewpoints by Patrick Duggan, a scholar in the Theatre and Performance Studies, may be helpful for us to understand illness as a traumatic experience. In the introductory chapter of his book *Trauma-tragedy: Symptoms of contemporary performance*, Duggan problematizes the usage of "post" in medical description and points out the "very present-ness of traumatic hallucinations" (23). He argues that trauma is the violation of "constructions of self and family that have been built up over many years of life experience", which "calls into question all which we might hold sacred, our understandings of safety and privacy" (28). Contextualizing his argument to experiences of illness, I think though being ill and recovering from diseases do not involve violent confrontation with external forces, but rather, might be seen as confrontations with internal weapons that continuously bleed one's wounds even if one physically recovers. In my close-reading section of the essay, I will expand on the connection between trauma and illness as well as how disease can be understood both physically and symbolically.

Many scholars consider illness itself as a potentially traumatic experience, and thus they investigate autopathographical works' therapeutic potentials in relation to the sufferer-survivors. For Duggan, works related to traumatic expression help narrators themselves "restore themselves" (5) because by constructing the work, they are simultaneously "acting out" their experiences and "working through" it (5). In other words, the process of creation becomes a part of self-exploration in understanding and re-constructing one's identities. Stephen K. Levine, a professor in Philosophy and Poetics in the Arts, Health and Society, echoes this viewpoint. In his book *Trauma, Tragedy, Therapy: The Arts and Human Suffering,* Levine regards artistic practice as not only a powerful way to respond to trauma but with potential for leading new ways of

living (40). Connecting to Aristotle's notion of catharsis, Levine argues that art has a cathartic potential and that its creativity facilitates the process of self-reintegration after traumatic experiences.

Levine's emphasis on the artistic quality of autopathography coincides with Aronson's viewpoint. By giving autopathography another name, "the patient's tale", Aronson blends artistic nature with illness as the theme (1) and makes a similar argument with Levine that creating this piece of art has therapeutic potential for patients. Nevertheless, I think the phrase "patient's tale" warrants critical examination: the word "tale" is evocative of folklore or fiction, and might suggest that patients' narratives have the potential of reaching audiences from various backgrounds. However, after defining autopathography as the patient's tale, Aronson immediately continues with an argument that only emphasizes the therapeutic nature of the work for patients themselves. The inconsistency in Aronson's analysis leaves an ambiguity in his argument regarding whether he considers autopathography as an art piece able to impact a wider range of audiences or solely as a practice with limited artistic quality during a psychotherapy treatment.

The question regarding whether there is a conflict between illness narratives' cathartic quality and its artistic value is mentioned by Williams in his research on graphic pathology. Williams defines this subgenre of autobiography as "the memoir of the artist's own disease of suffering" (353), and in this way, a type of autopathography. Williams interviews several novelists if they had some cathartic experience from making a comic book about trauma and records the diversity of these authors' responses. Nicola Streeten mentions the irony when considering the therapeutic function of the writing experience: though writing the book becomes a "symbolic act of leaving that part of life behind", when publishing it, Nicola has to spend the

following few years “talking about it more than ever before” (Williams 358). Differently, Gloeckner considers her writing process of “compressing chaotic entries in her teenage diary” into a “coherent story” has healing potential as it turns testimony “overwhelmed by occurrences that have not settled into understanding or remembrance” into “full cognition” and “events in excess of our normal frames of reference” (Williams 358). However, this emphasis on linear narrative seems to contrast with Nettelbeck and Duggan’s viewpoints which both argue that narratives about traumatic experiences disturbs linearity of time due to the one’s inability to separate recurrence of trauma to its original event. In my essay, I will further explore how illness narrative has a degree of tolerance of chaos and should not be interpreted in traditional aesthetic theory.

Another debate raised by seeing illness memoir as artistic creation is that if and how the editing and publishing impact the writer’s self-construction and memory, which relate to their process of healing. Many authors are not satisfied with the finalized version because there is a discrepancy between the published story and their true accounts of diseases as it hinders them from reconstructing their self-images and disturbs their memories regarding traumatic experiences. However, for Gloeckner, it seems that there is a possibility for reconciliation regarding the conflict between the “published graphic novel”, for example, and “therapeutic writing” (Williams 361-362). Instead of separating “fiction” from “real”, Gloeckner indicates that the expression of “emotional truth” and its ability to reach a wide range of audiences is more important and has the capacity of healing when she realizes her work can help others with their struggles (Williams 361). This view echoes Duggan’s perspective that as trauma itself blurs the boundary between reality and imagination, it would be fruitless for writers as well as readers to distinguish between truth and fabrication in the storytelling. In the analysis that follows, I

connect this argument with Aronson's suggestion on the balance between facts and fabrication. I emphasize that the notion of "truth" and "reality" are relative rather than absolute.

To sum up, compared with traditional medical journals, autopathography highlights patients' perspectives and their subjectivity. In addition, because of the traumatic nature of illness and its disturbance on one's self-construction, autopathography has the potential to help sufferer-survivors reflect their identities and provides potential for re-creating the notion of "self". However, there is still ambiguity regarding how this process takes place and whether the cathartic function is achieved on a metaphysical level or is a relieving process perceived by narrators themselves. Throughout this thesis, I discuss the healing process in detail by analyzing the characteristics of autopathography as well as how autopathographical works impact authors, people suffering similar issues, and general audiences. I show how this genre can be both personal and social by initiating public ethics discourse.

From “Person” to “Patient”

The Altered Self

A common focus in illness memoir is the discussion of pain related to disease. This pain can be either physical, psychological, or both simultaneously. Audre Lorde’s depiction of her “pain and terror” in *The Cancer Journals* explains how different types of “wounds” are involved and intertwined with each other in her experience with breast cancer: “it was very hard for me not only to face the idea of [my own fragile mortality], but to anticipate more physical pain and the loss of such a cherished part of me as my breast (40).” Different from medical journals with primary focus on one’s physical pain, Lorde reflects her illness as a social experience in which the notion of survival is complicated with the predictability of death and psychological burden of altered self-construction. Lorde’s experience can be seen as traumatic according to Duggan since having cancer, a disease sometimes without effective curable methods in current medical fields, forces one to “puts [their] life into question again and again” (Duggan 34). For Lorde, this destabilization is caused by the collapse of “physical and symbolic boundaries” between “death and life, illness and health, the infected body and its apparently healthy counterpart” (Tanner 116). To explain it, though death is unavoidable for every human-being, mortality as a perception of distant future is mostly understood as an abstract concept. However, the diagnosis of cancer materializes this imagination and transforms death into an imminent and unchangeable fact, which may take place in a few years or months**.** Sometimes the expected suffering can be more torturous because one’s inability to change their current situation is manifested in their everyday life. This idea may remind us of the etymological connection between the word “fate” and “fatal”: a situation can be “fatal” (Oxford English Dictionary), extremely desperate, when one realizes their inability to change the doomed fate. Here, in association with death, fate is not an

abstract concept but becomes a tangible image indicating one's "fragile mortality" (40) and suggests their incapability of taking actions to escape.

