

***Book as Body: The Meaning-Making of Artists' Books in the Health Humanities***

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## Abstract

### ***Book as Body: The Meaning-Making of Artists' Books in the Health Humanities***

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This research-creation dissertation investigates how artists' books' text, images, form, materiality, and other sensory engagements merge to communicate lived experiences of illness and disability. I ask how the meanings of these abstracted book-bodies adapt and change when they are re-interpreted by readers, and how this can be an effective strategy for forming relational understandings of what it is like to live with illness. Within the framework of a phenomenological practice, I show the generative potential for empathy and intercorporeal exchange that often occurs when engaging with another's artist's book. Next, I describe past practices of artists who have deployed artists' books in negotiating the biomedicalization of their illness experience. I then reflect upon my own contribution to the intersection of artists' books and healthcare, *Field Notes: How to Be With*. Finally, I analyze the outcomes of artist's book workshops I developed and conducted with multiple communities, including biomedical personnel. These distinct, but inter-related research-creation practices indicate how patient communities can devise tacit and multi-sensory expressions of embodied phenomena that may otherwise be difficult to communicate through verbal means alone. From a health humanities perspective, the pedagogical potential of reading and making artists' books may assist in resisting systemic pressures for clinical efficiency and unseat biases towards illness and disability. This research-creation dissertation thus serves as a philosophical, pedagogical, and pragmatic example of how to engage with artists' books in health contexts. It examines how the formation of archival, hand-made book objects constitutes a legacy of lived experience that may be called upon, again and again, to share and understand life, death, illness, health, unease, and wellbeing.

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This thesis is not a single heroic effort, but comprised of a combination of collaborators who generously lent their voices and expertise to this research. The workshop participants and interviewees provided perspectives into the concept of books and bodies that would not have been possible otherwise. Dr. Stella Bolaki supervised and partnered with me to conduct the UK fieldwork that comprises much of this dissertation, and with whom I share a passion for artists' books. Her efforts to assemble the Prescriptions Collection of artists' books set the stage for this investigation. Most of all, I acknowledge the long-standing collaboration with my sister, Dr. Devan Stahl, who continues to show her bravery by making herself vulnerable. The generosity of sharing her stories and medicalized body not only motivates this research, but continues to build community with all those with lived experiences of illness.

I also extend my sincere gratitude to SHHRC Vanier, Mitacs, Hexagram, Milieux, the Carolyn & Richard Renaud endowment, the Rose and Leon Zitner endowment, and the Humanities PhD program for funding and supporting wonderfully unconventional interdisciplinary research-creation like mine. These programs prove there is space for the thinking that occurs during artful making and play within academic scholarship.

Finally, I give my deepest gratitude to my friends and family who have always supported my pursuit of the arts. Even though these pursuits have taken me far away from home, our frequent video calls have always made me feel close. And to my partner Julien Pestiaux, who did not balk, even for a second, as I turned our entire small apartment into a make-shift art studio so I could complete this work during the Covid-19 shutdowns. I am eternally grateful for your unending enthusiasm and love that buoys my dreams.

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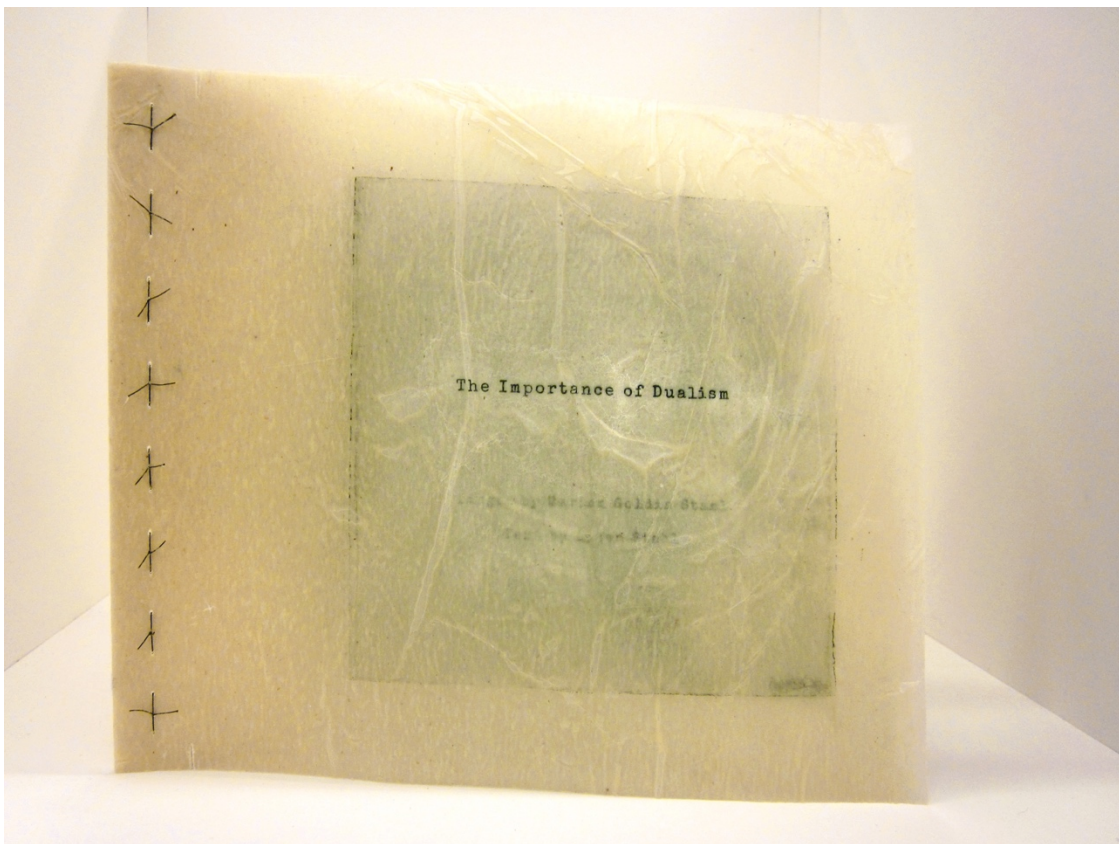
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## Introduction

I will convey to you that the book is a body. The very language used to describe books reveals our bodily relations with them. Books contain a head, headers, and headbands; footers, joints, a spine, face, and back. The materials we use to create books have parallel corporeal significance: signatures, guillotines, scalpels, and bone folders. Books are enveloped in leather or cloth, then placed within jackets to keep them protected. Engaging with a book is an activation of bodies. Far from an inert activity, reading a book is an embodied performance of cracking its spine, skimming pages, skipping over sections, flipping through chapters, or diving into a good read. Our bodies' remnants become a part of the books we hold dear. Our oily fingerprints yellow the corners of pages, creating a pallor and texture not unlike an aging complexion. The well-worn creases we impart to our most beloved books evoke the wrinkles inscribed on the surface of skin.

Books join bodies together through time and space. Books capture a time of the author, require time from the reader, and yet, resist time entirely as an archival form. They mediate the wide spaces between the writer and reader as they entangle the perception and imaginations of both parties. Books also take on a life of their own. They seem to possess a self-determined quality as they pass from hands to hands or journey to reside in far-reaching collections. From any distance, books intermingle the consciousnesses of the author with every subsequent reader—a connection that is made all the more corporeal and significant if that book was carefully and lovingly made by hand.





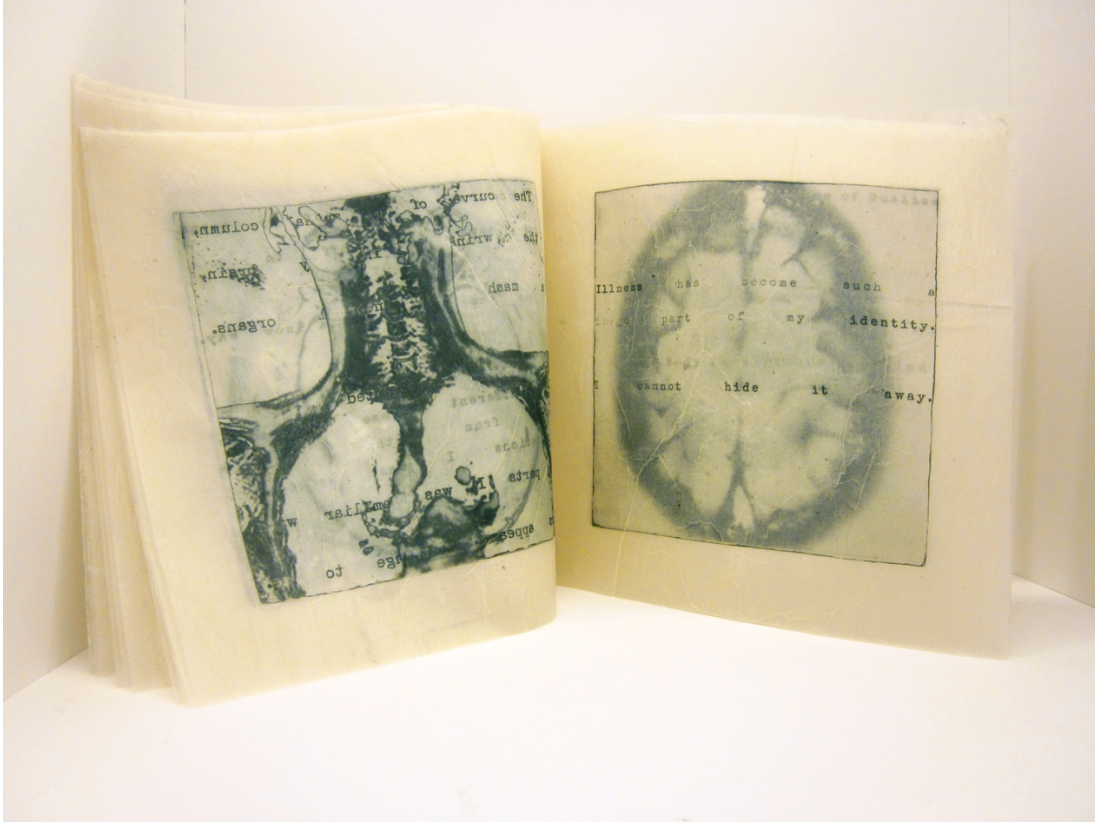


Figure i: Darian Goldin Stahl, *The Importance of Dualism*, Photo-intaglio, 6" x 5.5," 2014.

My first artist's book was an attempt to understand another person's body—that of my sister, Devan (See Figure i). Six years after her diagnosis of multiple sclerosis, Devan procured and shared with me several complete sets of her brain and spinal MRI scans that her neurologist copied onto a CD. Devan thought, since I was an artist already studying the history of medicine and printmaking, that I could somehow use these biomedical images in my work. Scrolling through the black and white digitization of her body, I was first struck at how alien these scans felt. I could not even recognize my sister's face, and while they told her physicians what they needed to know about her disease, they communicated absolutely nothing about *her*, the impact her diagnosis had on her sense of identity and future plans, nor what it felt like to live daily with the symptoms of MS.

Even though this was an entirely digital medium, I was also struck by the seeming pagination of Devan's body. As I scrolled my cursor up or down, I was able to dive *through* each layer of her anatomy. I imagined every minute slice of her MRI scans to be a piece of paper that could be stacked and bound one on top of the other, and pulled across my thumb to form the animated illusion of a flip book. With that thought, I felt compelled to "corporealize," that is, give a body to, these digital scans. In the format of an artist's book, Devan's narrative could be printed alongside the images of her body in order to rectify the reduction of her illness into those flat scans, and then to share her experience with others as an artist's book edition. I believed the translation of Devan's body into a book was my gesture of care. I was letting her know I was deeply considering the impacts of the diagnosis on her life, and, in a small way, bending the

world she moves through towards more empathetic understandings of what it is like to live with illness.

This thesis emerges from our initial collaborative bookmaking practice and expands it to include an investigation of other artists' books that engage topics of illness and medical encounters. I also examine how teaching bookmaking within a health humanities context can promote empathy with those who live with illness. Artists' books can be a means of creating understanding and empathy between patients and healthcare professionals (as well as the general public) when they actively address the disconnection between medical diagnoses and the embodied, lived experiences of illness. Fostering these connections through the productive blending of intimate sensory engagement, temporality, performativity, imagery, and narrative of artists' books may help to mend this gap.

By employing research-creation bookmaking practices, my investigations will address the following questions: *How might artists' books communicate the lived experiences of illness?* How might an intimate engagement with these works create empathetic relations between the reader and the book's subject? Can artists' books change the way readers view illness? If so, how might we understand this method of meaning-making through a phenomenological point of view? In addition to these relational questions, I uncover how the the *process* of creation informs or even transforms an ill person's sense of identity and agency.

