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## **Self-Care: Seeking Queer Liberation from the Medical Gaze and Genetic Fatalism**

**Abstract:** Genetic diagnostics are radically and rapidly changing perceptions of health. Individuals with identifiable pathogenic genetic differences are now being made into cultural mutants. Unlike other forms of embodied difference, these diagnostics rely on a high statistical probability of developing a disease, known as genetic risk. As such, individuals with a mutation are often subjected to perform the same clinical labor as those who are already sick with a disease, which can involve invasive medical surveillance, preventative surgeries, and family planning. *Self-Care* is my artistic attempt to reckon with these biotechnological ruptures in identity caused by the rising use of genetic diagnostics in medicine. Using my body, *Self-Care* weaves a narrative about health, gender, and identity that seeks to resist the confines of the medical gaze. The work features a specially designed chest binder housing living BRCA1 mutant breast cancer cells, which allows the artist to take on the caring responsibilities of their cancer before it emerges in their body. Building off the artwork, this paper explores contemporary issues surrounding Hereditary Breast and Ovarian Cancer Syndrome in global healthcare systems. Traversing the boundaries between sick and healthy, male and female, and parent and child, this paper sets out to both present the scholarly research surrounding *Self-Care* and provide a platform of critical self-reflection for the artwork to question how best we can care for ourselves and others.

**Keywords:** BRCA1; breast cancer; bioart; medical gaze; genetic diagnostics; queering the body.

### ***Mutants: The Genetic Body and Identity***

In recent decades, medicine has entered its *genomic era*, and genetic data and testing have become of increasing value in the biomedical context.<sup>1</sup> Genetic testing reduces the body to a series of nucleotides and categorizes any variations based on their status as pathogenic – disease-causing.<sup>2</sup> Susan E. Kelly attributes the *genomic era* to the emergence of the metaphor of *the genetic body*. Kelly elaborates that *the genetic body* describes the changing “modes of production, technoscientific identities, social relations, and broader interfaces with biomedical, cultural and governmental

<sup>1</sup> Kay E. Davies, “The Era of Genomic Medicine,” *Clinical Medicine* 13, 6 (December 1, 2013): 594–601.

<sup>2</sup> Susan E. Kelly, “From ‘Scraps and Fragments’ to ‘Whole Organisms’: Molecular Biology, Clinical Research and Post-Genomic Bodies,” Print, in *New Genetics, New Identities*, ed. Paul Atkinson, Peter Glasner, and Helen Greenslade (London: Routledge, 2007), 44–60.

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modalities that have characterised the genetic era”<sup>3</sup>.

*The genetic body* gives way to the concept of *genetic risk*, which characterizes the influence of a perceived risk for a genetic-related disease without providing any “concurrent ability to treat”<sup>4</sup>. Kelly explains that genetic risk can also become part of the subjective experience and identity, which has become evident in numerous studies.<sup>5</sup> This paper focuses its analysis on Hereditary Breast and Ovarian Cancer Syndrome (HBOC) and its involvement in breast cancer narratives.

Cancer narratives have a history of impactful autoethnographic exploration with authors such as Audre Lorde, Jackie Stacey, and S. Lochlain Jain working to dismantle societal stereotypes and expectations concerning gender, sexuality, and race. However, in the framework of the genetic body, the structure of disease narratives radically shifts. Kelly elaborates that with the *genetization* of the body, preventative medicine becomes the primary mode of care, subjecting patients to constant lifestyle surveillance and the burden of responsibility for their own health.<sup>6</sup>

The moment a pathogenic mutation diagnosis marks a perceptual shift for an individual. Despite the perceived health of the body before diagnosis, the body is suddenly and abruptly thrown into a new reality defined by its awareness of the constant risk of developing a disease. Based on genetic risk, the disease narrative also shifts, as the patient’s subjective experience and the level of associated risk inform the construction of the sense of self as either healthy or sick.