As the journal unfolds, Lorde further explains different forms of struggles that create traumatic experiences. She points out the distinction between anxiety and fear, noting that fear is a constant emotion she continues to deal with concerning the potential reoccurrence of another cancer, while anxiety is an "immobilizing yield" and a "surrender to namelessness, formlessness, voicelessness, and silence" (14). The emotional response of anxiety ties to the "literal and symbolic assaults on autonomy" of being ill and placed in a hospital which limits one's action (Tanner 117). One example would be Lorde's reflection on her physical change after mastectomy. Describing the breast as a "cherished part of [her]", Lorde indicates how the corporeal body shapes one's self-construction. After the surgery, when looking into the mirror, she uses words "awkward" and "wrong" to describe her changed body which she considers as having "nothing to do with any [her] [she] could possibly conceive of" (44). If Lorde's previous reflection on her pain in dealing with breast cancer indicates how illness blends physical wounds with psychological struggle, then this narration points out the association between physical loss and the damage of self-construction. Though breast usually is tied to sexuality and considered as a representation of femininity, Lorde's sentimental feeling of the loss of her breast does not suggest her self-association with traditional gender expressions. Instead, she perceives the breast as a material existence that interacts with the construction of selfhood. [3]

We should also be cautious while exploring the transformation of selfhood in autopathography. Many scholars, especially those influenced by deconstruction and poststructuralism, criticize the epistemological and ontological status of self as an illusion

[3] The concept of selfhood and its connection to ontological reality will be discussed later in the essay.

constructed by dominant ideological apparatuses. In Lorde's experience, her discussion of the mastectomy does not suggest her agreement towards the existence of an unified identity. Instead, from my perspective, the alteration of her body complicates contemporary discourses of subjectivity. While human experiences can not be validated as "real" but representation of reality, I do not think Lorde's sense of loss post-mastectomy should be considered as mere illusion. Her experiences of physical loss intervenes the discussion of ideology and subjectivity by scholars, which is mostly on a theoretical level, and promotes a nuanced understanding of embodied selfhood. The transformation of selfhood does not presume the existence of a singular identity neither before nor post surgery. Instead, considering being ill as a traumatic, social experience, we may reflect on the notion "self" discursively by noticing the relation between material and psychological construction of the body and the dynamic between patients and doctors in medical settings. For example, Laura Tanner explores how the medical waiting room could limit one's autonomy by placing them as "patients" in fixed positions. The hospital's architectural design both physically and symbolically limits an individual's activity: lying on the hospital bed and being transitioned to the operating room, a person loses their social identities[4] and is viewed as an object to be acted on. Lorde's discussion of mastectomy contextualizes this argument: she experiences a sense of powerlessness because of the inability to control her body and physical appearance. The hospital degrades her to a body waiting to be performed by doctors. In other words, the loss of self should not be simplified to an inconsistency of two identities pre and post surgery. Instead, it connects to a reconstructed power relation between medical practitioners and

[4] By using the plural "identities" here, I aim to highlight that I do not support the assumption of an essential unified selfhood. Instead, in this context, I am alluding to social roles a person usually uses to refer to themselves and their freedom of defining or embracing different identities outside of medical settings.

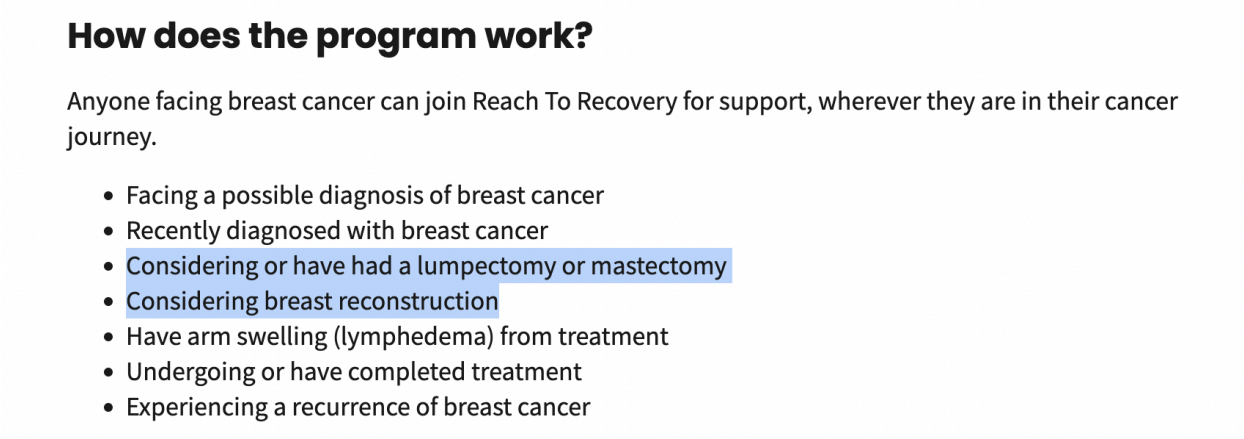
patients, which further emphasizes the thesis's argument that illness is a comprehensive social experience.

Critique of Prosthesis

Though illness and mastectomy alter one's embodied selfhood, Lorde emphasizes that attempts of hiding the wound to pretend to be the older self would only further the sense of alienation. Her viewpoint can be contextualized in her critique of the advocacy of prosthesis. Two days after her surgery, Lorde had a visit from a woman from the Reach for Recovery who has also survived breast cancer, both wearing a prosthesis and suggesting Lorde to put one on as well. Before delving into her critique of the prosthetic breast, Lorde disagrees with the level of priority for women post-mastectomy concerned by medical practitioners. In particular, after surviving serious illness such as cancer, she points out that she expects more guidance on the recovery process and how to avoid future recurrence instead of the reconstruction of the breast.

This critique also sheds light on the caring system post surgery nowadays. The screenshot below belongs to the introductory section of Reach to Recovery's website. From the first three bullet points "facing a diagnosis", "recently diagnosed", and "considering a lumpectomy", we could conclude that the page follows a chronological order regarding people's issues in dealing with breast cancer. However, as I highlighted in blue mark, what follows having a surgery is not advice on recovery but those on "breast reconstruction". This sense of urgency in reconstructing breasts, as Lorde points out, not only neglects survivors' real need and concern for future prevention but degrades the serious illness to a mere cosmetic concern. It should be noticed that neither Lorde's narration nor this manuscript tries to criticize institutions such as Reach to Recovery for having malignant purposes. Instead, this unconscious emphasis on physical

appearance reflects social norms imposed on women. The immediate need to preserve one's embodied "femininity" suggests that "beauty" is not a choice for women but a chain imposed on women by disguising itself as a part of "social normalcy."



How does the program work?

Anyone facing breast cancer can join Reach To Recovery for support, wherever they are in their cancer journey.

- Facing a possible diagnosis of breast cancer
- Recently diagnosed with breast cancer
- Considering or have had a lumpectomy or mastectomy
- Considering breast reconstruction
- Have arm swelling (lymphedema) from treatment
- Undergoing or have completed treatment
- Experiencing a recurrence of breast cancer

The screenshot above belongs to the introductory section of Reach to Recovery's website.