My goal is not only to investigate what bookmaking can offer the artist, but also how artists' books may impact and sensitize health practitioners. How might taking the time to read and make artists' books in health humanities contexts counter systemic pressures of clinical efficiency that lead to the dissatisfaction of patients and practitioners alike? Additionally, how can research-creation practices fit within a positivist medical paradigm? Does passing a book between one and another, experiencing its sensorial form, and readings its pages effectively open up the possibility for patients and physicians to find shared understandings of illness together? Overall, this research-creation project examines if a sense of wellbeing can be fostered with those who experience illness through this process of making, discussion, and mutual incorporation.

### *Methodology and Methods*

The methodology I use for this research-creation thesis is a feminist-informed phenomenology. Phenomenology is apt for this investigation because it examines lived experiences, and in particular, re-examines habituated phenomena. This re-examination is especially significant when the matter at hand concerns how the body changes in times of illness and how artists alter the typical reading of books. Making up for critical gaps from its initial proponents like Maurice Merleau-Ponty,<sup>1</sup> contemporary feminist phenomenologist like Gail Weiss<sup>2</sup> and Elizabeth Grosz<sup>3</sup> provide a framework for this philosophical practice that is cognizant of how identity, geography, culture, personal experience, and ability all influence perception, thereby making objectivity an impossibility. Subjectivity is crucial to our discussion of artists' books because the abstracted body portrayed in book-form makes every subsequent reader just one of a multiplicity of determinants for its meaning. The ability to evoke personalized significance forms the basis of the connective power of artists' books and keeps the medium lively and dynamic.

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<sup>1</sup> Maurice Merleau-Ponty, *The Visible and the Invisible* (Evanston: Northwestern University Press, 1968).

<sup>2</sup> Gail Weiss, *Intertwinings* (Albany: State University Press of New York, 2004).

<sup>3</sup> Elizabeth Grosz, *Volatile Bodies* (Bloomington: Indiana University Press, 1994).

I apply phenomenology, and in particular the phenomenology of illness, to the making and reading of artists' books. For example, I understand the reversibility of perception described by Merleau-Ponty and others through an embodied bookmaking practice that conceptualizes the interconnectivity between author and reader. In short, I ask, "How do you touch a book, and how does a book touch you?" There are also explicit connections between phenomenology and books that make it a methodology particularly apt for this investigation. The "leaves" Merleau-Ponty describes, that is, the dual property of inward and outward perception,<sup>4</sup> also describe the leaves of a book: the folding of a two-dimensional plane back into itself that creates each folio. Bookmaking and examples of specific books will be used throughout this thesis as evidence of the philosophy in practice.

I use a mixed-methods approach to the thesis questions, including historical research on the intersections of medicine and bookmaking, sensory readings contemporary artists' books on illness within archives, expert interviews, and developing pedagogical artist's book workshops as case studies for the medium's ability to elucidate illness experiences. However, the primary method that can be traced across this thesis is research-creation.

Research-creation is a geographically Canadian, and Montreal-based in particular, term for the kinds of evidence and knowing that can only occur through creative processes and outcomes.<sup>5</sup> Other names and articulations for this method in North America and the UK include arts-based research, artistic inquiry, a/r/tography, among many others.<sup>6, 7</sup> Scholars and pedagogues like Elliot Eisner began promoting the collaboration between science and arts-based research methods in the US in the early 1980's, stating that "each sheds its own unique light on the situations that humans seek to understand."<sup>8</sup> Although creating art has always been a method of researching the given world, experience, or cognition, it is only recently (the 1990's for Canada) that creating art as a method and output of research was formally recognized by universities in the form of a PhD, as well as new streams of funding from federal organizations like the Social Sciences and Humanities Research Council (SSHRC). US proponents like Patricia Leavy,<sup>9</sup> Shaun McNiff,<sup>10</sup> and Susan Finley<sup>11</sup> continue to form conceptual rationales and pragmatic methods for conducting arts-based research, and Canadian scholars like Natalie Loveless, Erin Manning,<sup>12</sup> Kim Sawchuk, and Owen Chapman<sup>13</sup> nuance and analyze the potentiality of research-creation to form new knowledge.

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<sup>4</sup> Merleau-Ponty, *The Visible and the Invisible*, 138.

<sup>5</sup> Natalie Loveless, *How to Make Art at the End of the World* (Durham: Duke University Press, 2019), 4.

<sup>6</sup> Ibid.

<sup>7</sup> Patricia Leavy, *Method Meets Art: Arts-Based Research Practice* (New York City: Guilford Press, 2015), 5.

<sup>8</sup> Elliot W. Eisner, "On the Differences Between Scientific and Artistic Approaches to Qualitative Research," *Review of Research in Visual Arts Education* 7, no. 1 (1981): 7.

<sup>9</sup> Leavy, *Method Meets Art*.

<sup>10</sup> Shaun McNiff, "Art-Based Research," in *Handbook of the Arts in Qualitative Research: Perspectives, Methodologies, Examples, and Issues*, eds. J. Gary Knowles and Ardra L. Cole (Los Angeles: Sage Publications, 2008), 29-40.

<sup>11</sup> Susan Finley, "Arts-Based Research," in *Handbook of the Arts in Qualitative Research: Perspectives, Methodologies, Examples, and Issues*, eds. J. Gary Knowles and Ardra L. Cole (Los Angeles: Sage Publications, 2008), 71-82.

<sup>12</sup> Erin Manning, "Ten Propositions for Research-Creation," in *Collaboration in Performance Practice*, eds. Noyale Colin and Stefanie Sachsenmaier (London: Palgrave Macmillan, 2016), 133-141.

<sup>13</sup> Owen Chapman and Kim Sawchuk, "Research-Creation: Intervention, analysis and 'family resemblances,'" *Canadian Journal of Communication* 37 (2012): 1-22.

Research-creation applies in this thesis not simply to the study of others' artists' books, but to creating new work that is in itself a method of consolidating interdisciplinary knowledges into a form where their intertwinings become clear. Once research takes on the form of a shareable object, the proposition that a sensory and embodied engagement with artwork can produce new meaning that could not be ascertained through other more traditional means (like this written thesis component) becomes demonstrably evident. Ultimately, the research-creation is the primary evidence for the research questions.

The research-creation outcome of this investigation is the artist's book, *Field Notes: How to Be With* (see Figure ii). This piece merges all of my fieldwork and other research methods into a tangible object editioned to five. Through the creation and reading of this artist's book, I show how the merging of text, image, form, and temporality enables an embodied communication of our encounters with medicine.

The text in this artist's book results from my expert interviews with eighteen UK and US scholars working at the intersections of humanities and healthcare. I then excerpt and rearrange their voices within *Field Notes*, as if these researchers were debating one another. This text brings up some of the most vital concerns in the burgeoning field of health humanities, such as the inclusion of arts-based pedagogies, the position of nonhuman beings in research, and centering the perspectives of patients.

The images in *Field Notes* are made in three collaborations. First with my sister, whose medicalized body continues to be closely surveilled as her identity evolves from a chronically ill woman to a chronically ill mother. Devan's MRI scans of her spine and brain are complemented in this work with fluoroscopy and ultrasound scans of her pelvis. Devan's continued partnership in our artist's book projects grounds a philosophical framework with the real-world experience of being ill.

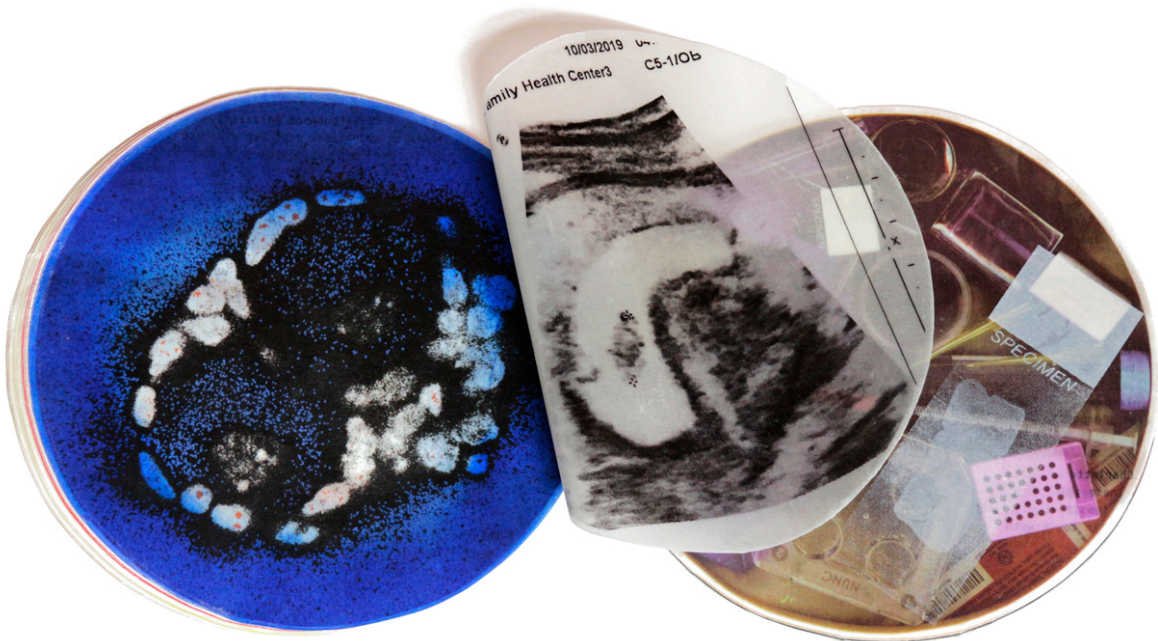


Figure ii: Darian Goldin Stahl, *Field Notes: How to Be With*, Wax, silk, toner, and embroidery, 8" round, 2020.

The second collaboration is with two scientists during my artist residency at the McGill University Fertility Research Laboratory. To get a well-rounded perspective of what health research looks like, I found it necessary to embed myself in the daily life of the laboratory where experiments and discoveries may go on to impact people like my sister. At the end of my time in the lab, we gathered the daily ephemera of the scientists' work, like colorful syringes and biohazard bags, to create assemblages together on the bed of a scanner. Although I was unable to photograph the mice whose bodies enable the scientists' research, I honored them as golden embroidered pages and by including radiant microscopy of their dissected ova.

The final image collaboration present in this work is with each reader. Along with the readers' role in activating the book-body and intermingling their imaginations with the perspectives within, the method of translucent printing I developed enables their hands to become literally implicated in the compositions. Imbuing silk with beeswax and pigment to form a transparent substrate, I then layered toner between incredibly thin sheets of malleable wax medium. The results portray richly saturated, illusionistic depth on an utterly flat surface, while also preserving transparent negative space to complicate each page with the hands and images that lie beneath.

The pages of *Field Notes* merge the aesthetics of science and medicine with printmaking, and entangle the networks of human, animal, and synthetic materials that power health research. My goal in paginating this research into an artist's book is, first, to make these relationships tangible to the reader. What may feel like distinct realms, like a fertility laboratory or the home where a first ultrasound is hung, exist along a continuum of scientific discovery to real-world impact. The layering of image and text merge the interdisciplinary and collaborative research that evidence these relations, while the transparency enables each reader to see themselves within the narrative.

Next, by taking the form of an artist's book, I exemplify the potentiality of the medium to contribute new knowledge within health contexts. Although each of the aforementioned components of research are thoroughly detailed within this adjoining written thesis, I consider this object to be the research outcome. I finished *Field Notes* before this writing, and many of my conclusions about the role of artists' books to form a nexus between makers and readers could not have been reached without the primary process of creation.

The research-creation methods I exemplify in this investigation extend beyond my own collaborative studio practice and into the pedagogical. To further evidence the accessibility of research-creation to elucidate experiences of illness, I developed "Book as Body" artist's book workshops for mixed groups of health researchers and those with experiences of illness. I guide participants through the process of creating an artists' books on a topic of a bodily concern, which is then shared, held, and interpreted by the other participants as a form of collective meaning-making. Through these workshops, I exemplify how applied phenomenological research-creation can be employed within the health humanities classroom. If my goal is to proliferate the use of sensory and artistic methods of understanding lived experiences of illness, then it is necessary to model such pedagogies aimed at those who do not necessarily have any prior arts experience. Positioned as healthcare research, such artistic inquiry also exemplifies the potentiality of subjective meaning-making for learning, rather than solely seeking objective, singular truths of the natural world. Therefore, research-creation is the principal method of investigation that binds all of the chapters of this thesis together.

