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Theorizing Family Inheritance: Vulnerability, Grief, and Gnosis

Vulnerable, adj. /'vʌlnərə(ə)bəl/: That may be wounded; susceptible of receiving wounds or physical injury. (Oxford English Dictionary)

To be vulnerable brings to mind the possibility of physical injury and an inability to control or protect the body, as demonstrated by the Oxford English Dictionary. A vulnerable being “may be wounded” and is “susceptible of receiving wounds;” such a body serves as the object upon which an act is done by an outside entity. The body is the domain to be protected from external threats. Yet, what happens when the threat is internal? What if the body is made vulnerable due to a malformation or mutation within the protected space rather than an external enemy? These questions framed my approach to the *Family Inheritance* project and led me to develop a theory of vulnerability situated in systems of relations and biopolitics. Ultimately, this project employs Judith Butler’s notion of vulnerability as a “mode of relationality” positioning the conception of the genetically vulnerable self in conversation with one’s genetics, generations of family, and understandings of bio-ethical responsibility. To enact and to illustrate this understanding of vulnerability, I employed a framework of grief and gnosis to construct the visual essay. Grief and gnosis serve as a narrative for the affective experience of genetic vulnerability.

To illustrate how *Family Inheritance* theorizes vulnerability as a set of bio-political relations, affectively experienced in terms of grief and gnosis – this paper proceeds in three parts. First, I outline the method of data collection for the visual essay and how secondary sources informed the structure of the booklet. In this section grief is presented as a narrative form for understanding how I wrestle with genetic vulnerability, while offering a conception of gnosis as

the ultimate goal of the project. Second, I compare my theorization of genetic vulnerability with conceptions of social, physical, and economic vulnerability. In particular, I examine vulnerability as a state of risk, vulnerability as agentic, and the construction of bio-ethical responsibility for one's vulnerability. This essay concludes with a reflection about subjective methodologies and the act of witnessing and knowledge production that occurs through such projects. This final section returns to the idea of gnosis as a way of knowing that can emerge from subjective methodologies to the benefit of broader society.

A Framework of Grief

For *Family Inheritance*, I knew I wanted to use photography and creative writing as a way of representing my relationship with my father and my own self-perception. Writing has been a core part of my identity my whole life and the way I process information and emotions. Photography is my father's hobby; it is one of the ways he expresses himself. Thus, the merging of images and words demonstrates his process of negotiating his illness while I confront our genetic history.

Photography, however, does more than represent my father in this visual essay. Images serve as generational memories to be examined and understood. They offer a look into my family's past, functioning as "agents of memory."¹ These memories are not mine. They are moments of a family and a past I do not know. As the researcher, then, I have to interpret their significance, mine them for my heritage, and understand their place in my exploration into genetic vulnerability. This research occurred as a family activity, beginning with me bringing large boxes up from the basement. The majority of the images used in the project pre-date my existence, so I spent hours sitting with my parents going through the photos learning about my

¹ Jose van Dijck, "Digital photography: communication, identity, memory," *Visual Communication* 7, no. 1(2008): 57-76.

relatives and hearing stories of events from their childhoods. In some cases, those photographed were forgotten. The “old world” photos, as my mom called them, depict individuals from the Ukraine whose names have faded away with death and dementia. Spidery writing on the back conveys information lost in translation, as no one in our family can read or speak Ukrainian or Polish anymore. Nonetheless, I developed an intimacy with these photos. I recognized eyes, lips, and noses – the visual genetic inheritance that marks one like the other. Even though I had developed a relationship with the images and the relatives they represented, I still needed a way to frame them.

Paolo Favero’s “Tainted Frictions,” a visual essay about color in the colonial encounter, opts for a nonlinear, free form, unbounded essay. This format follows Favero’s critical approach, asking the viewer to reflect on the space of the gaze and engage with conceptions of colonial recognition.² However, for *Family Inheritance* I wanted a more narrative format. I wanted to walk the viewer through the experience of wrestling with genetic vulnerability. Given the topic and the idea of genes as something passed through the family, I decided to build a scrapbook. This format resembles a family photo album that can be perused for memories, while also allowing for annotative writings and illustrations. *Family Inheritance* combines photos, writing, and illustrations to walk the viewer through a visual memoir about genetic vulnerability.