In addition, as we discussed in the previous section, Lorde's sense of loss is not only physical but psychological. In other words, mastectomy and the experience of surviving cancer challenge her self-perception and force her to reconsider her identities. However, the recommendation of wearing a prosthesis, especially introduced to her after just two days of the surgery, gives Lorde no time to reflect on her "selfhood" and the connection to her altered body. Instead, it tries to hide the difference and deny Lorde's change both physically and symbolically.

From my perspective, the woman from Reach For Recovery, recommending the prosthetic breast and saying that "you'll never know the difference" is ironic: though the prosthesis is designed and worn to conceal the differences of one's changed body after surgery, the action of wearing it reminds the user's the wound they want to hide and even make the differences after surgery more obvious. The irony inside prosthesis echoes Lorde's commentary on the woman's prosthesis: admittedly she could not tell the differences, but "both breasts [of the

woman] looked equally unreal to [her]" (42). In other words, prosthesis prevents women from recognizing their changed body and makes them "remain forever alien to [themselves]" (44).

Nuanced Differences regarding Types of Serious Illness

The painful experience caused by illness can also be found in *The Collected Schizophrenias* by Esmé Weijun Wang. Suffering from schizophrenia, she has been "psychically lost in a pitch-dark room" (4). This sense of loss does not only relate to her inner psychological struggle but is entangled with the social perception of mental illness. Connecting to the characteristic of traumatic experiences in which a person's life is "put into question again and again", we can interpret Wang's expression of senselessness as the deconstruction of her individuality in relation to the interplay of psychiatric predicament and social stigmatization. Wang's encounter with a woman at a writer's residency can address this point: after hearing Wang sharing her educational experiences at Yale and Stanford and appreciating her "good face and good outfit", the woman comments that "you don't seem to have those … tics and things" (54). If the woman's reluctance of using the phrase "mental illness" suggests the negative social implication of having mental problems, then her negation of Wang's illness based on Wang's intellectual ability and physical appearance suggest how mental illness ties to one's identity construction. This association further demonstrates that a mental disorder such as schizophrenia is not just an objective notion defined by the *Diagnostic and Statistical Manual (DSM-5)* but a traumatic experience shaped by social norms and stereotypes.

The internalization of mental illness as a component of one's identity is also emphasized when Wang talks about the selections of language in addressing mental health problems:

> "In the language of cancer, people describe a thing that 'invades' them so that they can then 'battle' cancer. No one ever says that a person is cancer, or that they have become cancer, but they do say that a person is manic-depressive or schizophrenic, once those illnesses have taken hold (70)."

This depiction points out the nuanced differences between physical and mental illnesses. The saying that someone "is schizophrenic" interprets mental disorders as intrinsic qualities of the sufferers and suggests a value judgment to people with these issues. Wang's interrogation of the language in reference to people with mental disorders suggests the pervasive public stigmatization and confusion in understanding mental health problems.

To tackle this problem of addressing mental health issues, Wang mentions that in her peer education classes, she was taught to use "person-first language": instead of the statement that "she is schizophrenic", the saying that she is a person "with schizoaffective disorder" seems to express the subtlety of mental illness in a better way. However, as Wang points out, this "person-first language" suggests that there is a normal-functioning person "without the delusions and the rambling and the catatonia" in one's consciousness (Wang 70). This attempt in separating the "mad" self from the "normal" one suggests our continued emphasis on humans as rational beings and an assumption of the essential existence of a "healthy" and "abled" core . It also complicates the definition of "illness" regarding mental health: not only defined as a physical problem, but mental disorder also suggests the pathologizing of one's psychic state, which is inseparable from the constructed social norms. Wang's autobiographical writing sheds light on a rework of defining mental health problems which critically and dialectically consider the meaning of "health".

The dichotomy between material body and psychic state is complicated by Bauby's experience articulated in the film *The Diving Bell and the Butterfly*. As the metaphorical meaning of "butterfly" suggests, being completely paralyzed gives Bauby an opportunity to indulge in his mind and escape his physical "diving bell". However, from the film, we can also argue that his physical immobility positions him as an audience in the world in which he can only watch others' actions and reflect on but not be able to intervene. In other words, his physical body influences his perception of the world, which can be seen as an estrangement from traditional Cartesian thinking. The narration from Bauby and Wang both skepticism towards the separation between mind and body. Levine's notion "receptivity" that describes survivor-suffers' experience of trauma sheds light on this issue. Levine suggests that besides the conscious ego there is a productive shaping in the process of perceiving. This shaping, he explains, "is not done by the conscious ego but [can] nevertheless take place (40)." Thus, we may say that it is possible that mental health issues have "receptivity"[5] that shapes one's experience and constructs a part of one's individuality. Therefore, people should not be degraded by mental health issues since insanity is not the proper word to depict their states. In other words, instead of separating

[5] Questioning Cartesian conception that "human subject as being defined by consciousness", Levine argues that though the survivor-sufferer is unable to remember and shape the traumatizing event, they are not in the absence of this experience (39). He develops the notion "receptivity" to describe survivor-suffers' experience of trauma: as a third term between activity and passivity, "receptivity" can be interpreted as "active passivity", which is "an experience that happens without the ego's knowledge and control" (39). Thus, for the theory of trauma, Levine rejects the emphasis on survivor-suffers' coherent subjectivity and proposes that we only need to find appropriate ways to respond to it. His argument ties to his support of post-Cartesian thinking that we are "able to conceive of [this kind of experience] without an ego (40)."

the ill crust from the assumed "impeccable self" (Wang 70), we should avoid potential pathologization and view people with mental health issues as holistic human-beings.

Lack of Diagnosis as "Prosthesis"

Besides the controversial debate between body and mind separation, in Wang's experience dealing with schizophrenia, we can find that sometimes medical practitioners deliberately hide the relatively more accurate definition of mental issues from patients as they believe that this concealment could protect patients from further social marginalization. Wang tries to explain the rationale of her first psychotherapist, Dr. C, who chooses to describe her condition as bipolar disorder rather than diagnosing her with schizophrenia in order to preclude stigmatization. The therapist's reluctance to diagnose Wang with schizophrenia is more obvious if we read between the lines of the therapist's letter to Wang: "I think you may have schizoaffective disorder - a slightly different variant than bipolar I (7)." The phrase "a slightly different variant" can be considered as an alternative expression or euphemism to schizophrenic disorders. However, this attempt to make Wang's mental issue seemingly less threatening does not comfort Wang or reduce her symptoms. Rather, the discrepancy between the depiction of bipolar disorder and hallucinations she is experiencing confuses her and furthers her feeling of the sense of "loss" (6). Wang's frustration echoes Lorde's reflection of her experience with breast cancer regarding the lack of visibility:

> "And yes I am completely self-referenced right now because it is the only translation I can trust, and I do believe not until every woman traces her weave back strand by bloody self-referenced strand, will we begin to alter the whole pattern (11)."