### *Literature review and Contributions to Knowledge*

This thesis primarily engages the disciplines of artists' books, the phenomenology of illness, and the health humanities. Artists' books are a relatively new medium that was only coined in the 1970's as a distinct genre. As artist's book scholars like Stefan Klima,<sup>14</sup> Charles Alexander,<sup>15</sup> Joan Lyons,<sup>16</sup> and Johanna Drucker<sup>17</sup> point out, the medium has had fluctuating appeal since its conception, which has resulted in a dearth of literature on the topic and especially from a philosophical and sensory perspective. However, the diversification of artists' books, capacity to provide missing voices in library holdings, and their appeal to women in particular have led to a resurgence of interest in the medium for the 21<sup>st</sup> century. Regarding artists' books that concern illness in particular, a foremost scholar is Stella Bolaki,<sup>18</sup> who recently edited an issue of the *Journal of Medical Humanities* on the topic<sup>19</sup> and is the principal investigator for the Prescriptions Collection out of the University of Kent. This project commissioned and collected over seventy artists' books on the broad topics of health, illness, and mortality. Many of these artists' books are cited as primary resources within this thesis.

For the discipline of artists' books, this research-creation thesis contributes valuable methodologies for their making and reading. Specifically, I outline the aspects of *bookness*, that is, our engrained and preconceived notions of structures and formats for various printed matter, how artists manipulate these aspects to form overt and tacit meaning, and ultimately, how these objects perform a sense of embodiment with their readers. Much of the literature concerning artists' books focuses the art history and categorization of the medium, but what is far less discussed is their relational force and philosophical methodologies for empathy creation. The written word in conjunction with an activation of the senses enables multimodal strategies for expression that can hardly be matched by any other medium, which is well worth a thorough investigation. When the topic of these works concern illness, disability, and medical encounters, their potentiality for countering bias and stigma through mutual incorporation positions artists' books as a medium of vital importance. I aim for this thesis to contribute a substantial rationale for situating these artists' books as primary resources in health research.

S. Kay Toombs, Havi Carel, Drew Leder, and Elaine Scarry provide the foundational literature on the phenomenology of illness and symptoms like pain. Toombs outlines the essential aspects of illness,<sup>20</sup> which encompass the topics of lived experience within the artists' books I discuss. Carel's book, *The Phenomenology of Illness* (2016), details how intercorporeality can be formed with ill persons around shared experiences. This concept is especially important for elucidating the connectivity experienced while co-creating, sharing, and reading another's artist's book.

Phenomenology is a largely discursive practice of description and interpretation, but what about the sensations or experiences that are difficult or cannot be put into words? To create more

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<sup>14</sup> Stefan Klima, *Artists Books* (New York: Granary Books, 1998).

<sup>15</sup> Charles Alexander, *Talking the Boundless Book: Art, Language and the Book Arts* (Minneapolis, Minnesota Center for Book Arts, 1995).

<sup>16</sup> Joan Lyons, *Artists' Books: A Critical Anthology and Sourcebook* (New York: Visual Studies Workshop Press, 1985).

<sup>17</sup> Johanna Drucker, *The Century of Artists' Books* (New York: Granary Books, 1995).

<sup>18</sup> Stella Bolaki and Egidija Ciricaite, *Prescriptions: Artists' books on wellbeing and medicine*, (London: Natrix Natrix Press, 2017).

<sup>19</sup> Stella Bolaki, "Artists' Books and Medical Humanities," *Journal of Medical Humanities* 41 (2020).

<sup>20</sup> S. K. Toombs, "The Meaning of Illness: Phenomenological Approach to the Patient-Physician Relationship," *Journal of Medicine and Philosophy* 12 (1987): 219-240.

opportunities to form shared experiences, Elaine Scarry's *The Body in Pain* (1993) and Drew Leder's *The Distressed Body* (2016) both conclude in the productivity of materializing lived experiences as objects that can be held and intimately known by others. Scarry explains that, because a phenomenon like pain is extremely difficult to express, object-ifying it outside of the body as a creative, sharable form may disperse the effects of isolation incurred when one feels unheard.<sup>21</sup> What's more, feelings of understanding and connectivity are especially present within a sustained collaboration, where two people may share in "the pleasure of world-building rather than pain as the occasion of their union."<sup>22</sup> Leder agrees that creating objects with and for others imbues them with a sense of caring, and when held, fosters a sense of "mutual incorporation," or giving active consideration to the experiences of another "through a natural empathy."<sup>23</sup> These phenomenological practices account for the intercorporeality felt in the midst of engaging with another's artist's book—an intimacy that allows diverse maladies to be touched, seen, read, and tacitly known by others.

The applied aspects of this research-creation thesis are a wholly original approach to the phenomenology of illness. Although Merleau-Ponty (and many other phenomenologists since) employs a study of artworks like Cezanne's to understand perception and the visible,<sup>24</sup> I take this practice a step further and ask what *making* art with and for others is able to elucidate. Artists' books, like the ones presented in this thesis, activate not only vision but multiple senses to initiate embodied relations between authors and makers. As well, there has never been an explicit connection made between the intercorporeal potential of artists' books and the phenomenology of illness in my review of the literature. The objects given as examples by Scarry and Leder include warm clothing and quilts—creations of care and comfort for others. I argue that creating artists' books with and for others is also a method of showing care, as my collaborative practice with Devan exemplifies. This thesis evidences how artists' books contain the capacity to intertwine phenomenological 'flesh,' which is a novel contribution to this philosophical practice.

The third discipline this research-creation thesis engages is the health humanities, which is a broad and inclusive field for health research that may fall outside of strictly clinical boundaries. Rather than a set of pedagogies for mobilizing the humanities within medical school, generally known as medical humanities, the *health* humanities widely applies to health research conducted across any number of disciplines, such as the social sciences, literature, and art. The health humanities begins with the acknowledgement that biology and physiology are but links within a network of factors that determine one's health and wellbeing. Once released from a scientific paradigm, humanities- and arts-based methodologies may be better suited to engage with the social determinants or understandings of health and illness, especially in partnership with non-specialist populations. If health professionals aim to cultivate more productive, informed, and aligned partnerships with patients, then it is necessary to take seriously the notion that the humanities are integral to such aims. The integration of humanities and arts methodologies into healthcare institutions is gaining momentum, and this thesis contributes a conceptual rationale and practical models for employing artists' books in health research, particularly as primary resources of illness experiences.

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<sup>21</sup> Elaine Scarry, *The Body in Pain* (Oxford: Oxford University Press, 1985), 170.

<sup>22</sup> *Ibid.*, 291.

<sup>23</sup> Drew Leder, *The Distressed Body* (Chicago: The University of Chicago Press, 2016), 94.

<sup>24</sup> Maurice Merleau-Ponty, "Eye and Mind," in *The Essential Writings of Merleau-Ponty*, ed. Alden L. Fisher (New York: Brace & World, Inc., 1969), 259.



Emerging health, medical, and critical medical humanities scholarship provided by Paul Crawford,<sup>25</sup> Alan Bleakley,<sup>26</sup> and Jane Macnaughton<sup>27</sup> (respectively) support *practice*-based approaches to health pedagogies, like participatory theater or creative writing, rather than solely the intellectual study of philosophy and case studies. A utility perspective of arts-based pedagogies suggests they can improve communication skills and tolerance of ambiguity, which are two leading causes of medical error.<sup>28</sup> In a more intrinsic evaluation, research-creation pedagogies enable students to access deeply buried emotions and counter the systemic pressures for time and stoicism that can ultimately lead to burnout and a perception of indifference from their patients.<sup>29</sup> Although studying art and museum visits are on the rise within health humanities syllabi, *making* art has yet to find a solid purchase in these classrooms.

For the field of health humanities, into which I situate the research-creation practice of making books on illness experiences, this thesis provides a detailed example for how artists' books can be incorporated into healthcare learning. While the growth of the health humanities pedagogies has primarily focused on patient narrative and literature, the power of communicating lived experience through the senses via artists' books has been generally overlooked. Given the gap of investigation between the phenomenology of artists' books and the health humanities, I am in the unique position to connect these fields of study and point its direction for future research and applications.

### *Chapter Structure*

The first two chapters of this thesis set the groundwork for how bodily phenomena are translated into book forms, how centuries of printing and bookmaking have set a visual standard for various types of printed matter, and finally, how artists flip these conventions in their artists' books in order to communicate experiences of illness. These initial chapters frame conceptual and longitudinal perspectives of bodily representation in and as books, which are then used to examine subsequent examples of artists' books. The last three chapters concern the role of artists' books in the health humanities, including the dissemination of artists' books within institutional archives, employing them directly in the clinical setting, and health humanities pedagogical case studies. The arch of this thesis moves from broad ideas about the book as a body, and concludes with specific examples of student-makers and their books.

Chapter 1 provides a philosophical foundation on which to build the meaning-making of artists' books, namely, phenomenology. The examination of lived experience and sensory evocations of artists' books position phenomenology as an apt framework for this investigation. It is also applied to account for the feelings of connectedness between makers and readers. The chapter is structured in a 'question and answer' format, which illuminates the most pertinent questions a reader may initially have about artists' books and how they are related to topics of

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<sup>25</sup> Paul Crawford et al, *Health Humanities* (Hampshire: Palgrave Macmillan, 2015), 6.

<sup>26</sup> Alan Bleakley, "Transitions in Health Humanities — Towards a 'Critical' Health Humanities that Embraces Beauty," in *In/Sight 2: Engaging the Health Humanities*, eds. Lianne McTavish and Pamela Brett MacLean (Edmonton: University of Alberta Press), 12.

<sup>27</sup> Jane Macnaughton and Havi Carel, "Breathing and Breathlessness in Clinic and Culture: Using Critical Medical Humanities to Bridge an Epistemic Gap," in *The Edinburgh Companion to the Medical Humanities*, eds. Anne Whitehead and Angela Woods (Edinburgh: Edinburgh University Press, 2016), 296.

<sup>28</sup> Alan Bleakley, "When I say... The Medical Humanities in Medical Education," *Medical Education* 49 (2015): 960.

<sup>29</sup> Arno K. Kumagai, Elizabeth K. Jones, and Anne L. Kittendorf, "Creative art and medical student development: A qualitative study," *Medical Education* 51 (2017): 174.

illness. The first questions are as simple as, “What are artists’ books?” Later questions are more complex: “What do artists’ books *do*?” This chapter also outlines the aspects of bookness. Capitalizing on or subverting facets of bookness prevail as the guiding source of influence for artists to overtly and tacitly communicate their lived experiences. The practice of phenomenology is sustained throughout this research-creation thesis as the primary methodology for both creating and reading artists’ books.

Chapter 2 takes on a longitudinal perspective of the intersections of books and bodies, which have set in place the standards of human representation within the visual culture of medicine. This chapter also demonstrates how “The Book” has become a transcendental icon of knowledge, whose methods, images, and forms are appropriated and reproduced again and again through the centuries until the standards for bookness are set. I demonstrate the staying power of these conventions by comparing historical anatomical treatises and contemporary artists’ books on the body. I argue that examining the long arc of medical representation is vital for our contemporary conceptualization of medical objectivity and patient subjectivity, as well as the role of artists for collapsing such dualities. The centuries-old examples of collaborative bookmaking procedures between anatomists, illustrators, printmakers, bookbinders, and publishers, while different in purpose and scope to artists’ books, nevertheless exemplify how an artist’s representation of the body breathes life and meaning into medical specimens. This study is meant to bring a full-circle perspective on the potential of reintroducing artistic representation into research on the body.

Chapter 3 then examines how specific artist’s bookmakers expand and subvert the aspects of bookness by manipulating their text, imagery, temporality, and form to communicate encounters with medicine. These perspectives are informed by my fieldwork in the UK as a visiting scholar in the University of Kent Medical Humanities Program. With a high concentration of researchers situated at the intersection of health and art in the UK, I had the opportunity to interview over twenty scholars to get a sense of the most emergent debates within the health humanities. These perspectives frame my subsequent reading of the numerous artists’ books on illness held in the University of Kent’s Prescriptions Collection that heavily influenced the research outcomes of this thesis. To merge all of these voices and artistic perspectives, this chapter is structured as a sensory reading through *Field Notes*, which arranges the interviewees and visual collaborations within a layered form.