Memoirs, according to Amy Boesky, serve as a way for cancer patients to negotiate their diagnosis. In particular, Boesky examines memoirs written by women who have cancer as a result of an inherited BRCA gene mutation. For these women, memoirist writing serves as a way to process their learned vulnerability – what Boesky calls “diagnosis.” Through the memoirs the women find a place for “regaining agency and voice...within a more complex and nuanced form

² Paolo S. H. Favero, “Tainted Frictions,” *American Anthropologist* 119, no. 2 (2017):361-364.

of knowing (gnosis).”³ My visual memoir serves a similar purpose. It operates as a location through which I can come to a gnosis about family and genes.

A memoir requires narrative structure, which occurs in family photo albums through a grouping of similar images to portray an event or a person. Yet this album could not center on a specific event or a single person since it was to serve as an intergenerational exploration of genetics. Instead, the album’s narrative needed to confront difficult emotions and realizations similar to my experience over the last few months. This choice to emphasize the emotions of genetic vulnerability led me to the stages of grief.

Grief can occur at a moment of loss, but it can also arise during periods of radical change. Such change can be experienced as losing the past or a loss of a desired future. In confronting my family’s history with cancer and our possible genetic risk, it felt like a loss of innocence and a loss of carefree living. The significance of grief in *Family Inheritance* became all the more vivid as I read Elisabeth Kübler-Ross’ stages of grief in *On Death and Dying*. Although Kübler-Ross works with terminally ill patients and their families, I recognized a familiar trajectory. I read a narrative that paralleled the feelings I’ve negotiated since September, from the moment of shock at diagnosis through the sense of isolation and depression to acceptance and hope. With this recognition I found the organizational layout for *Family Inheritance*.

Family Inheritance traces my emotional process through a marriage of photography and writing as a memoir of genetic vulnerability. The collage of images works to have the viewer see and feel family inheritance as I have.⁴ The link between image, words, and grief seeks to take

³ Amy Boesky, “From Diagnosis to Gnosis: writing, knowledge, and repair in breast cancer and BRCA memoirs.” *Perspectives in Biology and Medicine* 58, no. 1 (2015): 75.

⁴ Clive Pope, “My dirty story about gardening: a visual ethnography,” *Qualitative Research Journal* 16, no. 3 (2016): 156.

this personal narrative and apply it to larger social conversations about genetics and conceptions of vulnerability.⁵

Genetic Vulnerability

As stated in the introduction, conceptions of vulnerability often place the threat external to the body. For folks of color, the threat comes from a society that devalues their humanity and sees them as disposable. In the case of genetics, however, the threat comes from inside. The unseen internal brings danger. Yet, both of these examples situate vulnerability as a mode of relationality, whether it is between social groups or self and genes.

Judith Butler encourages us to understand vulnerability as a mode of relationality so as to recognize the persistent and fluid state of being vulnerable.⁶ The body becomes defined by its interactions with others – the slip and slide of encounter. Through practices of (mis)recognition, bodies are interpreted as human/non-human, belonging/non-belonging, or alien.⁷ Within these moments of encounter bodies become (in)vulnerable. For instance, Trayvon Martin’s black body within a white neighborhood made him vulnerable as non-human and non-belonging.⁸ Cindy Glaude’s body also became vulnerable in relation to white males and the colonial system of extermination.⁹ This relational framework connects genetic vulnerability to more common approaches.

The relationality of vulnerability, as presently theorized, can occur between groups, the body and the state, genders, etc. Vulnerability, then, can emerge in the relationship between self

⁵ Desiree D. Rowe, “Autoethnography as Object-Oriented Method,” in *Doing Autoethnography*, eds. S. L. Pensoneau-Conway et al. (Rotterdam: Sense Publishers, 2017), 229.

⁶ Judith Butler, “Bodily Vulnerability, Coalitions, and Street Politics,” *Critical Studies* 37 (2014): 103.

⁷ Sara Ahmed, *Strange Encounters* (London: Routledge, 2000).

⁸ Wendy Hesford, “Surviving Recognition and Racial In/justice,” *Philosophy and Rhetoric* 48, no. 4 (2015): 536-560.

⁹ Sherene H. Raczack, “Gendering Disposability,” *Canadian Journal of Women and the Law* 28, no. 2 (2016): 285-307.

and body. This relationship does not necessarily ascribe to the Cartesian mind-body dualism, but recognizes that the body, at times, can act differently and limit the self we mentally construct. Take the situation of a child trying to walk or an adult limited by an injury, in both cases the mind, the personality, the aware self wants to walk, but the body will not function in sync with this desire. Similarly, a sense of self develops separate from the links of DNA and chromosomes that compose and run the physical body. One can then develop a sense of vulnerability in relation to their own genetics when they learn they are predisposed or at an increased risk for certain illnesses. The internal body becomes a threat the self and external, living physical body.