Since language as a referential system is supposed to sustain the signifying process, I think Lorde's phrases "self-referencing" and lack of trusted "translation" establish a comparison between language and social structure. In other words, the inadequacy of representing different patterns and components in the current linguistic system exemplifies the invisibility of marginalized groups because of social hegemony. In this sense, I argue that the lack of appropriate diagnosis in Wang's situation shares similar metaphorical function with the advocacy of prosthetic breasts in Lorde's narration. As prosthesis suggests a denial of Lorde's transformed selfhood post-mastectomy, the therapist's refusal to make appropriate diagnosis in Wang's case unsettles Wang's self perception. Like Lorde, Wang is unable to articulate her frustration. In other words, Dr. C's choice of using alternative phrases to avoid diagnosing Wang with schizophrenia adopts a similar mindset with the advocacy of prosthesis post-surgery: both are artificial constructs designed to hide one's altered appearance, physical and mental, internal and external, after illness. Identifying with "a slightly different variant" disorder has similar social functions compared with wearing a prosthetic breast: both mask differences and perform a sense of normalcy while simultaneously generating further alienation pertinent to self-perception.

Wang's situation can be contextualized with her argument that a diagnosis is more "comforting". Contrary to her therapist's expectation, Wang points out that a diagnosis is more "provides a framework-a community, a lineage" (5). In other words, even a potentially stigmatizing diagnosis actually enables Wang to more fully understand herself and situate herself

in relation to others with schizophrenia, both throughout time and in community. Wang explains that though the diagnosis says she is "crazy" it also suggests that she is crazy "in a particular way" (5). By naming the struggles she is experiencing, a diagnosis helps her form a better self-perception and even provides possible ways for healing. In addition, it creates a sense of belonging for her to integrate into a community with similar sufferings. It is worth noting that at the beginning of her first chapter, Wang uses "we" to describe the impact of schizophrenia on people. This choice of the subject of the sentence combined with the word "collective" in the title of her book suggests that instead of "wearing" a prosthesis, forming a collective narrative to address the sufferings of people with the schizophrenias and [their] tormenting minds" (4) is a more appropriate approach to relieve suffer-survivors' struggles and pressure.

The importance of understanding and articulating one's illness is further explained by Duggan. In his theory "trauma tensions triangulation", Duggan points out that since the original event related to trauma is absent from the survivor-sufferer's memory because of its violent destruction to oneself, they tend to forget the event. However, because of the "repetitive and uninvited intrusions of the fragmented memories of that event", survivor-sufferers also have an "overwhelming need" to speak about trauma in order to comprehend and finally move beyond it (Duggan 26). In other words, the inability to trace the original trauma-event makes the expression and representation of trauma have therapeutic functions for survivor-sufferers as they can better comprehend trauma-event as well as trauma-symptoms. For Wang, diagnosis can be seen as one way to represent her suffering as it to some extent undermines the degree of her "madness" and suggests that there are possible treatments to improve her situation. What is more, the categorization that the diagnosis enables Wang to feel that she is represented by others since people under the same diagnosis share similar symptoms and traumatic experiences.

Though classification implies boundaries and limitations, it increases visibility of the group by providing eligibility. That is to say, diagnosis provides Wang a pathway to acknowledge and address her sufferings. Thus, diagnosis has a metaphorical function of affirmation and understanding. Wang's sense of relief after being diagnosed should not be interpreted only as a support of the naming of diseases but as an advocacy of finding, developing, and placing more emphasis on the collective expression of storytelling which raises awareness of traumatic experiences in dealing with illness.

Seeking Collective Narratives

The desire to be represented can also be found in Lorde's narrative. Defined as "other in every group [she is] part of", Lorde mentions her difficulty in finding models for "what [she is] supposed to be in [facing cancer]" (28-29). The lack of role models in Lorde's experience coincides with Wang's inability to find predecessors before she was diagnosed with schizophrenia. It should be noticed that both authors' search for role models does not suggest that they want to find someone with the same identities as them. Though they are marginalized by dominant social groups, they do not try to reverse the power relation since the advocacy of an opposite position would still limit itself in the existing hegemony. Instead, they advocate for a recognition of diverse identities that do not fit into a singular social code.

Both of their struggles can be understood through an intersectional framework[6] that illuminates how Lorde and Wang are positioned at the intersection of marginalization and

[6] Kimberlé Crenshaw points out "intersectionality is a lens through which you can see where power comes and collides, where it interlocks and intersects." In other words, it "helps us see, predict, and interact with the pre-existing structure" ("Intersectionality Matters" 37:03).

stigmatization: for Wang, the "model minority myth" that connects Asian students with high-functioning gives her more stress to reconcile with herself and to talk about her experiences to her family and friends; for Lorde, the "cosmetic sham" (16) among women due to dominant values in the patriarchal society impose "silence" (9) to women suffering from breast cancer to share their experiences. Thus, her words below can be seen as a courageous attempt to address the impacts of breast cancer:

> "For months now I have been wanting to write a piece of meaning words on cancer as it affects my life and my consciousness as a woman, a black lesbian feminist mother lover poet all I am. But even more, or the same, I want to illuminate the implications of breast cancer for me, and the threat to self-revelation that are so quickly aligned against any woman who seeks to explore those questions, those answers. Even in the face of our own deaths and dignity, we are not to be allowed to define our needs nor our feelings nor our lives. (25)."

Many sufferers from breast cancer have the tendency to make their differences invisible. Thus, the conflict between their imagined selves as the ones before having mastectomy and new physical selves with prosthesis increases their inner struggle and prevents them from "revealing" their experiences to others. In this way, breast cancer becomes a subject forbidden to talk about, and sufferers are socially and psychologically separated from each other. This lack of public narrative even makes the experience more painful and traumatic when a person has to deal with it since they are not only forced to face death but confront it and make decisions alone. Considering the obstacles one may face in dealing with serious diseases due to their identities,

we might say that Lorde's emphasis on developing more works that address the commonality of suffering has a therapeutic function for both the artists themselves and people sharing similar experiences. Her legacy of producing autopathography to increase visibility of women suffering from breast cancer not only emphasizes the social pressure imposed on them beyond physical pain, but also serves as a resistance to social hegemony. By sharing her experiences of refusing to wear prosthetic breasts in her journal, Lorde interrogates the demand of singular physical appearance imposed on women and challenges social hegemony that sexualizes women by tying breasts to the representation of femininity.

Medium Specificity in Making Sense of Illness

Though the word "autopathography" has its self-referencing nature to autobiography, which are mostly composed as written pieces, with its emphasis on the social experience of medicine and illness, autopathograhical works can take in various forms. The variety of autopathography's narrative possibilities can tie to its healing potential for authors: suffering from serious illness as a traumatic event violates "constructions of self and family that have been built up over many years of life experience" and "calls into question all which we might hold sacred, our understandings of safety and privacy" (Duggan 28). In other words, in the moment of its occurrence, the sufferer-survivor is only concerned with surviving the event rather than understanding it" (Duggan 26). Though this experience of temporal blanking during the event can be seen as a self-protection mechanism, the revisit of traumatic experience after a period of time can bring sufferer-survivors with accumulative disturbance. As Duggan points out, the "impossibility of assimilating the event as it happens" makes it even more "real" than the event itself to survivor-sufferers when they try to imagine and reconstruct the event (25). Thus, autopathography and the process of composing it provide them an opportunity to form a narrative of their illness experience. In other words, autopathographical works help narrators "restore themselves" because by constructing the work, they are simultaneously "acting out" their experiences and "working through" it (Duggan 5).