Chapter 4 invests in a close examination of one artist’s books, Martha Hall, and the strategic employment of her works within clinical interactions. Hall’s practice exemplifies the capacity of artists’ books to influence practitioners’ understanding of illness, as sharing these books led to more effective communication with the oncologists charged in her care. After Hall’s death from a reoccurrence of cancer in 2003, her books have since been used as pedagogical source materials in medical humanities classrooms, where they sensitize future health practitioners to differences in communication styles and expectations for quality time they can expect to encounter with their patients. Hall’s books show how the accounts of one’s lived experiences can endure as artist’s books, as her legacy continues to influence new generations of health learners as part of medical school library archives.

The final chapter outlines the “Book as Body” artist’s book workshops I developed and conducted in Canterbury and Paris as case studies for practice-based health humanities pedagogies. These workshops apply a phenomenological process of making and reading artists’ books on the topic of symptoms. After detailing the making procedure, I use the artists’ books created by the participants as well as transcriptions of the group critiques as evidence that the

workshops indeed promote collective reflections on others' lived experiences. These case studies also exemplify how, even though a book is made with a particular experience in mind, their meaning is expanded to include the perspectives of their readers that ultimately facilitates an embodied and relational perception of symptoms. This chapter is meant to serve as a replicable model for practice-based approaches to phenomenology and research-creation.

Artists' books are first and foremost an experiential medium whose full meaning can only be grasped through handling. Although there are essential compromises to providing text about the artists' books rather than a direct experience of them, I have sought out permission from each artist to reprint images of their artists' books within this thesis, and provide a sensory description of each work to make up for these deficiencies. Through such rich description, I aim for readers to be inspired to seek out such works in nearby collections in order to experience artists' books firsthand. As well, by providing detailed instructions for making an artist's book on a phenomenon felt within one's body, I aim for readers to try this reflective practice out for themselves. In and through the creation process, we may understand ourselves anew, and enable others to understand us for the first time.

## Chapter 1

### The Phenomenology of Artists' Books

#### Introduction

To read an artist's book on illness is to experience the embodied form *with*, while simultaneously *apart from*, its maker. The artist has identified a bodily phenomenon, imagined its form, labored it into being, and shares this materialization of her consciousness with each reader through an intimate encounter with her book. As an artist's abstracted expression of her body, the reinterpretation of an artist's book also implicates the reader in a multiplicity of co-created meanings. The artistic and sensory choices of the bookmaker initiate such meanings, while its significance emerges from an entanglement with each reader's unique perception of the book-body. Artists' books are thus inherently relational, and the bond between bodies that occurs while one holds, senses, reads, and performs another's handmade book is a connective force between two people that is forged again and again, through time, and over any distance.

To conceptualize the power of artists' books to express lived experiences of illness to and with others, I begin this thesis with an investigation what artists' books *are* and the phenomenological practice of creating an artist's book. Next, I examine what they *do*. In the traversal of inception to dissemination, I will employ the most useful terms and practices from related philosophies to conceptualize the meaning-making and relational qualities of artists' books.

I situate my study of artists' books on the body within the Anglophone Western context, and particularly in regard to collections within the UK, US, and Canada. I include artists' books on the broadest topics of health and illness, including themes of profound or life-long chronic illness, acute or short-term illness, injury, disability, mental illness, bodily distress, mourning, pregnancy, changes to body schema, and medical experiences more generally like doctor-patient encounters. In all cases, the books relay not only the effects of illness on the body, but also the far-reaching impact of those changes on personal relationships and daily life. I choose this broad scope because of the relatively small number of primary artist's book sources and collections that engage with the topic of illness and to promote a wider applicability of this research. For ease of reading, I include all of these articulations under the titles of 'illness' or 'illness and disability' with full concessions of the understatements or reductionism of these terms.

Additionally, I fully acknowledge that some communities might find this overarching characterization problematic, particularly disability activist and pregnancy communities who do not identify as ill. Although the histories, contexts, and members of these communities may be different, changes to bodies often share impacts to socioeconomic, political, and relational aspects of lived experiences. Another link between these topics is the fundamental misunderstanding and miscommunication between outsiders and those directly impacted: that although one is experiencing bodily unease, there also remains the likelihood for wellbeing and even health. This is the lens through which I investigate artists' books within the vast topics of illness, health, ability, disability, birth, and dying. However, I envision a future where each of these categories has its own robust artist's book collection database to employ for equally in-depth investigations.

To structure this first chapter, I have chosen a 'question and answer' format because of the relative newness and obscurity of this medium. For example, although almost anyone can

conjure up numerous examples of famous paintings or sculptures, prompting one to name an artist' book would most likely be met with confusion. I have therefore attempted to anticipate the readers' initial queries of artists' books and thoroughly answer each in order to build a common foundation of discourse for the subsequent chapters.

### **What is an artist's book?**

In the immediate decades after curator Diane Perry Vanderlip coined the term 'artist book' in 1973 as a distinguishable medium, much of its mainstream potential has been stymied by critics, curators, and scholars trying to pin down what exactly an artist's book *is*.<sup>1</sup> Even the name for the medium, from 'book arts,' 'artistic books,' and 'bookworks,' to the controversial inclusion of a possessive apostrophe in 'artists' books,' has been the topic of much debate. In an effort to move well away from this mire and instead focus on the medium's function, I will only briefly touch on its definitions while admitting to this contentious endeavor.

Given the unstable definition of artists' books, it could be simpler to categorize the medium by stating what it is not: a bound collection of photographs of an artist's work (also known as a photobook or catalogue); a self-published or small press periodical or magazine (known as a 'zine'); a hand-crafted cover and binding of blank pages (handmade journals or sketchbooks) or containing another author's text (a hand-crafted special edition); text artfully arranged on a page (concrete poetry or calligram); or an illustrated narrative (also known as comic books or graphic novels). However, even these distinctions are blurry as one could find noteworthy exceptions to each that identify as artists' books. Therefore, I assert that an artist's book, in its most broad definition, is *an object of fine art that conceptually and formally engages with some aspect of a bookness*.<sup>2</sup> Attempting to taper artists' books under a more focused definition risks limiting the medium's sheer breadth of form, topic, context, or purpose. To keep artist's books dynamic and versatile for their makers and readers, using the most inclusive definition possible will also prove to be the most productive.

Artists' books experiment and play into our culturally engrained expectations of 'bookness' to evoke or disrupt our memories and associations with print media. Covers, turning pages, a rectangular form, graphic printing, bitmapping, black text on white paper, typography, font, embossment, Braille, bullets, columns, regimented matrixes, text blocks, image blocks, paragraphs, reading left to right, margins, gutters, headers, footnotes, endnotes, bibliographies, and citations; as well as the conventional layouts of novels, magazines, newspapers, catalogues, journals, notebooks, sketchbooks, scripts, comics, cookbooks, children's books, coloring books, pop-up books, flip books, photo albums, yearbooks, how-to manuals, textbooks, dictionaries, encyclopedias, rolodexes, calendars, guidebooks, travel books, language translation books, coffee table books, pocketbooks, scrolls, hymnals, bibles, and more can all be considered articulations of bookness. As you read this laundry list, you probably flashed through images of each example in your mind, proving the existence of preconceived expectations of bookness for various forms of print media. These aspects of bookness all contain their own history of communicating information, and artists then incorporate and manipulate these facets and all of

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<sup>1</sup> Stefan Klima, *Artists Books* (New York: Granary Books, 1998), 12.

<sup>2</sup> This definition has been devised between a number of sources, including: Johanna Drucker, *The Century of Artists' Books* (New York City: Granary Books, 1995); Stefan Klima, *Artists Books: A Critical Survey of the Literature* (New York City: Granary Books, 1998); and Joan Lyons, *Artists' Books: A Critical Anthology and Sourcebook* (New York: Visual Studies Workshop Press, 1985).

their referents as a self-reflexive conceptualization of how knowledge gets transferred.

Artists' books span the full range of bookness to evoke particular associations and meaning. For example, sticking to the conventions of traditional leather-backed bookbinding can give an artist's book a sense of publishable peer-reviewed authority, while completely resisting the signs of bookness tend to veer these works into the purely subjective realm. For my focus on artists' books that express the lived experiences of illness, I am most interested in the kind of limited edition, hand-made artists' books that are multi-sensory and balance poetic with didactic media. Although artists' books are contextualized as aesthetic fine art objects, meant to evoke the same wonder and emotion as any other artistic medium, the media-specific inclusions of text and image provide the artist with more control over the 'reading' of their work and the chance of maintaining the particularities of the author's auto-ethnographic investigations of bodily unease through the interpretive process.

To fully answer what an artist's book is, I take up the provocation of this thesis' title, *Book as Body*, through a phenomenological framework that conceptualizes how the binding of an artist's book seems to animate a bound stack of pages. The perceived vitality of an artist's book stems from its ability to form bodily and psychological connections between its maker and its reader. First, reading another's book becomes an intimate engagement between two people. Holding, reading, touching, smelling, spending time, and moving through a book ensures at least a cursory bodily connection with and through this object. Next, the psychological impression a book can make relies on the tacit and active interpretation of the reader. Taking in an abstracted form, the reader then has the opportunity to layer in her own associations, memories, and experiences between the book's form and content. An artist's book, therefore, is more than captivating read; it is a site for the intertwining of bodies and consciousnesses.

To explain the felt connections between people through their book creations, phenomenologist Maurice Merleau-Ponty's theory of 'flesh' is a useful concept:

Flesh is not matter, is not mind, is not substance. To designate it, we should need the old term 'element,' in the sense it was used to speak of water, air, earth, and fire, that is, in the sense of a general thing, midway between the spatial-temporal individual and the idea, a sort of incarnate principle that brings a style of being wherever there is a fragment of being. The flesh is in this sense an 'element' of Being.<sup>3</sup>

"Flesh" here is not a boundary of skin between the self and other; it is the site for an invisible give and pull of sensation between human, material, and nonhuman beings. Flesh is also wound up in the sharing of ideas, as Merleau-Ponty explains, and how these ideas carry across time and space. I argue artists' books object-ify elemental flesh. The merging of sensory expression, temporality (not only during its performance but as an archival artifact), and disseminatable ideas inherent to the artist's book make this medium an exemplar for a phenomenological practice.

The circulation of books from hands to hands also supports the thesis that artists' books are inherently phenomenological. As flesh radiates and extends our bodies to the limits of our vision, the range of our voice, and the reach of our hands, flesh is also gathered back into the body through the senses in equal measure from the things and beings that surround us. Elizabeth Grosz explains that this elemental flesh "does not just clothe subjects, objects, and their relations

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<sup>3</sup> Maurice Merleau-Ponty, *The Visible and the Invisible* (Evanston: Northwestern University Press, 1968), 139.

with its touch; it doubles back on itself as the invisible underside of the visible.”<sup>4</sup> This redoubling of flesh can be conceptualized through bookmaking, wherein the flat space of a sheet is suffused with language and sensory information from the world, layered, folded back into itself along a spine, bound into a mass, and finally covered with a thicker skin. This book-body becomes an externalized artifact of its maker’s lived experience, the dissemination of which can now greatly extend her flesh’s reach. The invisible redoubling of flesh is performed whenever one’s artist’s book is opened. Such a phenomenological framework gives language and form to the enduring impressions of an artist’s book long after its creation, and even after the lifetime of its maker.

Grosz explicitly calls upon the form of books to elucidate the reversibility of flesh: “The body is a page or material surface, possibly even a book of interfolded leaves, ready to receive, bear, and transmit meanings, messages, or signs, much like a system of writing...some of which have been effaced, others of which have been emphasized, producing a body as a text which is as complicated and indeterminate as any manuscript.”<sup>5</sup> In holding the book, experiencing it through its symbolic, sensory, and textual content, its meaning can become a part of my consciousness. The artist’s imagination and labor to create her book-body can then become a part of my own, its carnal matter merges with mine. The ‘book as body’ allegory is here fully realized as a phenomenological investigation of the visible and the invisible—of elemental flesh. When we read an artists’ book, we can now define this interaction as an engagement, expansion, and layering of flesh.

### **Why artists’ books?**

I see the medium of artists’ books to be the most apt creative form to effectively relate experiences of illness for a myriad of reasons. First, the sheer versatility and control makers have over their multi-modal artists’ books ensures that they can express the particularities of their experiences (or leave more space for open interpretation) in the manner they see fit. As well, the accessibility, materiality, mobile, performative, and intimate aspects of artists’ books make this form uniquely suited to form meaning and foster productive communication on what may be difficult discussions to begin out loud.