The idea of genetic vulnerability also comes across in the way genetic predispositions are discussed. Each of the books by physicians that I read about genetics referred to mutations as “inherited vulnerabilities.”¹⁰ Robert Klitzman even connects this genetic vulnerability and places it in conversation with sense of self. He writes, “individuals may assess the relevance for themselves of a newly affected relative and develop a personal sense of vulnerability....issues emerge of how individuals incorporate this personal sense of vulnerability into their identity and sense of themselves.”¹¹ Here Klitzman alludes to a relationship between genetic risk and self that produces vulnerability. A mode of relationality emerges between self and body in the experience of learning about genetic risk and the language of medical professionals.

One side effect of this relationship of vulnerability is that the genes remove agency of the aware self. To feel vulnerable objectifies the body making it that which something happens to or something is acted upon. Genetic vulnerability makes the self feel incapable of controlling their

¹⁰ Theodora Ross, *A Cancer in the Family* (New York: Avery, 2016); Siddhartha Mukherjee, *The Gene* (New York: Scribner, 2016); Robert L. Klitzman, *Am I My Genes?* (New York: Oxford University Press, 2012); David Scadden, *Cancerland* (New York: St Martin’s Press, 2018).

¹¹ Klitzman, *Am I My Genes?*, 170.

health. Yet a presumed agency is necessary for existence within a neoliberal society.¹² The hyper-individualism of neoliberalism mandates that the self must have control over their body and actions.¹³ We can see this discipline mentality play out in the concept of genetic vulnerability.

The current market for genetic testing positions itself within a rhetoric of knowledge and action. Invitae, a genetic information company, claims “Genetic insights can change everything” and mass market books frame testing in terms of reclaiming power.¹⁴ Theodora Ross writes, “Knowing is better than not knowing. Clarity is better than confusion. There are options for cancer prevention.”¹⁵ What this language reveals is a belief that the individual should acquire knowledge about their genetic vulnerability in order to be a proactive neoliberal citizen. Thus, genetic testing becomes about personalized medicine, individual agency, and disciplined action.

Emphasizing the individual and placing the burden on them serves as a bio-ethics for neoliberalism. This merging of biopolitics, the governing of life and death, and neoliberalism provides the perfect backdrop to the emergent genetic testing market. Bio-ethics, according to Rosi Braidotti, shifts responsibility for health and healthcare from the social to the individual. Limiting access and benefits to “an individual’s manifest ability to act responsibly by reducing risks and exertions linked to the wrong life style.”¹⁶ One’s health and genetics become a matter of capital to be protected for the benefit of the system rather than to the sustaining of the individual’s life. Agency, then, is actually not restored to the genetically vulnerable in the age of

¹² Butler discusses the agentic self as necessary for mobilization and mobilities as key to social life. (102)

¹³ Rosi Braidotti, “Bio-Power and Necro-Politics,” *Springerin, Hefte fur Gegenwartskunst* 13, no. 2 (2007): 18-23; David Harvey, “Neoliberalism as Creative Destruction,” *The Annals of the American Academy of Political and Social Science* 610 (2007): 34.

¹⁴ Invitae, “Homepage,” accessed November 16, 2018, <https://www.invitae.com/en/>; Ross, “A Cancer in the Family.”

¹⁵ Ross, “A Cancer in the Family,” 15.

¹⁶ Braidotti, “Bio-Power and Necro-Politics,” 5.

genetic testing. Instead, genetic vulnerability accrues value by allowing the neoliberal system to determine whose health is worth the risk – those performing preventative measures.