Catherine Belling writes that “pathographies begin not with the emergence of disease but with the emergence of the narrator-author as a diseased person”<sup>7</sup>. After a genetic diagnosis, individuals may have to live their lives performing for the medical gaze as an already diseased person, thereby enacting a blended performance of identity while waiting for their expected disease to emerge. The medical gaze, a term coined originally by Michel Foucault, to refer to the framing of a patient’s body within the realm of the clinic as one that searches for deviance, and the bodies viewed are subjected to intervention by the expert authority of doctors.<sup>8</sup> In the context of HBOC, these performances for the medical gaze can include the clinical labor of routine medical surveillance to preventative surgeries and hormone therapies, mirroring many clinical labor tasks of a cancer patient. The medical gaze in these cases often can treat

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<sup>3</sup> Ibid, 46–47.

<sup>4</sup> Ibid, 48.

<sup>5</sup> Ibid, 47; Allyn Mcconkie-Rosell et al., “Living With Genetic Risk: Effect on Adolescent Self-Concept,” *American Journal of Medical Genetics Part C (Seminars in Medical Genetics)* 148, 1 (February 2008): 56–69; Hannah Badal et al., “Preiving: How Unaffected Women with a *BRCA1/2* Mutation Navigate Previsor Identity,” *Health Communication* 35, 10 (August 23, 2020): 1256–65; Robert L. Klitzman, “Am I My Genes?: Questions of Identity among Individuals Confronting Genetic Disease,” *Genetics in Medicine* 11 12 (December 1, 2009): 880–89.

<sup>6</sup> Kelly, “From ‘scraps and fragments,’” 47–48.

<sup>7</sup> Catherine Belling, “Narrating Oncogenesis: The Problem of Telling When Cancer Begins,” *Narrative* 18, 2 (May 2010): 229–47.

<sup>8</sup> Michel Foucault, *The Birth of the Clinic* (London: Routledge, 2002): 89–90.

bodies with a certain risk of developing a disease as already diseased and untrustworthy.<sup>9</sup>

In the case of HBOC, the *previvor* narrative has emerged in breast cancer discourses, as coined in 2000 by Sue Friedman of the organization Facing Our Risk of Cancer Empowered (FORCE).<sup>10</sup> *Previvor* refers to people identifying as survivors of the predisposition of a disease.<sup>11</sup> The term was coined as an attempt to build a sense of identity and community for those *pre-diseased*.<sup>12</sup> However, the *previvor* narrative has an emphasis on the act of choice, even though this agency is limited by a disease's unpredictability and the social and legal consequences of a genetic diagnosis.<sup>13</sup> Another prevalent issue is that a large portion of *previvor* narratives focus on maintaining societal expectations of gender and body norms, especially in the narrative of surgical reconstruction, with Angelina Jolie's being a notable example.<sup>14</sup>

This is where *Self-Care (2021-Ongoing)* aims to intervene. Rather than taking on the label of *previvor*, in *Self-Care*, I declare myself a mutant to attempt to break free from the entrapments of binaries, such as male and female, healthy and sick, parent and child. Mutational identity is a stark contrast to the *previvor* discourse, as it does not bend to the notion that the event of embodied difference mirrors the survivor narrative of cancer. *Previvor*, taking half its name from the word survivor, implies that this genetic difference is something to overcome, to endure, much like cancer.<sup>15</sup> However, even with HBOC, other notions of embodied difference must be accounted for, including kinds that extend beyond a singular body, as these kinds of mutations can impact an entire family. Therefore, I employ the emerging framework of Jason Zingsheim's *Mutational Identity Theory*. Zingsheim describes *mutational identity* by stating:

Mutational identity leads us to view identity and individuals as composed of multiple mutants or subjectivities. A historical individual is not simply a mutant; rather he or she is composed of a multitude of mutants – a team of subjectivities – each shifting and morphing, with his or her own power, and with unpredictable relationships to others.<sup>16</sup>

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<sup>9</sup> Jessica Polzer, "From active participant in health to (pro)active manager of genetic risk: (re)making the ethical subject of risk in the age of genetics" (PhD Dissertation, University of Toronto, 2006).

<sup>10</sup> Badal et al., "Previving," 1256–1265.

<sup>11</sup> Ibid.

<sup>12</sup> Ibid.

<sup>13</sup> Bryna Siegel Finer, "The Rhetoric of Previving: Blogging the Breast Cancer Gene," *Rhetoric Review* 35, 2 (March 15, 2016): 176–88; Kelly, "From 'scraps and fragments,'" 47–48.