#### *Accessibility*

There is a comfort and familiarity with books that may make this medium perhaps more approachable than say, painting or drawing. Books are one of the first media we engage with as infants and often have continued direct contact with throughout our lives. When prompted to create their own books, makers will already have at least a cursory idea of what their creations may look like and an understanding that books are objects for all walks of life. These factors lower the stakes for their creations or the feeling of not having enough ‘artistic ability’ to create a book. The obscurity of artists’ books is helpful in this regard, because a new bookmaker will most likely not hold a canon of renowned artists’ books in their mind to compare their own novice creations against. Likewise, a reader might not have a sense of needing preparatory knowledge of ‘art culture’ in order to interpret an artist’s book. Finally, one does not need to possess an understanding of literature to glean the meaning of an artists’ book, which often do not include large amounts of text. As artist’s book scholar Ulises Carrion attests, our innate

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<sup>4</sup> Elizabeth Grosz, “Merleau-Ponty, Bergson, and the Question of Ontology,” in *Intertwinings*, ed. Gail Weiss (Albany: State University Press of New York, 2004), 23.

<sup>5</sup> Elizabeth Grosz, *Volatile Bodies* (Bloomington: Indiana University Press, 1994), 117.

ability to create connections between form, image, and text “appeals to the ability every man possesses for understanding and creating signs and systems of signs.”<sup>6</sup> The ubiquity of books as a domestic commodity for all ages resists a perceived artistic exclusivity, and may lower the psychological barriers of entry for intrepid makers.

The accessibility of artists’ books extends throughout their physical creation. Artists’ books are highly flexible forms of fine art because they can be extremely intricate in design and construction, or as modest as a single folded sheet of paper or bound stack of photocopies. It is a medium that, in its simplest form, can be learned in an afternoon. One can then choose the medium they are most comfortable with to populate its contents, such as photography, drawing, sculpture, printmaking, or collage. This final aspect is particularly useful for incorporating other ready-made and deeply meaningful media like biomedical scans, personal photographs, physician appointment cards, test results, or journal pages. An artist may even choose to incorporate larger objects or artifacts alongside their book within a book box. If there is a meaningful image or piece of ephemera, chances are there is a way to represent it within one’s artist’s book.

### *Materiality*

Artists’ books can be said to communicate within an economy of means, thanks to the expressive potential of materials not typically found in commercially printed books. Within a hand-crafted page, a multiplicity of communications can occur all at once. From their color, texture, shape, folds, turning pages, smell, symbols, and so many other non-linguistic signs, it could take a novel to describe the context and sensations that occurs in a single artist’s book. Medical humanities professor Maria Vaccarella also finds what artists’ books and artistic books like graphic novels “do in one panel will require ten, twenty pages in a novel. It’s amazing for the patient who can actually communicate that to the readers, and the readers that can actually recognize it.”<sup>7</sup> This medium, in other words, is a compact force for material expression.

In addition to sensory aspect of artists’ books that all serve to thicken the flesh between makers and readers and increase the possibility of an embodied relation, the types materials used to construct the book also enfold additional layers of meaning and influence. For example, the artist may incorporate traditional book materials to form connections with the history of printmaking and bookmaking: leather binding, marbled paper, gold trim, rag paper, linen thread, oil-based inks, moveable type, foil lettering, woodcuts, or engravings. Artists employ these traditional bookmaking materials to imbue their creations with historicity or foster an air of authority in relation to its reader. Given the absence of first-person patient perspectives in the history of prestige medical publication, such illustrious artists’ books, in an attempt to fill in gaps of knowledge of what is like to live with bodily unease, highlight these neglected voices as worthy of equal investigation through their choice of materials.

Similar to Merleau-Ponty’s description of elemental flesh, the networks of beings and materials that go into creating a book are what Jane Bennet deems *actants*, or “sources of action that can be either human or nonhuman; it is that which has efficacy, can do things, has sufficient coherence to make a difference, produce effects, alter the course of events.”<sup>8</sup> As phenomenology takes seriously the notion that the objects we create have vibrancy and a power influence, so too

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<sup>6</sup> Ulises Carrion, “The New Making of Books,” in *Artists’ Books*, ed. Joan Lyons (Rochester: Visual Studies Workshop), 42.

<sup>7</sup> Maria Vaccarella, interview by Darian Goldin Stahl, February 12, 2019.

<sup>8</sup> Jane Bennet, *Vibrant Matter* (Durham: Duke University Press, 2010), viii.



does an investigation of artist's book materials further expand the flesh of the book to the non-human beings that went into it. A close consideration of artists' books that employ common bookmaking materials like goat leather covers, fish skin binders, calf skin vellum, rabbit skin glue, cow bone folders, insect-derived pigment, silk, or beeswax brings further awareness to our networks of relations with nonhuman lives. An artist should consider not just the power and agency of a bound book assemblage, but also the interconnectedness of each actant in attendance. Further, by shining a light on all the separate actants that go into making a single book, we as artist-actants can make fully informed and ethical choices about the materials we choose to include in our books, and perhaps forge a new lineage of gentler material practices.

### *Mobility*

One of the goals for this research is to investigate how artworks can mediate communication between those who live with bodily unease and the greater public. The key features of artists' books as opposed to nearly all other artforms are their invitation to touch and disseminate as a mobile medium. Although reading an artist's book is generally a one-to-one experience, the editionable, portable, and disseminatable aspects of artist's books makes them particularly useful for artists to reach a great number of people. Books thus have a mobile life: they are pulled off the shelf, handed to a friend, archived in public collections, and in an edition, can exist in many distant locations simultaneously.

How artists' books reach their audiences has evolved over time. As will be expanded upon further in Chapter 2 of this thesis, artist's books were often disseminated directly to the public through the mail in the 1970s in an effort to circumvent what was perceived to be an exclusionary professionalized gallery system. The recognition of artists' books as valid primary sources of experience worthy of artistic acclaim and collection is on the rise. Today, in addition to private artist's book distributors, artists' books are acquired and circulated as part of academic or public library rare book collections.<sup>9</sup>

New archives are forming to acquire artists' books and employ them for pedagogical workshops and coursework due to their aesthetic qualities, which will be thoroughly unpacked in Chapter 4. One such pedagogue and librarian, Cathleen Miller, uses artists' books on the topic of illness from the Maine Women Writers Collection to instruct fine art, creative writing, and healthcare students.<sup>10</sup> The Wellcome Trust, renowned British collection of all things artistically medical, recently established its own artist's book collection in 2016 in recognition of the unique communicative capabilities of the medium.<sup>11</sup> The goal for these special collections is to make artists' books accessible for researchers and the greater public as first-person accounts of illness.

### *Performativity*

The act of turning a page is not incidental, but part of the performance of transforming two-dimensional plane into a form with depth and timing. Bookmaker and theorist Johanna Drucker explains that the binding of pages around a spine "goes beyond mere convenience of constraint and fastening and becomes a means to articulate these relations"<sup>12</sup> of space and time. The use of transparent pages, for example, continuously transforms the spatial relationships of layered pages as a reader peels back and replaces each one. The constant oscillations between

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<sup>9</sup> Klima, *Artists Books*, 55.

<sup>10</sup> Cathleen Miller, interview by Darian Goldin Stahl, July 29, 2019.

<sup>11</sup> Melanie Grant, interview by Darian Goldin Stahl, March 27, 2019.

<sup>12</sup> Johanna Drucker, *The Century of Artists' Books* (New York: Granary Books, 1995), 74.

flatness and volume exhibit the rhythmic vitality, almost like a breath, of artists' books.

Due to the durational and physical aspects of reading a book, this medium can be seen as a hybrid of sculpture and performance. As well, the activation of an artist's book implicates the reader as an essential co-performer in an improvised duet. Unlike other durational works like film or music, the reader sets the timing based on her own pacing and level of engagement. An artist's book can often be commenced at any point, skipped around, or even flipped backward and its meaning will still be conveyed. Therefore, artists' books have a flexible performativity that is not restricted to a passive, linear rendition like most other time-based or narrative media.<sup>13</sup> If the aim of a book is to implicate its reader as a co-creator in its meaning, then requiring her to engage her own body in the activation of this art is essential to its work.

### *Intimacy*

Finally, I choose the medium of the artist's book for its potential to foster intimate relations. The feeling of closeness between the reader and maker is due in part to the physical touching necessary to perform an artist's book. The private one-on-one engagement with artists' books also fosters feelings connectedness, like a pleasurable meeting between friends, and furthered by the experience of holding such a rare and valued hand-made object. Elaine Scarry, on the topic of experiencing another's creation, explains, "It is almost universally the case in everyday life that the most cherished object is one that has been hand-made by a friend: there is no mystery about this, for the object's material attributes themselves record and memorialize the intensely personal, extraordinary because exclusive, interior feelings of the maker for just this person—This is for you."<sup>14</sup> First-person books in small editions add to the treasured quality of the object, and feel as though we are being invited to share in another's interiority or rarified archive.

The preciousness of handcrafted artists' books seems to eclipse the sum of its pages. As Drucker summarizes:

Many of these books have an auratic quality, an often-inexplicable air of power, attraction, or uniqueness. . . . Books that have an aura about them generate a mystic, a sense of charged presence. They seem to bear meaning just in their being, their appearance, and their form through their iconography and materials.<sup>15</sup>

The auratic charge of a book may have to do with how much the object exemplifies the body of its author. When one's artist's book is also an extension of her body, imbued with the consciousness of its author and made material for others to see and feel, "here the pages of a life are also the skin, surface, of a body which cannot help reveal the scars as the history of experience."<sup>16</sup> These books can be seen to represent so much of the author's experience that they become a bodily-proxy or synecdoche of her very being. The enormity of such an invitation to handle and experience a part of another is made palpable.

All this is not to say that artists' books are always effective. One of the greatest strengths of this medium, that it engages a reader through the performance of reading, can also be a

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<sup>13</sup> Klima, *Artists Books*, 64.

<sup>14</sup> Elaine Scarry, *The Body in Pain* (Oxford: Oxford University Press, 1985), 292.

<sup>15</sup> Drucker, *The Century of Artists' Books*, 93.

<sup>16</sup> *Ibid.*, 104.

hindrance. Not everyone who looks at art also wants to perform it. The ability to glean meaning quickly or appreciate aesthetics passively in say, a museum setting, is a more common but completely different way of experiencing art than artists' books require. Books request your close attention and above all your time, which can be difficult to secure from busy art-goers when there is so much else to see. As well, in an art market that values grandness and large-scale media to create impact, the very compact nature of bound pages—so useful for storing and transporting this artwork over vast distances—restricts viewing to a small space that may not grab viewers from a distance. Finally, the institutional desire to preserve an artist's book is often at odds with the need to touch a book. Glass display cases kill the vitality, spatial relations of turning a page, and truncate an engagement of the senses into viewing only a single spread. These reasons are a large part of why the medium has not easily proliferated within museum settings for general audiences.

However, the fact that artists' books are not entirely well known has allowed it to remain malleable and approachable. Without overarching institutional standards or convention for what an artist's book should look like, pioneering makers are taking the medium in exciting and imaginative directions. Further, it seems the subculture and grassroots positioning of bookmaking allows the medium to be adapted for each maker community. For books on difficult topics like illness, the versatility of the artists' book make this medium flexible enough to communicate full spectrums of lived experiences based on how the makers see fit.

### **How does one make an artist's book on the topic of illness?**

In order to translate experiences of illness, loss, healthcare, disability, or wellbeing as an artist's book, it is helpful to first focus on the phenomena itself and formulate a description of its lived experience. This is not to say that one could not work entirely intuitively or prelinguistically in the creation of a book, but that the intricate interrelations of pages, image, text, and form can be more coherent with a foregrounding investigation of one's sensing body. Therefore, the practice of phenomenology not only helps us to conceive of a book as a body, but also helps us articulate and build a sensory repertoire for the translation of body to book. I will situate the creation of artists' books using Merleau-Ponty's discursive method before specifically investigating the lived experience of illness with contemporary phenomenologists like S. Kay Toombs, Drew Leder, and Havi Carel.

Phenomenology is particularly helpful in the creation of artists' books because, like art, phenomenology is non-prescriptive. It is subjective and open to a multiplicity of interpretations and applications based on each maker's own history and intentions. It is an accessible practice to a wide range of individuals because it places primary focus on one's *experience* of illness or disability, rather than any specialized knowledge of the scientific causes of disease. The focus on subjectivity positions the individual as the expert in her own bodily accounting.

Phenomenology, Merleau-Ponty explains, “consists in re-learning to look at the world”<sup>17</sup> that has become routine, falls into the background, or habituated in order to critique the norms and presuppositions of everyday experience. Merleau-Ponty scholar Ariane Mildeberg further explains that phenomenology is not a lens to view the familiar world through, but rather “it is a *practice* that makes us more aware of the nature of human experience and perception.”<sup>18</sup> It is a practice of giving active attention to a phenomenon so that it may be examined anew. Artists are

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<sup>17</sup> Maurice Merleau-Ponty, “What is Phenomenology?” in *The Essential Writings of Merleau-Ponty*, ed. Alden L. Fisher (New York: Harcourt, Brace & World, 1969), 42.