Bio-ethical responsibility with regards to genetic vulnerability causes one to do a cost-benefit analysis. Yet this analysis within neoliberal logic does not consider the family or the emotional state of the patient. Lisa Ku, a genetic counselor with University of Colorado Health, noted in an interview how direct-to-consumer testing centers on the individual without concern for familial consequences. These tests also overlook the possible emotional consequences of learning one is genetically predisposed to cancer. Ku emphasizes that it is a genetic counselor's role help the patient consider their own emotional health, the possible impact on family members, and to determine if learning of one's genetic vulnerability is the smartest path. This holistic approach differs from the neoliberal model that prioritizes knowledge and information over emotional well-being.¹⁷

Although Ku's approach to genetic testing diverges from the direct-to-consumer model, her framing of the results situates the patient within a state of vulnerability. Ku mentions that genetics are something we cannot control and that once we know something we cannot un-know it. These statements reinforce genetic vulnerability as a state of threat and lack of agency. The body once again becomes the object. Ku's speech around proactive actions only reclaim agency slightly. She does acknowledge that there are preventative measures, but genetics is "not concrete science," leaving the genetically vulnerable to feel as if their still incapable of gaining control over their body.¹⁸

Yet, vulnerability does not need to remain a state of threat and incapacitation. The information that leads to genetic vulnerability can be useful. Agency and voice can be reclaimed.

¹⁷ Lisa Ku (genetic counselor) in discussion with author November 9, 2018.

¹⁸ Ibid.

Through narrative, genetic vulnerability can be adapted and integrated into one's identity – reunifying the body and self.

To Know and To Witness

Finding a way to overcome genetic vulnerability was one motivation for undertaking this visual essay. Anxiety about my family's genetics has been weighing on me since I was a child with the first heart testing I underwent and then again when physicians showed concern about the amount of colon cancer on my dad's side. However, the most recent bout of cancer in my family – and my own thoughts towards the future – made the importance of learning about genetics all the more important. Such a subjective project is not easy for me. Even though I like to think I put a piece of myself in each of my projects, I am always able to keep a researcher's distance from the material. This time, however, I was the researcher and the subject.

As mentioned in the first section of this essay, *gnosis* serves as the ultimate end of the project. *Gnosis* functions as a way to reclaim agency and voice, but moving past information and towards a reintegrated self. Narrative can lead one towards *gnosis* as a form of “reparative aesthetics.”¹⁹ Through the reparative aesthetics of the visual essay, I can mobilize genetic vulnerability to work for me rather than against me. The concluding pages of *Family Inheritance* demonstrate that vulnerability does not have to be a threat. Similar to how Butler discusses mobilizing vulnerability in concert as a political act of agency against systems of power, families can collaborate to bring the relations of vulnerability into open and frank conversation.²⁰

Ku, Ross, and other physician authors discuss the importance of open dialogue within a family as a way of taking back control over one's inherited vulnerability.²¹ This control, however, is not that of the neo-liberal false agency. Neo-liberal illusions of agency emphasize

¹⁹ Boesky, “From Diagnosis to Gnosis,” 87.

²⁰ Butler, “Bodily Vulnerability.”

²¹ Lisa Ku, November 9, 2018; Ross, *A Cancer in the Family*; Klitzman, *Am I My Genes?*.

the individual at the expense of the communal. In family dialogue, vulnerability is mobilized in coalition. From this communal, open dialogue, vulnerability becomes a tool to fully knowing one's self – body and mind – and navigating the generational choices necessary to confronting that which makes us vulnerable.

Placing the self in scholarship, such as autoethnography and this visual essay, functions as a location for coalitions and alliances to be formed. Through a study of memory and personal affiliation, scholarship can serve as witness to issues gone unacknowledged. Patricia Nguyen recognizes the power of subjective methodologies in her analysis of the performance *salt|water*. Nguyn acknowledges how her family informed performance acts as witness to the experience of Vietnamese refugees, embodying their vulnerability. This witnessing, however, is not just a form of catharsis, but a political act crafted to spur other political acts.²² By engaging the self in her work, Nguyn brings to life memory and makes it public.

Subjective scholarship accepts the humanity of the researcher and understands that the issues scholars study have an impact on their lives. Self-reflection does more than serve the scholar; it contributes to broader knowledge in two ways. First, subjective methodologies make researchers understand the vulnerable position of being an object of study. It makes scholars more empathetic and conscious of their research methodologies by humanizing interlocutors and making real the topics of study. Second, subjective methodologies provide an in-between space where scholarship can potentially reach publics. In placing ourselves in our work we may be more able to make it accessible outside of the academy and work with publics to understand and, perhaps, come to a *gnosis* about social concerns previously unacknowledged. Subjective

²² Patricia Nguyn, “*salt|water*: Vietnamese Refugee Passages, Memory, and Statelessness at Sea,” *Women's Studies Quarterly* 45, no. 1 and 2 (2017): 97.

methodologies should therefore be encouraged as a practice of humanity and scholastic collaboration with publics.

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