The term "autography" coined by Gilian Whitlock sheds light on our discussion on the narrative forms of autopathography. As a "specific conjunctions of visual and verbal text in the genre of [comics] autobiography", it is used by a few artists to process "the traumas of their lives" (Williams 355). The deliberate use of "white spaces or gutters" to separate the visual from written pieces explicitly reveals the self-constructed nature of the story. Nevertheless, this

artificiality of comic strip can be suitable for artists to generate autopathographic works: it gives artists more freedom for not "[making] any grand claim for truth" while using the portraiture of their self-image to deliver a sense of honest emotional truth to the reader (Williams 356).

The paradox between audiences' awareness of the performance and the emotional experience of embodied reality can also be found in other media. For example, Duggan proposes that "theatre seems uniquely suited to portray the complex realities of trauma" (30). He explains that the interaction between actors' action and audiences in a live performance may generate more immediate emotional response from audiences. The interplay of audiences' immediate sensory experience and actors' actions. correlates with the complexity of traumatic experiences which are neither truthful accounts nor representations of the original trauma-event.

Duggan's emphasis on the interactive and performative potential of theater in the expression of traumatic experience promotes me to investigate cinema and its nuanced differences compared with theater since it is a more modern invention and more frequently used in contemporary artistic creation. Invented as a way of recording, the camera distances itself from audiences, and thus the film is usually considered as something that happened in the past or in a fictionalized setting while creating the illusion of likeness. Since the film camera usually imitates human's eye movements to make it easier for audiences to follow (take the 180-degree rule as an example) and sounds are reference of photographic images to enhance the constructed unity, audiences can experience a sense of realness when they are watching the movie. Different from theatre with "variability of each performance", audiences can experience a paradoxical feeling in cinema: the film's manipulation of various components in its construction creates an illusion that they can feel the events first-hand, while simultaneously aware of their artificiality reminded by the fixed mise-en-scene. Thus, it is paradoxical for interrogating the efficacy of

composing autopathography in cinematic form: though a film attempts to represent traumatic experiences with more accessible devices, it simultaneously interrupts the sufferer-survivor's self-expression because of the intervention of these technologies.

Another difference between theater and cinema is the degree of manipulation in the profilmic events. Unlike the theatrical stage on which actors can adjust their performance during each act, a film can be tailored in specific ways in accordance with the director's preference. During the French New Wave Movement, for example, auteur theory proposed that the camera was a "cinematic pen." This proposal linked film directors to literary authors, and suggested similarities across their processes of signification. This theory rejected the traditional film industry's form of studio projection, and instead suggested that the director was the major force of cinematic creation and that cinema is not just a recording of theatrical performance but has unique artistic expression. As this theory highlights, similar to writers of literary works, directors have dominant control over film production. However, because autopathography centers on the embodied selfhood of the suffer-survivor, we may wonder if films influenced by the auteur theory can generate a gap in the traumatic expression due to the intervention of directors. That is to say, this artistic creation with the director as the driven force may be in danger of hindering the survivor-sufferer's self-expression compared to books for which authors themselves are those experiencing traumatic events. Alternatively, the director as another mediator may facilitate the narration of the suffer-survivor's experience. With their expertise in the use of cinematic devices, the director can potentially further enhance the emotional connection between the sufferer-survivor on-screen and audiences. For example, directors could adopt specific cinematic techniques such as montages and selections of shots to promote audiences' imagination while leaving them spaces for reflection.

The Diving Bell and The Butterfly as Autopathography

With its cinematic style inherited from the French New Wave, the film *The Diving Bell and the Butterfl*y exemplifies this paradox in the traumatic representation using cinema as a medium. Directed by Julian Schnabel, this 2007 film is based on the French journalist Jean-Dominique Bauby's memoir of the same name. Similar to the memoir, the film focuses on Bauby's life after a massive stroke that left him with a condition defined as locked-in syndrome. Also known as "pseudocoma", it is a condition in which "patients remain aware and alert but are not able to communicate verbally or by gesticulation" (Dudzinski 34). Different from Bauby's physical body trapped inside a "diving bell", his mind and imagination are as free as "butterfly". By blinking his left eyelid, which is the only part of the body he is able to move, Bauby points out letters to an interlocutor and completes his memoir. The film can fit into the genre of autopathography since it narrates the story from Bauby's perspective. Instead of emphasizing the patient's paralyzed body and trying to arouse audiences' sympathy with the risk of objectifying the suffer-survivor, the film centers on Bauby's self-expression with its unique cinematography. Audiences could track Bauby's emotional instability and his fluid subjectivity with selections of shots and montages that externalize his inner psychology.

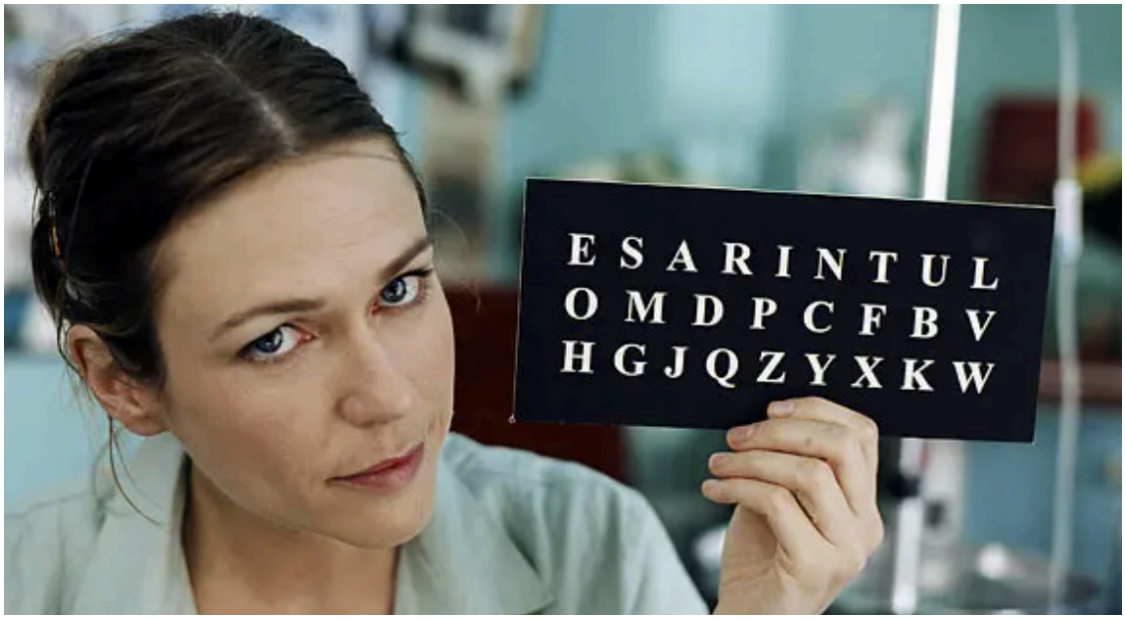
Considering Bauby's peculiar writing experience, we may find the film can more effectively recognize his laboring process in comparison with the written memoir. Though readers know the difficulty Bauby experienced to compose the book, our speed of reading may create an inconsistency with his hardship of writing: although Bauby "writes" in an extremely time-consuming way, blinking his left eye as his therapist read a list of letters to spell out his messages, readers may actually find the writing easy to follow or even skim the text. Thus, even though the memoir is written from the first-person perspective, readers may be unable to feel the

toughness Bauby experienced. Or, it may take some time for readers to attach themselves to Bauby and find how the effort he spent in the process of creating the memoir is integrated in the writing itself.