<sup>14</sup> Angelina Jolie, "My Medical Choice," *The New York Times*, May 14, 2013, sec. Opinion.

<sup>15</sup> Badal et al., "Previving," 1256–1265.

<sup>16</sup> Jason Zingsheim, "Developing Mutational Identity Theory: Evolution, Multiplicity, Embodiment, and Agency," *Cultural Studies? Critical Methodologies* 11, 1 (November 13, 2010): 24–37.

With *Self-Care*, I aim to analyze the context of gender, biopolitics, queerness, and inter-generational trauma through *Mutational Identity Theory*. Zingsheim explains the theory is “adept at plumbing the multiple, kinetic, and material levels of subjectivity and identity, representation and reality, and power and resistance”<sup>17</sup>. These are facets necessary to account for how these identities are in states of constant flux regarding HBOC.

Concerning Kelly’s genetic body metaphor, when diagnosed with a pathogenic mutation, the body and the subjectivity of the person are irreversibly fragmented by the lurking potential of disease.<sup>18</sup> For example, the general risk of developing breast cancer for BRCA1 mutational carriers is roughly estimated to be 72%, while there is a 44% chance of developing ovarian cancer throughout an individual’s lifetime.<sup>19</sup> However, this risk can shift based on other factors, such as breast tissue density, hormones, and lifestyle. The mutation for BRCA is also highly heritable, as it can be expressed as pathogenic even if only one mutational allele is inherited.<sup>20</sup> In these cases, the monster of breast cancer is not something that suddenly emerges or has an outward cause but is one that haunts a family. It is inherited in the way ghosts and monsters plague a new owner of a house, growing in power as the new owners also inherit the experiences of those before them. Through *Mutational Identity Theory*, the identities of individuals with HBOC are in constant flux throughout their lifetime and exist with multiplicities in their identities, each with their own subjectivities, that intersect through multi-generational lineages and bodily materiality.<sup>21</sup>

## Self-Care

*Self-Care* aims to critically examine the role of the self and its relationship to care in the context of HBOC, specifically looking at BRCA1 mutations. The project uses my own body, genderqueer identity, and experiences as an autoethnographic framework for exploring global perspectives on notions of health and disease concerning embodied genetic differences. A major feature of the artwork is a chest binder designed to house living BRCA1 mutant breast cancer cells, which enables the wearer to attempt to care for them (Figure 1, Figure 2).

The title of the work originates as a critique of the meaning ascribed to the notion of *self-concept* in scientific studies and the shifting roles in preventative healthcare frameworks, which Jackie Stacey describes in her *Teratologies: A Cultural Study of Cancer* as shifting the weight of responsibility of disease onto the individual.<sup>22</sup> This

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<sup>17</sup> Ibid, 35.

<sup>18</sup> Kelly, “From ‘scraps and fragments,’” 45–47.

<sup>19</sup> Karoline Kuchenbaecker et al., “Risks of Breast, Ovarian, and Contralateral Breast Cancer for *BRCA1* and *BRCA2* Mutation Carriers,” *JAMA* 317, 23 (June 20, 2017): 2402.

<sup>20</sup> Nancie Petrucelli, Mary B. Daly, and Tuya Pal, “BRCA1- and BRCA2-Associated Hereditary Breast and Ovarian Cancer,” *GeneReviews*® [Internet], September 4, 1998, <https://europepmc.org/article/MED/20301425>.

<sup>21</sup> Zingsheim, “Developing mutational identity theory.”