<sup>18</sup> Ariane Mildeberg, interview by Darian Goldin Stahl, March 4, 2019.

particularly suited for this practice because they “show how the things become things, how the world becomes world”<sup>19</sup> by materializing it according to their own point of view.

*Phenomenology of Illness* (2016) author Havi Carel explains that the many changes to one’s habitual world in times of illness make these experiences particularly useful for scrutinizing the norms that structure our society, and re-examining what it means to live a good life.<sup>20</sup> That is, it is easier to notice the every-day when it becomes disrupted. The process of inquiry into the givenness of the world can also be seen in artists’ books. As bookmakers subvert our preconceived notions of bookness, they make us keenly aware of how our own bodies have become accustomed to engaging with print media. Disruptions to bookness alter the readers’ bodily performance of reading, which signal parallel meanings for how the author’s bodily habitus has also become disrupted by illness. The embodiment of the artist’s book makes readers more aware of another’s lived experience through this relational performance.

The first step in a phenomenological practice of creating artists’ books is to attempt to examine a bodily phenomenon as pure sensation—before psychological influences and explanations can arise. Even though this is an impossible endeavor, a thorough sensory inquiry of the body may nevertheless shine new light on a habituated phenomenon. As an auto-ethnographic, inward facing investigation, a maker may answer a series of sensory questions to articulate a phenomenon or symptom, such as:

Where is my symptom located? How does my symptom move? How does my symptom feel? What temperature is it? How heavy is it? What does my symptom sound like? What does my symptom look like? What color is it? How large is my symptom? What does my symptom taste like? What does it smell like? What emotions does my symptom provoke?<sup>21</sup>

Although these questions might appear inapplicable or strange, such strangeness requires us to investigate our bodies in new and unexpected ways, which may, as Carel prompts, interrupt our habitual ways of understanding of our bodies and communicating experience.

An examination of a bodily experience consists not only of my own perception of it, but how I perceive others perceiving me as well. Therefore, we also experience our bodies in relation to others who impart their own perceptions back to us. Given the intersubjective and reciprocal relation of flesh, the next step in a phenomenological artist’s book practice may be to answer another set of questions about our outward-facing relationships with a phenomenon, such as:

Does my body move through space differently now? Have the spaces I frequent changed? Have I stopped doing certain things I used to enjoy? Have I taken up new activities? What creative adaptations have I made to continue my pursuits? How have my future plans changed? How has this symptom effected my relationship with family, friends, and people I just meet? Have some relationships fallen away, and have others strengthened?

With this list of articulated experience, a bookmaker can incorporate or intertextually

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<sup>19</sup> Maurice Merleau-Ponty, “Eye and Mind,” in *The Essential Writings of Merleau-Ponty*, ed. Alden L. Fisher (New York: Harcourt, Brace & World, 1969), 277.

<sup>20</sup> Havi Carel, *The Phenomenology of Illness* (Oxford: Oxford University Press, 2016), 208.

<sup>21</sup> A full meditative list of questions surrounding the sensory interpretation of symptoms is provided in Chapter 5 of this thesis.

translate them into the material space of a book. An artist may engage with any number of materials, forms, texts, movement, duration, and images to convey her bodily phenomenon. I will now show how some of the most pervasive experiences of bodily unease can be expressed in and as an artist's book. Although there are many changes that can occur to the lived body in times of illness, I focus on three that are particularly salient and relevant to the process of (Carel 2016)bookmaking as well: dys-appearance and temporality.

### *Dys-Appearance*

Phenomenologist and M.D. Drew Leder uses the concept of the “disappearing body” to describe how one does not consciously perceive her body when the will and the body's ability to perform her will are harmonious. Objects can also ‘disappear’ through the skillful incorporation of their mass and function into our bodies' movements.<sup>22</sup> For example, the object-ness of a traditional book tends to fall away as our eyes become accustomed to moving across the page and our hands reflexively turn the pages. It is as if the text floats in space when the book object becomes a part of our habitual, disappearing body.

On the other hand, when the accustomed movements of the body are altered or no longer possible due to impairment, the parts of the body seem to push themselves forward as the objects of full attention. This state of hyper-awareness is what Leder defines as a “dys-appearing body”<sup>23</sup> because the body can be felt to be dysfunctioning in its rebellion against our will. Dys-appearing can occur as inward-facing symptoms like numbness or pain, or in outward-facing social settings when “the body can appear as ill, disabled, aesthetically flawed or socially awkward, objectified or sexualized, or as attracting negative attention from others, as in the experience of shame.”<sup>24</sup> When “those organs that were once compliant, the very agents of one's identity and capabilities,”<sup>25</sup> dys-appear, the changes to one's body cannot be ignored.

To convey the concept of a dys-appearing body in an artist's book, one option is to construct a book in such a way as to work against our habituated movements through it. The artist may, for example, change the orientation of her book or the direction of text to disrupt its reading ease. She may make her book as small as possible or use extremely delicate papers so the reader must ever-so-carefully navigate through it to prevent damage. To impart a feeling of frustration, the artist may bind her book in extremely complex, disorienting, or completely unreadable arrangements. An artist may also use unconventional, estranging, or unsettling materials like say, raw flesh, to compel a bodily reaction from the reader. These options add atypical movements and sensory engagements to books in ways that bring our full focus to its form and content. All of these strategies force the reader to pay closer attention—to give this book-body one's full attention in order to perform it—just as its author pays an inordinate amount of attention to her own dys-appearing body.

### *Temporality*

Phenomenology and disability scholar S. Kay Toombs explains that the memories of the lived body inform one's *habitus*, or how one moves through the world primarily, without thinking, and pre-reflectively.<sup>26</sup> Concerning the essential aspects of illness, Toombs explains how

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<sup>22</sup> Drew Leder, *The Absent Body* (Chicago: The University of Chicago Press, 1990), 17.

<sup>23</sup> *Ibid.*, 88.

<sup>24</sup> Carel, *The Phenomenology of Illness*, 57

<sup>25</sup> Drew Leder, *The Distressed Body* (Chicago: The University of Chicago Press, 2016), 16.

<sup>26</sup> S. Kay Toombs, “Illness and the Paradigm of the Lived Body,” *Theoretical Medicine* 9, (1988): 205.

one's habitus of speed, gesture, position, ability to move through space, and sense of time can become radically altered.<sup>27</sup> Toombs reports that those who experience intense pain often cannot accurately judge the passage of hourly time. One's sense of time can also be altered on much longer scales. The unpredictability of illness may prevent a person from projecting herself too far into the future, which compresses her timeline to a sense of 'living in the moment.' Externalizing these changes of temporality through the material and form of an artist's book, rather than narrative alone, can foster more embodied accounts of subjective time for those who read them.

The pace and rhythm of reading a typical book is developed for each individual until the repetitive duration of moving one's eyes across and down a page contains a certain amount of predictability. The retention of this bodily habitus is crucial for the artist to then creatively subvert the normative conventions of bookness. For example, the pages may be brimming with dense text and intricate imagery that forces the reader to slow down in order to glean its meaning; or the artist may fill her book with an inordinate number of pages to encourage a durational read. At the other extreme, an artist could make use of a flipbook format to experience her entire book in mere seconds. The artist might otherwise choose to sew all the pages shut or transform the book into an unreadable sculpture, which urges the reader view the book in totality as a single moment. By altering the viewers' pace moving through an artist's book, the artist brings attention to how engrained expectations of movement and temporality also change when experiencing illness.

### **How can we interpret artists' books?**

So far, we have focused on the creation of artist's books and strategies to express the lived experiences of illness. We can now turn our attention to the readers of these books, and how they may subjectively interpret these objects. It is no coincidence that the same sensory and discursive methods practiced in the making of artists' books can in turn make meaning from them. First, we perceive an artist's book through our senses, which is our embodied experience of the book-body on the pre-reflective level. We feel drawn in closer to artists' books as auratical and meaningful objects *before* we can reflect on why. As Mildenberg explains, "it is only belatedly that we use words and concepts to help explain what we have seen/felt/experienced."<sup>28</sup> Next, upon reflection, a reader uses the connotations between its form, images, text, and materials derived from her own personal memories and associations to cultivate meaning from an abstract artist's book. The inherent relationality of artists' books means that their meaning is ultimately co-created by the artist and each successive reader.

The artistry of this genre occurs in the balance between specificity and openness. If an artist's book is too didactic, it risks falling into a different category like a self-published memoir or artistically hand-bound illness narrative. If it is too abstract, then it ceases to communicate tangible lived experiences to the reader. An artist who seeks to form a relational encounter with her reader must weigh narrative writing and documentary images against truncated poetics, metaphorical configurations, and otherwise call on the reader's interpretative power of what has been abstracted. When one is able to insert their own their own sense of discovery between the pages of another's book, then this object is capable of mediating a reciprocal dialogue between maker and reader.

The subversion of bookness assists the interpretative potential of reading. The tension between the abstracted book-body the artist presents to us and our own innate expectation for a

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<sup>27</sup> S. Kay Toombs, "The Temporality of Illness," *Theoretical Medicine* 11, (1990): 229.

<sup>28</sup> Mildenberg, interview.

book to communicate information compels a reader to create new meanings from its strange arrangements. Neuro-Aesthetics researcher Barbara Maria Stafford explains, “Because the extrapolated items appear so unnatural as to be shocking...they stimulate our imaginative powers of inference. More than that, they change the strength of our synaptic connections since their puzzling appearance counters habituation and augments sensitization.”<sup>29</sup> This fracture from the familiar, like the practice of phenomenology, provokes us to approach an artist’s book with new sensibilities and forge our own meaning.

There is no right or wrong way to interpret an artist’s book because it is essentially a subjective experience. When a phenomenon is translated and materialized as an artist’s book, its reduction to a finite form inversely opens the book to a multiplicity of interpretations. For example, an artist intends to convey sensuality, regality, or lusciousness from her inclusion of velvet fabric, but a reader may interpret the use of this fabric as protecting something extraordinarily fragile. The touch of velvet is significant and meaningful, though differently, for the artist and each engaged reader based on her own history, connotations, associations, habitus, contexts, and background. Given phenomenology’s assertion that one is the expert of their own lived experiences, it is right to recognize the reader’s own understanding of another’s artist’s book as legitimate and significant. This hermeneutical openness is key to the relational aspects of artists’ books since, as Carel states, “the purpose of abstraction is to understand that world and then return to it with new sensibilities.”<sup>30</sup> Together, the artist and the reader add layers upon layers of meaning within every artist’s book to expand its relational significance.

An artist’s book is an offer to be in relation with the maker: to read her story, interpret her experience, and care for her book-body. If, as Eisner posits, the empathetic potentiality of artworks “banks upon the observer’s ability to imaginatively project himself into the life of another in order to know what that person is experiencing,”<sup>31</sup> then I argue that the multi-modal characteristics of artists’ books are more likely to compel such an imagining than a more homogenous artform. In a close sensory engagement of an artist’s book that necessitates interpretation, it is likely for the reader to identify with certain elements that are being portrayed and feel a kinship. However, as Iris Young points out, this feeling of empathy could be ironically rife with misidentification. When readers “imaginatively try to represent to themselves the perspective of members of oppressed groups, too often those representations carry projections and fantasies through which the privileged reinforce a complementary image of themselves.”<sup>32</sup> With this pitfall in mind, a better strategy to reading an artist’s book is not to imagine yourself in the artist’s position, since it is impossible to fully know another’s experience, but instead to come to her book with the expectation of being in productive relation alongside her: to listen closely and be with.

### **What do artists’ books *do*?**

This is the most philosophically important question for our investigation into artists’ books. In its most simple answer, artists’ books on illness alter how we see and understand altered bodies. Artists’ books might not actually resemble the things in the world they represent,

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<sup>29</sup> Barbara Maria Stafford, *Echo Objects: The Cognitive Work of Images* (Chicago: The University of Chicago Press, 2007), 45.

<sup>30</sup> Carel, *The Phenomenology of Illness*, 6.

<sup>31</sup> Elliot W. Eisner, “On the Differences Between Scientific and Artistic Approaches to Qualitative Research,” *Review of Research in Visual Arts Education* 7, no. 1 (1981): 3.