Comparatively, the film allows us to build a sense of intimacy with Bauby at the beginning of the movie: the shaky camera combined with the blurry images when the film starts hint us that we are seeing from Bauby's perspective. The use of extreme close-ups with shallow depth of field displaying the doctor' faces unsettle audiences by delivering a sense of being looked at as an individual and potentially being acted upon as a body. We may not normally sense this kind of intimidation as the spectatorship we experience on a daily basis do not explicitly manifest the division of power relations. To some extent, we may say that the film provides a more comprehensive representation regarding Bauby's traumatic experience compared to the written memoir: the scene that captures Bauby's speech therapist reciting the alphabet by frequency to him recognizes the contribution of other "actors" (his therapist and the alphabet[7]) in the process of composing his autopathography; the cinematic camera functioning as an externalization of his inner thoughts makes him be able to engage with the outside world and audiences outside the screen. In this case, we may consider the alphabet and camera as prosthetic devices since they extend Bauby's physical capacity and function as his additional body parts[8]. Compared with Lorde's critique of prosthetic breast, Bauby's association with it both physically and symbolically complicates our theorization of prosthesis: its inherent artificiality may not function as a hindrance to self-construction. Instead, it is able to facilitate one's artistic

[7] See the image below.
[8] The viewpoint that camera functions as an extension of one's physical body is mentioned in *Man With a Movie Camera* (1929).

expression by building emotional connections with audiences and generating a feeling that "the other's lifeworld can viscerally become [their] own (White)".



Bauby's speech therapist uses an alphabet by frequency to communicate with him.

Self-Perception and the Medical Gaze

The selections of shots combined with camera movements allows audiences to see from Bauby's viewpoint rather than looking at his visage. This use of first-person point of view enables audiences to further understand Bauby's suffering without victimizing him.

Instead of using a full shot to show Bauby's physical condition, the camera chooses to frame another paralyzed person lying on a movable bed (00:25:26). The diegetic sound of the moving hospital bed combined with restricted view furthers audiences to engage with Bauby's worldview. The nurse's saying that "the thing is broken, and I mean his legs" with the full shot of this paralyzed person effectively connects his condition to that of Bauby. The cinematography also emphasizes this association: as nurses gradually move Bauby away from the paralyzed

person, the camera, which represents Bauby's vision, continues to focus on him. Staring at him can be a way for Bauby to understand his physical condition. In other words, this person serves as a mirror in which Bauby rethinks of him and his connection to his own body with locked-in syndrome. In addition, the image as well as the nurse's vague description of the paralyzed person's situation create a sense of ambiguity. Though this full shot hints us that this paralyzed person shares similarity with Bauby regarding their physical immobility, the degree of likeness between Bauby and the paralyzed other is unknown to both audiences and Bauby himself. This visual logic suggests the uncertainty in seeing oneself through the image of others, which echoes Levine's viewpoint regarding the complexity of trauma and its representation: despite the similarity between the representation of the other and the sufferer-survivor's own condition, the true image of the self is not accessible to the person themselves. When it comes to traumatic experiences, which disrupts linear time and self-construction, one is only able to grasp a general sense of their shifted situation hinted by external sources without knowing the exact changes and how they would affect their social identities.

The scene which portrays Bauby's transition from his room to the hospital's public space also suggests his spatial entrapment because of his locked-in syndrome. As Tanner points out, the medical waiting room limits a person's mobility by placing them in fixed positions. Their subjectivity is endangered as they are unable to navigate the space but is physically immobilized in their places[9]. Bauby's locked-in syndrome even furthers this sense of configuration since his entrapment is both physically and symbolically. In other words, if the hospital room hinders patients' mobility by its structural designs and rules, then Bauby's disability intensifies this loss.

[9] Michel de Certeau differentiates the notion between "place" and "space" in *The Practice of Everyday Life* (1984): while "place" implies a stable configuration of positions, "space" is composed of "intersections of mobile elements." In other words, "space is a practiced place."

His corporeal body, the hospital bed, and the room interplay with each other physically and symbolically, creating a triple-layered "diving bell" that puts his autonomy at risk. Thus, in regard to the use of cinematography, its choice of avoiding displaying Bauby's full body image is a refusal to further the objectification of Bauby due to his locked-in syndrome and the hospital code of setting. If audiences could see the exhibition of Bauby's paralyzed body, then they would be complicit with doctors and the hospital structure, co-constituting the medical gaze. This deliberate selection of shot contextualizes Levine's imagination of new "artistic forms" to represent human suffering (19). Levine's viewpoint of avoiding direct representation of human suffering echoes the film's approach that makes an effort to not victimize Bauby as an object lying on a hospital bed and carried by nurses lacking subjectivity. In other words, audiences' sympathy can also be originated from a privileged position since their compassion is generated from inherent comparison between an abled and disabled body as well the body's connection to productivity. Therefore, rather than seeing Bauby as an object on the movie screen, audiences are able to be empathetic with him by seeing him sensing and contemplating the world. Connecting to the title of the film, I interpret the camera functioning as the "butterfly" with mobility that actualizes Bauby's "traumatic imagination" (Levine 19) and helps him escape the multi-layered "diving bell".

The full shot shows another paralyzed person, which can be a mirror of Bauby's physical state (00:25:26).

The sense of endangered embodied subjectivity is furthered when Bauby is moved by medical practitioners from the bed to the bath. The shaky camera only allows audiences to see the ceiling, which successfully imitates Bauby's limited sight. The swinging ceiling from Bauby's point of view is different from "the traditional conventions in narrative cinema" which enables us to see a broader world compared to what our eyes capture in daily life (Laine 297). The cinematic eye here forces us to accustom ourselves to the sense of dizziness that Bauby continues to experience. This alternation of worldview only suggests a different perception perspective without suggesting the abnormality of Bauby's vision due to the locked-in syndrome. Then, the diegetic sound of water and insert shot of Bauby's wobbly moving foot makes us

realize he is being washed by the nurses. If the discontinuity between different spaces suggests Bauby's inability to move his body, then the medium shot of the nurses connects his physical disability to a sense of powerlessness (00:25:47). The low angle shot of several nurses standing around contrasts with Bauby's position of being placed in the water and indicates that nurses, with normal healthy bodies, are seen as powerful and strong in the eye of a paralyzed person. Their eyes staring at Bauby combined with the voice "turn him around" even create a scary effect and makes audiences feel intimidated (00:26:01). To explain it, because all "voluntary speech and movement are impossible", Bauby becomes an object that can be moved by others (Dudzinski 34). Water in the bath generates a similar sensory experience to the montage of the diving bell under the sea shown before (00:25:00): physically, he can be drowned in both flows of water without other's assistance; symbolically, both the bath and the diving bell are prisons that trap him in.