<sup>22</sup> Klitzman, ““Am I my genes?”” 880–889; McConkie-Rosell et al., “Living with genetic risk,” 59–69; Jackie Stacey, *Teratologies: A Cultural Study of Cancer* (Oxfordshire: Routledge, 1997).

shift in frameworks emerges from what Michelle Murphy characterizes in the liberalist rise of health perceptions of the late 20<sup>th</sup> century, which moralized a “good patient” as one who was “self-informed”, “risk-aware”, and had “willingness” for biomedical interventions, which also contributed to late 20<sup>th</sup> century feminist ideology of the liberalization of the self.<sup>23</sup> Artistically and critically engaging with the legacy of these histories, the *self* that I arrive at in *Self-Care* is forever at odds with and is entangled in intersections of identity and subjectivities and care of others, searching for answers from global experts on the country-specific nuances of care, grappling with intergenerational trauma and misgendering within familial relationships, planning (and questioning if and how there can be) a future of lifelong care in consultation with doctors, and, most importantly, attempting (and often failing) to care for the needs of the living cancer cells within the work. *Self-Care* is critical of the neoliberal and post-feminist use of the *self*, as the work is critical of the very notion that the *self* and care of the *self* can ever be truly individualized constructs.



**Figure 1.** Photograph of the artist wearing the specially designed chest binder housing living breast cancer cells in *Self-Care* by Lyndsey Walsh. Photographer credit: Asya Kaplan.

<sup>23</sup> Michelle Murphy, *Seizing the Means of Reproduction* (Durham: Duke University Press EBooks, 2012), 118–119.



**Figure 2.** Photograph of *Self-Care* by Lyndsey Walsh in *m/other becomings* installation I at SOLU/Bioart Society. Photographer credit: Genietta Varsi.

*Self-Care*'s artistic approach is one that follows a queer and intersectional feminist approach, which I position to be in line with contemporaries, such as Adriana Knouf's xenofeminist approach to *Xenological Entanglements. 001b: Saccular Fount* (2020) and Mary Maggic's *Genital (\*) Panic* (2021). Knouf's *Xenological Entanglements. 001b: Saccular Fount* also confronts these multiple subjectivities of the self in efforts to take control of care regarding the production of hormones for hormone replacement therapy.<sup>24</sup> While in Maggic's *Genital (\*) Panic*, the self as a "disobedient" body is used to dismantle the medical gaze's power of pathologizing genitals through the hacking of medical surveillance in population studies to make space for "toxic variations", queerness, and all forms of otherness.<sup>25</sup> In both works, the artists employ queer and intersectional feminist approaches to challenge notions of care regarding queer and queering bodies to "rewrite our future" and "reimagine biological destiny".<sup>26</sup>

*Self-Care* derives its creative power from the genre of horror through its use of the *abject* to unsettle viewers regardless of their association with HBOC. The work enacts Julia Kristeva's notion of *the abject* by manifesting a physical intervention to destabilize the boundaries between self and other, in this case, myself and cancer, thereby allowing the threatening force of the *other* (cancer) to transgress the boundaries defining the sanctity of the body while also bestowing a material power as it is

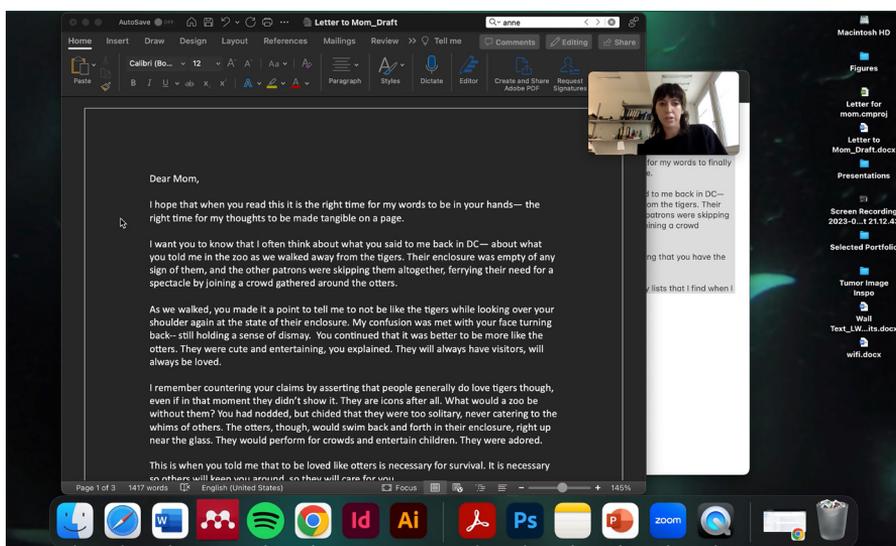
<sup>24</sup> Adriana Knouf, "Xenological Entanglements. 001b: Saccular Fount," TranxxenoLab, June 8, 2021, [https://tranxxenolab.net/projects/saccular\\_fount/](https://tranxxenolab.net/projects/saccular_fount/), acc. August 30, 2023.