<sup>32</sup> Iris Young, “Comments on Seyla Benhabib, Situating the Self,” *New German Critique* 62, (1994): 171.

but they excite our imaginations to connote meaning and make up for the inadequacies of other forms of expression. Bookmakers are transforming how illness is represented not only to organize and make sense of their own experiences, but effectively communicate the gaps in knowledge for others. Through creation, interpretation, and circulation, artists' books foster a sense of wellbeing and connection to their makers and readers.

### *A Sense of Wellbeing*

The often-random nature of illness can challenge one's most deeply held beliefs and upend what one once thought to be true about her body, relationships, and future. After her own life-altering diagnosis, Carel attests that "such an event challenges the ill person to reflect on her life and search for ways of regaining meaning."<sup>33</sup> Because it is difficult for most people to create meaning from a strictly medical understanding of the body, like the spontaneous proliferation of malignant cells or the development of lesions along the spinal cord, we seek out humanizing metaphors to ground these phenomena within a recognizable paradigm. Artists' books, with their potential for metaphorical expression, expound the meaning of a diagnosis by rooting it alongside the experience of illness, all within a tangible and shareable form. Such organizing objects can foster a sense of being understood, accomplishment, and order in the midst of unpredictable hardships.

Creating a book is an imaginative and physical labor. Phenomenological bookmaking practices that begin with a series of sensory inquiries, like those listed earlier in this chapter, prompt one to think deeply about her experience and organize sensations in a way that makes the most sense for her. Even before the process of creation, being prompted to think deeply about one's changing body can be a rewarding practice in itself. In her case studies, Carel found that "family, patients, health professionals, careers, and relatives of those who are ill have responded to phenomenological work by saying how positive and useful they found this framework, because it gave clarity and legitimization to their own experiences and thus has lessened their sense of isolation and of being unheard."<sup>34</sup> In addition, illness "experiences that are initially chaotic and confusing can, once phenomenologically articulated and ordered, lend new structure and order to the ill person's experience."<sup>35</sup> Even if an artist's book takes on a profoundly difficult subject, practicing a structure for reflection can nevertheless aid in the formulation of order and meaning that can ultimately stimulate a sense of wellbeing.

Next, the artist's must physically labor to create a meaningful object according to her own point of view. The maker is able to choose how best to compose the experiences of her life across, through, and out of pages, and what complex material metaphors emerge between covers. Having full creative agency over how one's body is represented can be a relief. In stark contrast to having very little say over what is revealed in other abstracted portraits, like biomedical scans, artists' bookmakers *choose* what they deem to be the most important facets of their experiences to portray within their book-bodies. Therefore, a goal of creating an artist's book on a difficult topic like illness is to provide someone who may feel a lack control over other aspects of her body full and holistic control over the presentation of her body in book form; she may then, if she chooses, invite others to understand her experience as well.

Creative expression is a way of integrating healing for the soul alongside of medicine's role of healing the body. Leder and Scarry both extol the wellbeing effects of materializing

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<sup>33</sup> Carel, *The Phenomenology of Illness*, 4.

<sup>34</sup> *Ibid.*, 128.

<sup>35</sup> *Ibid.*, 127.



bodily distress because it gives “greater attention to the embodied experience of the patient, the physical environments in which treatment unfolds, and the material things we use as agents of healing.”<sup>36</sup> In imaginatively and physically laboring to externalize potentially painful experiences as objects so they may be known by others, “it is through this movement out into the world that the extreme privacy of the occurrence (both pain and imagining are invisible to anyone outside of boundaries of the person’s body) begins to be sharable, that sentience becomes social and thus acquires its distinct human form.”<sup>37</sup> What was once hidden and difficult to describe can now be made present and experiential as many times as necessary.

By sharing her book, the artist invites the reader to partake in its promotion of wellbeing. The media we choose for our books can be saturated with care for the reader in a very literal sense. Artists may soak the pages in sweet-smelling beeswax or calming aromatic oils that waft up to the reader as she turns each page. Or more tacitly, the intention, craft, and labor extended in the creation of an artist’s book imbues it with a sense of care for each reader who spends the time engaging with its intricate form. The artist’s care is felt even if her physical body is absent, because her creations, as Scarry attests, “contain a collective and equally extraordinary message: Whoever you are, and whether or not I personally like or even know you, in at least this small way, be well.”<sup>38</sup>

The sensory nature of artists’ books promotes an intermingling of flesh and a sense of taking care. If the maker feels a sense of relief they are being heard and understood, then every reader is actively relieving some distress of the maker. When an artist materializes her experiences into shareable hand-held objects, “then those objects in turn become the object of perceptions that are taken back into the interior of human consciousness where they now reside as part of the mind or soul, and this revised conception of oneself... is now actually ‘felt’ to be located inside the boundaries of one’s own skin.”<sup>39</sup> The circular movement of unease from internal and invisible feeling, to external and experiential object, and then into a re-internalized perception, transforms pain “from a wholly passive and helpless occurrence into a self-modifying and, when most successful, self-elimination one.”<sup>40</sup> As one feels relief by materializing her unease, others can join in further dispersing that sense over a collection of readers who can relate, add meaning, and empathize with the artist through her book.

### *Constructing Intercorporealities*

An aim of building an archive or catalogue of self-representing artists’ books on illness is to fill some deficit of knowledge, an overlooked or misunderstood phenomenon of lived experience that can be set right through generative expression and interpretation. This process of mutual identification is what phenomenologists like Carel term as *intercorporeality*. Intercorporeality “encompasses not only one’s experience but also the social aspect of one’s experience of one’s own and other’s bodies, as well as how others’ experience of one’s own body might impact on their own experience of their body.”<sup>41</sup> Artist’s books have the potential to portray lived experiences that may subvert the readers’ expectations of what a body can do and the definition of a good and fulfilling life. Such shifts in preconceived notions and generation of

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<sup>36</sup> Leder, *The Distressed Body*, 74.

<sup>37</sup> Scarry, *The Body in Pain*, 170.

<sup>38</sup> *Ibid.*, 292.

<sup>39</sup> *Ibid.*, 256.

<sup>40</sup> *Ibid.*, 164.

<sup>41</sup> Carel, *The Phenomenology of Illness*, 54.

empathy position artists' books as vehicles for ethical intercorporeality.

Although illness and disability are universal conditions that will affect nearly everyone if they live long enough, all too often those who do not experience illness or disability formulate their ideas of illness from third-person, inaccurate, or even harmful portrayals in the media. It is therefore likely that a disabled person will experience discrimination and stigmatization, which “can be incredibly costly for the stigmatized person in terms of social relations, but also job prospects, income, and support networks.”<sup>42</sup> Unethical portrayals of illness and disability hinder the public's imagination to conceive of illness not as a series of losses, but as a valid way of being in the world complete with fulfillment and wellbeing. As Leavy posits, “if researchers working from a phenomenology framework are interested in accessing experience, and experience now occurs within a visual landscape, experience is embedded within its visual context.”<sup>43</sup> Put simply, accurate visual representation of illness matters to its perception from general audiences. To counter the misinformation and stigma surrounding illness and disability, self-representing or deeply collaborative artist's books can be a medium to set the record straight on what it is like to live with impairment and, ultimately, cultivate more ethical intercorporealities.

Instead of framing illness as simply a succession of dysfunctions, Carel takes an affirmative view of illness, whose “positive consequences include improving personal relationships and increased intimacy with family members and friends; a sense of purpose and focus; rediscovering the self; resilience; pride arising from overcoming difficulties.”<sup>44</sup> Affirming outcomes from illness and disability are all too often overlooked from those outside of these experiences due to a failure of the imagination to consider the fullness of a person's life, and not simply this singular aspect. Therefore, when artists' books present illness as a richly aesthetic and sensory object with a full range of ways to interact with the world, then we can also view illness and disability as affirmative ways of being.

As hermeneutical objects, artists' books not only give creative form and structure to lived experience, but also provide space for others to relate with the perspective in the pages. For other ill persons, such identification may counter the sense of isolation that can accompany experiences of illness. Even if the reader has never personally experienced to what is portrayed, opening an artist's book is an invitation to access and be with the author as she relays her story. Such ways of being with form intercorporealities around the shared object—an ‘*our experience*’ of the artist's book.<sup>45</sup>

Finally, intercorporeality can also be promoted in collaborative bookmaking practices. If one does not have the dexterity to create a book, then the relational aspect of artists' books is exemplified through a co-creation process. Additionally, an artist may work collaboratively with family members, friends, physicians, or caretakers to portray how experiences of illness also engage those around her. Even within fully collaborative practices, however, ethics must be taken into account when an artist is attempting to portray the lived experience of another person. It is critical to ask:

What are the politics at play when the artist is not part of the community they are

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<sup>42</sup> Carel, *The Phenomenology of Illness*, 75.

<sup>43</sup> Patricia Leavy, *Method Meets Art: Arts-Based Research Practice* (New York City: Guilford Press, 2015), 230.

<sup>44</sup> Carel, *The Phenomenology of Illness*, 126.

<sup>45</sup> *Ibid.*, 47.

representing? Are collaborative partners given parity throughout the process and outcomes of this work? How are subjects compensated and credited? How have the risks of stigmatization or harm in this portrayal been mitigated and accounted for?

Given these pitfalls, every standard of ethics must be taken to ensure that members of a collaboration do not end up marginalized in the creation of their book. This is not to say that collaborative artworks that portray difference should be avoided, because creating artwork with and for another person can be a worthwhile and fulfilling experience. Ultimately, bearing witness to lived experience and co-creating a book provides the opportunity for all parties involved to promote the care-taking potential of art, to thicken phenomenological flesh between partners, to see and be seen, to touch and be touched by an artist's book.

### *Mediated Connectedness*

For all of the reciprocities of phenomenological flesh mentioned thus far, we are not directly engaging with another's body but through the intermediary artist's book. As other scholars have pointed out, particularly postphenomenologists like Don Ihde<sup>46</sup> and Peter-Paul Verbeek,<sup>47</sup> the self-reflexive focus of phenomenology does not explicitly account for the representation of self through the creation of intermediary objects. This is particularly the case for an artist's book, where one can build connectedness *through* her book.

The strength of postphenomenology for this final section of what artists' books *do* lies in its explicit inclusion of intermediary objects to construct and alter perception. If I aim to better understand the lived experience of its maker, than it is essential to actively investigate how book-bodies mediate our understanding of another's lived world. This is not a dismissal of phenomenological principles of reversibility, but a critique and expansion that turns the focus of phenomenological inquiry to external objects, media, and technology as relational mediations between subjects.

The most important role of artists' books is to initiate ethical intercorporealities. When one's artist's book is the focus of attention, it allows the artist and reader, perhaps counter intuitively, to speak more directly about sensitive topics than might be possible otherwise. Artists' books allow one to communicate while circumventing the need for a direct or didactic narrative, which may be difficult or impossible to formulate on charged topics like illness, loss, or disability. Carrel explains the awkwardness of attempting to directly communicate when "the natural way in which we engage in social interactions becomes cumbersome in illness, weighed down by unspoken doubts and discomfort, and the effort required for genuine communication becomes greater."<sup>48</sup> Due to stigma, shame, privacy concerns, the desire to keep conversation light and easy, or simply not quite knowing what to say, the empty space between bodies can become a mire. The introduction of an artist's book into this liminality provides a comfortable focus for engagement.

In her own experiences of being ill, Jackie Stacey describes the need for a stepping-stone between silence and openness, from turning away to being with, because illness can be too terrifying a thing to acknowledge directly.<sup>49</sup> An intermediary artist's book acts as this stepping-

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<sup>46</sup> Don Ihde, "Introduction: Postphenomenological Research," *Human Studies* 31, (2008).

<sup>47</sup> Peter-Paul Verbeek, "Obstetric Ultrasound and the Technological Mediation of Morality: A Postphenomenological Analysis," *Human Studies* 31, (2008).

<sup>48</sup> Carel, *The Phenomenology of Illness*, 77.

<sup>49</sup> Jackie Stacey, *Teratologies* (London: Routledge, 1997), 63.

stone to break the uncomfortable silence around difficult topics, and when most effective, lead to open and direct communication. It is as if, through sharing an artist's book, the maker is saying, "Although we cannot communicate about this experience directly, either because it is too difficult or because I am not present with you in this moment, read and feel the care I put into this creation so you may know what it is I wish to share with you." Because the ill person has constructed this book herself, the most important things to know about the artist's experience are present at hand.