The film expands this sense of powerlessness by connecting physical entrapment with psychological struggle. As Bauby is washed by the nurses, the monologue goes on, saying that "I am forty two. They are washing me like a big baby." This narration connects our definition of "tragedy" in everyday life and that in works of art: while Bauby's suffering is caused by locked-in syndrome, which is "an actual occurrence" of a tragic event, his inner psychology externalized by the monologue relates to the collapse of one's self-perception (Eagleton 14). The identity as a "baby" in a hospital contrasts intensively with his previous roles as a middle-aged man taking care of his family and as the editor of a popular fashion magazine. The close-up shots of the nurses' hands on his motionless legs and arms further this sense of helplessness (00:26:23). Without a full shot of Bauby, only showing the different parts of his body suggests that in the nurses' perspective, he is only an object that needs to be cleaned or a task that needs to

be completed. The medical practitioners' gaze and actions on his body can also be interpreted metaphorically. Combining the plots about his relationship with his wife and mistress, we can portray him as a powerful male character that usually takes charge of others. Thus, the gaze from the nurses that objectifies him violates his assumed and accustomed social roles. This reversal of power relations drives Bauby to reconsider his identities and form new self-perception. Bauby's traumatic experience reinforces the sociological perception of illness proposed by autopathographical narration: disease not only degrades his physical mobility but destructs his social identities as an accomplished and capable man.

As this essay discussed above, though the film attempts to make audiences empathize with Bauby regarding his powerlessness, it does not highlight his physical vulnerability to arouse audiences' sympathy. Instead, it tracks Bauby's gradually transformed self-perception and how he decides to "never feel sorry for [himself] again" (00:40:41). The change of point of view echoes his shifted inner psychology. When Bauby realizes that his imagination and memory are not paralyzed, the film uses a full shot that allows audiences to see Bauby in a wheelchair for the first time. Compared with the scene which Bauby shouts in his inner mind saying that "put the mirror away" while seeing his warped mouth, this full shot suggests that Bauby accepts his physical state because he finds a way to "liberate" himself from the "diving bell" (Laine 296). The sequence of montages fading in externalizes his imagination. Different from previous parts of the movie that uses dim colors, the montages have saturated bright colors that indicates Bauby's changing of emotion. The insert shot of a butterfly flapping its wings serves as a visual cue for spectators to follow in the scenes changing from shrub to cliff, desert to sea, and modern days to the ancient past (00:41:22). The quickly moving images echo Bauby's free and roaming mind. The use of cinematic techniques facilitates Bauby's artistic thoughts. Connecting to this

essay's viewpoint of seeing a camera as a prosthetic device, I think the prosthesis in this case does not hinder self-expression. Instead, it assists Bauby's self-exploration and frees him from the diving bell immobilizing him.

The establishing shot firstly shows his full image (00:40:41).

Though Bauby gradually shifts his mind in response to the dramatic physical change and accompanying alternation of social perception, at first, he is reluctant to accept his sudden disabling. The mirror image of his wrapped mouth combined with his externalized inner thought "put the mirror away" addresses this point (00:27:32). Though he is angry with the mirror and unwilling to try to move his tongue, he is unable to control his body or express his thoughts. The extreme close-up of Bauby's mouth opened by the therapist's hand is striking (00:27:49). His forced opened mouth highlights his lack of body autonomy and his inability to express himself without the therapist's assistance.

The extreme close-up of Bauby's mouth, forced to be opened by the therapist (00:27:49).

In addition, Bauby's distorted mouth reflected by the mirror can create an unsettling effect for audiences. Connecting to the "mirror phase" in one's childhood defined by Jacques Lacan, the image in the mirror is crucial for the constitution of the ego. In other words, because of the lack of motor capacity, the mirror image is considered as the "ideal ego" imagined by children (Mulvey 1174). Since a child's "physical ambition outstrips [their] motor capacity", they imagine their mirror image to be "more complete, more perfect than [their] experiences [their] own body" (Mulvey 1174). With the structures of fascination, one's perceived "self" interplays with the "misrecognized" mirror image, which is constituted as the "ideal ego" superior to the body (Mulvey 1174). Bauby's locked-in syndrome and his self-comparison with a baby while being washed echoes Lacan's psychoanalysis since his embodied selfhood is inconsistent with his changed corporeal body. His reluctance to face the mirror indicates how the stroke creates traumatic experiences and deconstructs his self-identities. The images of his warped mouth

"penetrate his consciousness like uninvited intruders" (Laine 296) and compels him to accept the fact that he is no longer who he was due to locked-in syndrome. Since we are seeing from Bauby's point of view, the mirror not only reflects Bauby's physical condition but reveals a discrepancy between one's imagined self and the corporeal self-seen by others. Comparing the emotional stimulation this scene generates with that of the previous one showing another paralyzed person, we may find that seeing a full shot of a paralyzed person is less disturbing than viewing only a fragmented body part of Bauby. This difference in sensory experiences can be explained by our accustomed way of perception. From the other paralyzed person, we grasp a sense that there are parts of "selves" represented in the other; while from the mirror, we are forced to accept that the other, as we try to alienate from our self-construction, can be a representation of ourselves. At this moment, the gaze is not one-directional but "self-surveillance" mediated by the medical transforming space (Tanner 116). In other words, not only does Bauby reflect on his disabled body through the paralyzed other and through the unsettling mirror, but our spectatorship is challenged. We are not indifferent audiences outside the movie screen looking at others' performance, rather, we are reminded by the mirror of our own tendency to self-disguise in the process of formulating self-image and self-perception.

"Impaired" Male Gaze

Considering the gender roles of Bauby and the therapist, we may see the complexity in this scene. By interrogating the codes of language in films, Mulvey points out visual pleasure is the dominant ideological concept of cinema. The notion "male gaze" ties to the patriarchal order that objectifies women as "bearer of meaning" and "silent image" of desire (1173). The scene showing Bauby's interaction with his speech therapist exemplifies the concept of "male gaze"

proposed by Mulvey. When the speech therapist mentions that she is responsible for Bauby's training of his "tongue and lip", the extreme close-up of the therapist's breast combined with Bauby's inner thought "sounds fun" immediately sexualizes the therapist's job, which is a manifestation of masculinity.