<sup>25</sup> Mary Maggic, "MU | Genital\*Panic (2021)," MU Hybrid Art House, 2021, <https://mu.nl/en/txt/genitalpanic-2021>, acc. July 31, 2023.

<sup>26</sup> Ibid; Knouf, "Xenological Entanglements. 001b: Saccular Fount."

used to bind the chest as a form of non-binary gender expression.<sup>27</sup> In *Self-Care*, I enact *the object* as a lens to frame my subjectivity and disrupt the boundaries in binary constructions of gender, health, and relationships.

For context, I was diagnosed with my mutation at eighteen, which is thought to be an impactful time for developing what is known as *self-concept* or the beliefs one has about themselves.<sup>28</sup> This diagnosis also occurred while my mother was going through treatment for breast cancer. Currently, my medically assigned risk for breast cancer is a 94% probability of occurrence throughout my lifetime. Because I am medically assigned female at birth despite being non-binary, I have also experienced numerous frictions with my doctors to negotiate care that doesn't medically force the binary of male and female onto my body through preventative hormone therapies and the planning of preventative surgeries. The impact of gender politics in the treatment of breast cancer also surfaces in *Self-Care's* accompanying video work *Mommagraphy Techniques* (2022, Figure 3). In the video, my mother reveals to me that she decided to get breast reconstruction based on my father's perspectives about her body, and the surgeon who did her reconstruction made her breasts bigger than what she had asked for, which she personally does not see as medical malpractice. In the video, these are both statements that I respond to with shock and horror but come to later accept, as her subjective experience also informs my notion of self, as explored in my follow up video work *A Letter to My Mother*.



**Figure 3.** Photograph of *Mommagraphy Techniques* by Lyndsey Walsh in *m/other becomings* installation I at SOLU/Bioart Society. Photographer credit: Genietta Varsi.

<sup>27</sup> Julia Kristeva, *Pouvoirs de l'horreur (English) [The Powers of Horror]*, trans. Leon Roudiez (New York: Columbia University Press, 1982).

<sup>28</sup> McConkie-Rosell et al., "Living with genetic risk," 56–69.

In *A Letter to My Mother* (2023, Figure 4), I describe cancer as a family heirloom or an “inherited creature”, referencing the words and title of author Lidia Yuknavitch’s *A Letter to My Rage*.<sup>29</sup> Within *A Letter to My Mother*, I describe the ways that my mother, her mother, and her mother’s mother have all succumbed to a kind of familial legacy of cancer, as well as the stories and subjective experiences that have emerged with each person and inherited. I also attempt to grapple with my failures as a child to care for my mother, as I had abandoned her during her course of cancer treatments, and my perceived mother’s failure as a parent to care for me throughout my own struggles with gender dysphoria and the outcomes of medical interventions related to my HBOC. Notions of *self-concept* taking shape in *A Letter to My Mother* follow an approach consistent with Mutational Identity Theory, as they are intersectional, entangled in the subjectivities of a multi-person lineage, materially linked to embodied difference, and remain in flux.<sup>30</sup>



**Figure 4.** A screenshot of *A Letter to My Mother* by Lyndsey Walsh.

*Self-Care* also attempts to surface the subjectivities of the literal disease of breast cancer as a contributing agent in the artwork. The cancer cells that I use are from the cell line HCC1937. These cells are described as being sourced from a primary ductal carcinoma in the year 1995 from a 24-year-old female patient who is identified as

<sup>29</sup> Lidia Yuknavitch, “A Letter to My Rage” (Scribd Originals, 2020), Acc. August 30, 2023.

<sup>30</sup> Zingsheim, “Developing mutational identity theory.”

white with stage IIB breast cancer.<sup>31</sup> The cells were chosen for the artwork because of both their availability and their ability to materially embody the greatest fears of my parents, my doctors, and society about the threat breast cancer poses to my youth, my femininity, and my whiteness.<sup>32</sup>

Employing Donna Haraway's call to action of *making kin*, *Self-Care* attempts to make kin with the cancer that haunts both my body and my family's lineage of bodies.<sup>33</sup> I attempt to pervert the individualistic system in preventative medicine by taking on the responsibility of care for not only my own health but also the health of the cancer genetically and statistically assigned to me, exploring the interplay between our needs and desires. In turn, the cancer and its liquid nutrient media end up contributing to an act of gender liberation, as their role in the chest binder aids in flattening the appearance and queering of the chest.

However, HCC1937 is a notoriously difficult cell line to culture, and I have a history of accidentally killing them, despite my extensive experience and training in tissue culture. This profound irony has only fueled my desperate need to connect, causing me to re-program my entire life to cater to their every need and beg them not to die. While I am unsure if this dynamic has distorted my perception of genetic risk, it has forever altered my perception of cancer by unmasking its mystery. Additionally, when working with scientists to culture these cells, they often referred to them using the terms “whimsical”, “crybabies”, and “sensitive”, further giving this faceless *enemy* a relatable personality.

### **Self-Care Autoethnographic Findings**

*Self-Care* uses an autoethnographic methodology to explore global healthcare systems. Based on my lived experience, I have investigated care systems in the United States, the Russian Federation, and Finland in the context of HBOC. The role of genetic diagnostics in global healthcare frameworks is an emerging concept with country specific nuances, which has been noted by other researchers.<sup>34</sup>

I originally began documenting my own experiences with the US healthcare system in 2020.<sup>35</sup> These experiences have been fraught with legal and economic incentives to undergo invasive preventative procedures due to my insurance company's assertion that they would only cover yearly screenings as long as I didn't have cancer.<sup>36</sup>

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<sup>31</sup> Adi F. Gazdar et al., “Characterization of Paired Tumor and Non-Tumor Cell Lines Established from Patients with Breast Cancer,” *International Journal of Cancer* 78, 6 (December 9, 1998): 766–74.

<sup>32</sup> Zillah R. Eisenstein, *Manmade Breast Cancers* (Ithaca: Cornell University Press, 2001).

<sup>33</sup> Donna J. Haraway, *Staying with the Trouble: Making Kin in the Chthulucene* (Durham: Duke University Press Books, 2016).

<sup>34</sup> Jean-Christophe Bélisle-Pipon et al., “Genetic Testing, Insurance Discrimination and Medical Research: What the United States Can Learn from Peer Countries,” *Nature Medicine* 25, 8 (August 1, 2019): 1198–1204.

<sup>35</sup> Lyndsey Walsh, “Young and Healthy and Waiting to Get Cancer – Nautilus,” Nautilus, May 27, 2020, <https://nautil.us/young-and-healthy-and-waiting-to-get-cancer-237831/>, acc. on August 30, 2023.

<sup>36</sup> *Ibid.*

This follows legal issues in the United States that many anti-discrimination policies concerning genetic information do not apply to symptomatic individuals or individuals who have manifested the disease associated with their genetic difference with additional gaps leading to no guarantee of access to disability and long-term care insurance.<sup>37</sup> Additionally, the United States faces massive ethical issues concerning the neoliberal economization of care, marked by the pervasiveness of direct-to-consumer companies, such as 23andMe, whose services offer limited and subject-to-user-agreement changes in the protections over genetic data.<sup>38</sup> However, even the current realm of preventative programs concerning HBOC are inadequate, as my doctor's prescription of yearly mammograms contradict a European study's findings demonstrating mammograms under the age of thirty with HBOC can be harmful.<sup>39</sup> This assessment is due to the likelihood of the radiation from yearly mammograms to increase the risk of breast cancer for people with HBOC.<sup>40</sup>

As a technoscientific extension of the medical gaze, mammography serves as a historical example of systemic US problems in care practices that are connected to the militarization of care. Lisa Cartwright explains that in 1992, Congress gave the majority of their spending budget dedicated to breast cancer research to the US Department of Defense, which used it to invest in mammography technologies.<sup>41</sup> Cartwright remarks that this decision was heavily criticized because of the emphasis on mammography as it did not equate with breast cancer prevention, which was deemed to be a more worthwhile research goal.<sup>42</sup> Despite its associations, Cartwright reveals that mammography is not well-designed for screening breast tissue, as radiography was made to “image bone and hard tissue with little depth resolution”<sup>43</sup>. Cartwright further explains:

Researchers in breast cancer diagnosis and screening often characterized the breast as an elusive object that actively eluded attempts at standardized screening through qualities encoded as “feminine”. The breast was characterized as too soft, too irregular in composition, and too

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<sup>37</sup> Bélisle-Pipon et al., “Genetic Testing, Insurance Discrimination and Medical Research.”

<sup>38</sup> Manuel Schaper and Silke Schicktanz, “Medicine, Market and Communication: Ethical Considerations in Regard to Persuasive Communication in Direct-to-Consumer Genetic Testing Services,” *BMC Medical Ethics* 19, 1 (June 5, 2018); Rachele Hendricks-Sturup and Christine Y. Lu, “Direct-to-Consumer Genetic Testing Data Privacy: Key Concerns and Recommendations Based on Consumer Perspectives,” *Journal of Personalized Medicine* 9, 2 (May 9, 2019): 25.

<sup>39</sup> A. Pijpe et al., “Exposure to Diagnostic Radiation and Risk of Breast Cancer among Carriers of BRCA1/2 Mutations: Retrospective Cohort Study (GENE-RAD-RISK),” *BMJ* 345, 2 (September 6, 2012).

<sup>40</sup> Simon N. Powell and Lisa A. Kachnic, “Roles of BRCA1 and BRCA2 in Homologous Recombination, DNA Replication Fidelity and the Cellular Response to Ionizing Radiation,” *Oncogene* 22, 37 (August 28, 2003): 5784–91.

<sup>41</sup> Lisa Cartwright, *Screening the Body: Tracing Medicine's Visual Culture* (Minneapolis: University of Minnesota Press, 1995), 143–144.

<sup>42</sup> *Ibid.*

<sup>43</sup> *Ibid.*, 162.

changeable to image clearly... Rather than adapt the technology to its object (or to the dominant perception of its object), radiologists more often attempted to adapt the breast to the technique... In short, women's bodies were regarded as inherently resistant to a technology that could save women's lives.<sup>44</sup>

*Self-Care's* accompanying film *Mommagraphy Techniques* references this by collaging and remixing archival footage from the US National Institute of Health.

A large portion of the research *Self-Care* emerged from took place in St. Petersburg, Russia in collaboration with ITMO University's Art & Science Centre in 2021. During this research residency entitled *Prophylaxis*, I interviewed experts in genetic testing and sociology about HBOC, the impact of genetic data laws, and so-called 'women's healthcare' in the Russian Federation. In comparison the United States, the outcomes of these interviews revealed an eerily similar but different pattern of the militarization of care in relation to the intersections between so-called women's healthcare and genetics.

My interview with Dr. Anastasiia Novkunskaia, a sociologist from the European University at Saint Petersburg, revealed several interesting findings. She first explained that comprehensive healthcare is inaccessible for most Russians who live outside of major cities. However, it is normal for workplaces and schools to require gynecological exams, as this kind of medical surveillance begins in childhood with yearly exams starting at seven or eight years old. Although these exams are only performative and do not have legitimate medical value, they can cause individuals to feel a false sense of medical security through the clinical labor they must perform. Lastly, she explained that Russian healthcare for women is largely focused on pro-neo-natal issues, with most cases of genetic testing being implemented for fetal genetic diagnostic tests.

Legally, Russia has followed suit with many other countries in prioritizing genetic testing strategies. Vladimir Putin's official decrees from 2019 ordered the creation of genetic passports for all Russian nationals by the year 2025, under the National Chemical and Biological Security Strategy, and he also ordered the creation of a national genetic information database, placing genetic testing and data as a militarized form of care rather than a strictly healthcare-based approach.<sup>45</sup>

Despite these decrees, the legality of using genetic information in medical systems remains unclear. My interviews with the founder of Moscow-based genetic testing company OncoAtlas, Vladislav Mileyko, and one of the OncoAtlas' doctors, Dr. Aleksandr Reznik, confirmed that there is a massive lack of infrastructure for genetic testing and its implementation in healthcare within the Russian Federation. They also expressed serious concerns about the ethical and social impact of Putin's decrees. As

<sup>44</sup> Ibid, 159.