However, besides his left eye, he is completely paralyzed, and his inner thought is not decipherable to the therapist. Thus, he is different from traditional male protagonists in narrative cinema as his physical inactivity binds him to the same "seat as a spectator" (Mulvey 1179). What is more, though there are shots including the exhibition of the therapist's body, the scene we discussed above does not incite visual pleasure defined by Mulvey but unsettles audiences by challenging our position as irrelevant spectators. Here, the camera even delivers a sense of irony. Bauby's gaze is unfulfilled due to his inability to take actions. Even his commentary cannot be heard without the use of cinematic techniques. In this sense, we may regard the power dynamics between him and the therapist as an "impaired" gaze undeliverable to the supposed object.

Referring back to our discussion of prosthetic devices, the camera here serves a paradoxical function: though externalizing his thoughts, it is not his "butterfly" that represents his free flow of mind. Instead, it makes his "diving bell" more visible by reminding him and audiences of his physical incapability. In this way, different from the common omniscient perspective in films, *the Diving Bell and the Butterfly*'s limited view combined with Bauby's narration not only allows us to see the world from his view but can function as a testimony. The camera movements and selection of shots invite audiences to share experiences with Bauby while at the same time remind us of the mode of representation regarding self-construction. In other words, the cinematic eye helps us reconsider the literary "I" in his memoir.

Conclusion

Defined as "the study of the effects of any illness on the artist's life or art, or the effects of an artist's life and personality development on [their] creative work (Aronson 1)," autopathography emphasizes the patient's perspective and their experiences dealing with illness and traumatic experiences. The word "creative" may raise controversy regarding its connection to traditional aesthetic theory. With three autopathographical works I analyzed in this manuscript, *The Cancer Journals*, *The Collected Schizophrenias,* and *The Diving Bell and the Butterfly* (2007), I argue that rather than connecting "arts" and "creativity" to transcendence, they should be considered as innovative practices that not only are different from but challenge traditional narrative structures and assumed universal subjectivity.

The lack of linear narration can be tied to being ill as a traumatic experience. As Duggan points out, an individual experiences a temporal blank during the event. Thus, they are unable to distinguish the "original" trauma-event with the following traumatic hallucinations. In particular, Lorde uses the word "loss" several times in her journal entries and emphasizes that the pain is an interplay between physical wound and psychological struggle. Readers may also find there are some inconsistencies between Lorde's reflection and her journal entries. This problem is also mentioned in the film *The Diving Bell and the Butterfly* since Bauby's narration at the beginning does not match his relatives' reflection towards the ending. Connecting to our inability to distinguish trauma experiences from its "original" happening, I think the attempt to decide which version is more trustworthy is a fruitless approach. Just as the plural in the name "The Cancer Journals" suggests, all fragmented pieces can be validated by Lorde's feelings and reflections and constitute to her broader autopathographical narrative. Similarly, with his imagination as free

as the “butterfly”, Bauby aims to mobilize his narration without limiting in linear order or restrained by one version of truth.

The linearity of narration is commonly seen in autobiography. Tracing the development of the protagonist's life chronologically, audiences expect a consistent personality that repeats itself through the work. This assumed universal subjectivity is frequently criticized by poststructuralism scholars nowadays, arguing that the ontological sense of selfhood is a “fantasmatic cultural construct” (Major 44) realized by ideological apparatuses. Different from autobiography, I think autopathographical works destabilize this notion of unified self and reimagine their embodied subjectivity during the illness experience.

One of the explicit resistance to the imposed social norms would be Lorde’s rejection of prosthesis. The statement from the woman from Reach For Recovery, “nobody will know the difference” offers “empty comfort” (61). In other words, it denies Lorde’s altered self-perception intertwined with her changed physical body post-mastectomy. Further, the advocacy of prosthetic breasts from workers at Reach For Recovery and from doctors in the clinic (59) impose the singular definition of normalcy and one “correct” display of femininity to women surviving breast cancer. From my perspective, the notion of prosthesis that functions as an index of social norms can be theorized and expanded to analyze other works. For example, Wang’s inaccurate diagnosis by Dr. C shares symbolic similarity with Lorde’s experience with prosthesis. Though both Dr. C and medical practitioners Lorde meets do not have malignant intentions, their attempts on hiding and disguising the traumatic experience hinder Wang and Lorde to negotiate with their transformed identities. Thus, the lack of appropriate diagnosis in Wang’s case can be seen as an alternative form of “prosthesis” which also indicates social norms and furthers marginalization.

Bauby's case may promote a dialectical understanding of prosthesis. From my perspective, the cinematic camera can be seen as another form of prosthesis. Because he is completely paralyzed, the camera serves as an extension of his body that externalizes his thoughts and establishes conversation between him and people in the diegesis as well as audiences in front of the screen. In this way, Bauby's prosthesis can be seen as his "butterfly" that helps him escape the physical "diving bell". However, simultaneously, the mobilized camera contradicts with his physical entrapment. This can be exemplified by my discussion of the "impaired" male gaze: he cannot take actions and interact with his speech therapist. The externalization of his inner thoughts even furthers this contradiction between his imagination and physical inability. Thus, the camera can also be seen as the "diving bell" that reinforces his sense of entrapment.

The analysis of Bauby's situation and the symbolized "prosthesis" sheds light on my following argument: while offering critique of prosthesis, I am not suggesting a total rejection of it. The most apparent example would be Lorde's discussion of recommending prosthetic breast to women post-mastectomy. She does not try to persuade all women to reject prosthesis or establish a sense of superiority towards those wearing prosthetic breasts or conducting breast reconstruction. From my perspective, Lorde's work aims to enrich narratives and increase visibility of women's struggle with breast cancer in a material way. Thus, prosthesis could be offered as a choice rather than imposed as a part of social norm to women so as to regulate their appearance and perform their femininity.

Lorde's critical examination of prosthesis resists the danger of producing another binary. In particular, dichotomy could be formed, separating women not wearing prosthesis as independent from those preferring breast reconstruction as subjecting to traditional definition of

femininity. The rejection of binary images also sheds light on the manuscript's discussion of collective identity formation. Though both Wang and Lorde call for representation of their experiences and communities for people sharing similar experiences, I do not interpret their seeking for role models (Lorde 56) as attempts to find individuals sharing exact same identities. Instead, their narratives advocate for communities that embrace multiplicity of identities. In other words, "collective" voices, just like the formation of "self", should not be singular, but a combination of perspectives tolerating differences and incoherency. Lastly, this manuscript tries to use autopathography as an intervention to the debate between universal subjectivity connected to Romanticism and suspicion towards ontological selfhood in poststructuralism. By reflecting on their personal experiences dealing with disease, autopathographical authors have the opportunity to interrogate their self-perception and reconsider the existence of united "selfhood" through the process of transformation because of serious illness. Autopathography's discussion of multiple components interplaying with narrators' embodied subjectivity not only highlights a comprehensive understanding of illness as a social experience but promotes a discursive interpretation of identities. In other words, the lack of a resolution in autopathographcial works and the accepting fragmented, multiple identities propose a new mode of subjectivity construction while avoiding the danger of falling into essentialism or total negation of the notion "self".

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