<sup>45</sup> Polina Zvezdina, "У россиян могут появиться генетические паспорта" [Russians may have genetic passports], ПБК, April 9, 2019, <https://www.rbc.ru/society/09/04/2019/5ca72ca29a7947fd6d24a96f>, acc. August 30, 2023.

genetic data falls within this security strategy, they explained that there are already laws in place forbidding the exchange of genetic information and data between the Russian Federation and other countries due to the government's view that genetic data is a weapon that could be used to compromise national security.

Starkly contrasting the Russian Federation, the work's involvement as a commission of the *m/other becomings* with the Bioart Society in Finland revealed an entirely different approach to care. As part of a site-specific video for the *Self-Care*, I interviewed Dr. Kristiina Aittomäki, a Finnish expert on both genetic testing and breast cancer research. She explained how Finland has been a forerunner in the EU Beyond 1+ Million Genomes Project, which is working to create European networks for sharing genetic and clinical data.<sup>46</sup> She also discussed how Finland has extensive legal frameworks built around genetic testing and the use of genetic data as part of healthcare strategies, as genetic information is viewed as part of healthcare, which legally falls into the Finnish constitutional protection of right to life.<sup>47</sup> However, Finland has high populational frequencies of pathogenic founder mutations and ranks as one of the highest countries in the world with incidences of breast cancer.<sup>48</sup>

Since exhibiting the work, the Finnish Genome Act was expected to be accepted by the Finnish Parliament in June of 2022 and formally establish the Finnish National Genome Center, which would act as a centralized authority regulating the use of genetic information.<sup>49</sup> The current state of The Genome Act remains to be discussed with an agreement that the creation of the Genome Center is necessary to further assess the legal aspects and impact of bio-banked genetic data.<sup>50</sup>

## Conclusions

As genetic testing continues to become increasingly prevalent in medicine and more diseases are found to have genetic causes, there will be more individuals emerging as mutants who must grapple with the myriad of cultural, economic, and legal implications of their newfound identity. However, as mutants, these individuals possess generative power to spawn new narratives about the genetic body concerning identity, access to care, and the conceptualization of new boundaries between *health* and *disease*. *Self-Care* will continue to live on as an artistic attempt to care for and

<sup>46</sup> B1mg-Project.eu, "About the Beyond 1 Million Genomes (B1MG) Project," B1mg-Project.eu, <https://b1mg-project.eu/about/>, acc. May 28, 2023.

<sup>47</sup> Oikeusministeriö, "Hallituksen Esitys Eduskunnalle Laiksi Genomikeskuksesta" [The government's proposal to the parliament as a law on the Genome Center], *Finlex* (Finlex, 2022), <https://www.finlex.fi/fi/esitykset/he/2022/20220110#idm45843167893168>, acc. on August 30, 2023.

<sup>48</sup> Ibid; Hyuna Sung et al., "Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries," *CA: A Cancer Journal for Clinicians* 71, 3 (February 4, 2021): 209–49.

<sup>49</sup> Tiina Wahlfors et al., "Reaching for Precision Healthcare in Finland via Use of Genomic Data," *Frontiers in Genetics* 13 (April 26, 2022). Oikeusministeriö, "Hallituksen Esitys Eduskunnalle Laiksi Genomikeskuksesta".

<sup>50</sup> Oikeusministeriö, "Hallituksen Esitys Eduskunnalle Laiksi Genomikeskuksesta."

conceptualize the self and its entanglement of multiple subjectivities, as the work continues in its autoethnographic approach to site-specific installations. So far, the sheer range of historical, social, and political implications of the genetic body touched upon within the realm of the artwork and its autoethnographies demonstrates how issues concerning emerging disease identities based on genetic tests are not universal. Like self-identity and notions of self-care, they constantly are engaged in moments of rearticulation and redefining, forever attempting to find a more stable ground for life to grow.

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