## **Conclusion**

We have a shared cultural understanding of what books are and how they function, what we deem as *bookness*, but when artists creatively subvert and alter these facets of bookness to communicate aspects of their lived experiences, their books become powerful resources for understanding altered bodies. Artists' books are complex objects that reach out to be interpreted by others. The aim of conceiving and laboring an artist's book into being is to say something that could not have been possible otherwise, to increase the chance of embodiment by engaging multiple senses, to create an external artifact of lived experience that persists through time and space, and to proliferate ethical intercorporealities as a disseminated edition. Phenomenology gives us a useful framework to conceptualize the intercorporeality that occurs when holding and reading another's book, as well as a productive practice for making and interpreting them. Throughout this thesis, I will continue to hold tension between normative aspects of bookness and how artists manipulate them to complicate a straightforward read of text and image as I investigate the history of bookmaking and medicine alongside contemporary examples and pedagogical applications of artists' books today.

## Chapter 2

### *Book as Body: A Longitudinal Perspective*

#### Introduction

The progress of medicine can be understood by its images: from the drawn, engraved, or etched representations of the body printed and bound into tomes by collaborating anatomists and artists, to the digitally stacked slices of biomedical scans produced by penetrating waves of magnetic resonance. These visualizations teach us not only about the body, but how Western culture has enduringly arranged the structures of anatomy into paginated forms. This chapter investigates the intersection of bookmaking and medical knowledge, drawing a particular line through the aspects of bookness and illustration that have influenced our contemporary understanding of the body. I aim to show that the self-constituting substantiation of text and image, bound together within the symbol of learning and enduring knowledge—The Book—has continuously established an authority over the bodies imaged within.

My study of the aesthetic intersections of books and bodies here takes on a longitudinal perspective. Although historical books on anatomy and pathology are not considered artists' books, their printing techniques and artistry are intertwined with the development of a visual culture of medicine, which is then appropriated and critiqued within contemporary artist's book practices. On the other hand, even though the artists' books are not presenting medical knowledge per se, the artists employ the authority of the book form to flip the hierarchy between medical conceptualizations of disease and the health knowledge acquired through lived experiences of illness. Therefore, I argue that the entangled history of book arts, artists' books, and medicine have always capitalized on the elements of bookness to establish and disseminate knowledge of bodies.

To exemplify the link between historical medical books and contemporary artists' books, I focus on two works, *The Gynecologist* (1989) by Joan Lyons, and the *Cryobook Archives* (2010-present) by Tagny Duff. These books demonstrate how artists' appropriate past medical illustration and practices in order to form a critique of traditional medical paradigms, that is, the "held beliefs as to the nature of reality, origins, value, truth, and how things are supposed to be done within accepted conceptual frameworks."<sup>1</sup> I chose these two artists' books in particular because they materialize several points of enduring contention between those with medical power and those at their mercy, such as hierarchical knowledge and bias. By reprinting centuries-old illustrations or conducting bygone anatomical bookmaking practices, these artists exhibit the long arc of medical influence.

To begin investigation, I will first provide an abbreviated account of the development of artists' books as a distinct medium. Next, I briefly detail subcategories in the medium of artists' books and how these classifications intersect with patient self-representations within book forms. I will then contextualize the content *The Gynecologist* and the *Cryobook Archives* in a longitudinal perspective of medical books. Finally, I summarize the evolution of medical and health humanities as a collaborative and pedagogical space to reintroduce artistic representations of the body that counter biased attitudes from within medical institutions.

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<sup>1</sup> Shaun McNiff, "Philosophical and Practical Foundations of Artistic Inquiry: Creating Paradigms, Methods, and Presentation Based in Art," in *Handbook of Arts-Based Research*, ed. Patricia Leavy (New York: The Guilford Press, 2018), 26.

## Artists' Books: A Condensed History

Other authors like Johanna Drucker and Stefan Klima have thoroughly traced the origins of artists' books as an artistic medium,<sup>2</sup> and therefore only a brief summary will be recounted here to contextualize the artists' books I will subsequently unpack. I also seek to distinguish artists' books from their close relatives in this investigation of illness representation, as the book form has proliferated in artistic expression during recent decades. In addition to the genesis of the medium itself, I will also briefly trace the progression of printmaking processes that led to artists' books' production today, because these techniques are also intertwined with the dissemination of medical thought.

The first Western artists' books that resemble our current definitions for the medium are thought to be created by English philosopher, poet, artist, and printmaker William Blake (1757-1827).<sup>3</sup> Although there are extraordinary examples of aesthetic books throughout the centuries prior, Blake's books were unique for their time because they were entirely self-published, the pages were illustrated and editioned using innovative printmaking techniques he invented, and these books were explicitly produced as pieces of art in their totality. Blake manipulated the elements of bookness, such as innovatively merging text and image within a single etching plate, to propel the philosophical poetry he authored within. For example, in his book, *The Marriage of Heaven and Hell* (1793), Blake makes explicit parallels between etching and the origins of thought:

But first the notion that man has a body distinct from his soul, is to be expunged; this I shall do by printing in the infernal method, by corrosives, which in Hell are salutary and medicinal, melting apparent surfaces away, and displaying the infinite which was hid. If the doors of perception were cleansed everything would appear to man as it is, infinite.<sup>4</sup>

This passage was in response to John Locke's idea that the soul is a blank slate or white sheet of paper, which would then be written upon through life experience and the formation of ideas.<sup>5</sup> In contrast, Blake proposes that a person is more like an etching plate, which already contains some prelingual, inherent, and innate impressions, which become more evident and intelligible over time. Blake was able to conceive and articulate his philosophies in and through the printmaking process—a true indication of research-creation in the formation of an artist's book, though it would be centuries before this term was invented.

From the invention of moveable type in the Western world around 1450 and until the invention of offset lithography in 1875, bookmaking was a costly and grand affair that consisted of collaborating teams of booksellers, editors, page designers, illustrators, engravers, type setters, printmakers, and book binders and editioned to only a few hundred for their wealthy patrons and subscribers.<sup>6</sup> Therefore, Blake's one-man operation was quite unique. His self-publishing ventures allowed his philosophies to be printed unedited and without outside commercial

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<sup>2</sup> See: Johanna Drucker, *The Century of Artists' Books* (New York City: Granary Books, 1995); and Stefan Klima, *Artists Books: A Critical Survey of the Literature* (New York City: Granary Books, 1998).

<sup>3</sup> Betsy Davis and Jim Petrillo, "The Artist as Book Printer: Four Short Courses," in *Artists' Books: A Critical Anthology*, ed. Joan Lyons (Rochester: Visual Studies Workshop Press, 1985), 151.

<sup>4</sup> William Blake, *The Marriage of Heaven and Hell* (1793), plate 14.

<sup>5</sup> Michael Phillips, "'Printing in the Infernal Method': William Blake's Method of 'Illuminated Printing,'" *Interfaces* 39 (2018): 87.

<sup>6</sup> Richard Barnett, *The Sick Rose* (London: Thames and Hudson, 2014), 29.

pressures. He printed the books as they were ordered, which were admittedly very few, to cut down on his personal production costs. Blake's total control over the bookmaking process is a core feature of the medium that would come to be known as artists' books.

The industrial revolution streamlined book production and drastically decreased its price points. Therefore, any middle-class person could now afford to own books for the first time in history and were encouraged to help themselves to philosophy and literature even without a formal education. As the 20<sup>th</sup> century progressed, even more inexpensive forms of printmaking, like mimeography or xerography, enabled practically anyone to not only form a book collection, but even print editions of simple books for themselves.

The excitement of a new media option took hold in the Russian avant-garde, Futurists, Dada, and Fluxus art movements of early and mid-20<sup>th</sup> century. These movements aligned with the anti-capitalist potential of self-publishing low-cost books for the wide distribution of uncensored ideas. Artists employed the handmade artist's book to counter upper-class aesthetic sensibilities and revolutionize how artwork reached its audience.<sup>7</sup> No longer mediated by curators, these creations were sent straight to subscribers by mail in unnumbered editions.

Diane Perry Vanderlip curated the exhibition, *Artists Books* (sans apostrophe) in Philadelphia in 1973, coining the name of this newly recognized medium.<sup>8</sup> During this time, artists' books were seen as a political medium whose editions could be broadly disseminated as a purposeful subversion of the art market. The medium was taken up by those who had been denied entry into the traditional gallery systems, and so turned to independent publishing as an avenue to reach their audiences.<sup>9</sup> The low-barriers of entry for making artists' books and the promise of a wide viewership led to this art form being known as a 'democratic medium.'

After their initial surge of appeal, the popularity and uptake of artists' books floundered. Artist's book critics in the 1970's predicted a space for this medium alongside airport and drugstore magazine stands, which would enable the general public to easily purchase and own a piece of art.<sup>10</sup> Although self-published artist's editions can today be found in independently owned bookstores and online distributors, the prospect of mass commercial appeal and distribution never took root. There are a few reasons for this lack of populist uptake. First, the mimeographed artists' books did not achieve the same shelf-appeal as glossy full-color magazines. As well, the conceptual nature of these publications as a critique of the art market itself did not click with a general audience. To the uninitiated, these hand-drawn and stapled publications appear baffling and somewhat lackluster compared to formally published, hardcover books. Although early proponents of artists' books touted their potentiality as a populist medium, their almost singular appeal to an elite and conceptual art audience proved that this was hardly the case.<sup>11</sup>

A second concern for the medium was the in-betweenness of fine art and book object, which presents challenges for institutions who seek to collect and display artists' books. Galleries and museums work within a mandate to conserve and protect their acquisitions, thereby placing artists' books under glass display cases. Viewers can only stare at a static page of these books, truncating the read and prohibiting an embodied experience of them. Artists' books may then be

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<sup>7</sup> Johanna Drucker, *The Century of Artists' Books* (New York City: Granary Books, 1995), 50.

<sup>8</sup> Stephan Klima, *Artists Books: A Critical Survey of the Literature* (New York City: Granary Books, 1998), 12.

<sup>9</sup> Joan Lyons, "Introduction," in *Artists' Books: A Critical Anthology*, ed. Joan Lyons (Rochester: Visual Studies Workshop Press, 1985), 7.

<sup>10</sup> Lucy R. Lippard, "The Artist's Book Goes Public," in *Artists' Books: A Critical Anthology*, ed. Joan Lyons (Rochester: Visual Studies Workshop Press, 1985), 45.

<sup>11</sup> *Ibid.*, 48.

relegated to the museum library or reading room, which often has different hours, limited access, and does not receive the same kind of public footfall as the rest of the artwork. At its core, issues of display in museums or galleries presents a fundamental contradiction for a medium that was never meant to exist under glass or the halls of museums, but rather to reside in the hands of a reader.

The final reason this medium did not achieve its lofty initial goals is that the economics never added up. Without secure purchase orders from bookstores, the artists bore the full upfront expenses of publishing with little chance of selling enough low-price editions to recoup their costs, much less to make a living. Even when the aid of independent artist presses are available, these publication studios come and go as the volatile nature of funding springs and dries up. As well, it was (and still is) a common practice for artists and galleries to give away simple print publications as a gift for visiting their exhibitions, further undercutting expectations of paying for artists' books. Therefore, it was extremely difficult for artists to form a dedicated, sustainable artists' book practice. Instead, the field was dominated by artists like Ed Ruscha and his popular artist's book, *TwentySix Gasoline Stations* (1963), who had already achieved artistic acclaim in different media and could therefore afford to produce artists' books to an eager audience. In summary, the notion of mass distribution of low-cost artists' books placed undue economic burdens on the artists to compete with retail publishers for a general audience that simply did not exist.

In the latter part of the 20<sup>th</sup> century, the format and definitions for artist's book begins to schism. Although counter to their anti-capitalist roots, the proceeding decades saw the rise of more sculptural artists' books that made use of meticulous hand-crafted techniques and an attention to the reader's experience of its materiality—more closely resembling Blake's original artist's books than the Fluxus photocopied productions of the 1970's. To avoid the costly pitfalls of mass production, artists shifted to produce extremely small or even one of kind editions of their books. These kinds of artists' books, or what Drucker has termed *auratic objects*, “suggest a world in which the book is an artifact of winsome, recondite and esoteric, secret and precious, available to the initiate rather than the casual or widespread reader.”<sup>12</sup> Prized for their rarity, material aesthetic, and creative experimentation with the book form, the auratic artist's book attracts the attention of libraries and private collectors while also commanding significantly higher prices than their forebears, all of which has enabled a new generation of artists to form sustainable and innovative artist's book practices.

## **Taxonomy**

Releasing artists' books from the constraints of critiquing the art market itself, artists are free to use their books to engage with any number of politics and institutions, including medicine. As well, the fracturing definitions of what is or is not considered an artist's book has led to a proliferation of overlapping categories for artists to situate themselves within while grappling with topics of illness and disability. What follows is a brief taxonomy of medically oriented media that take on the book form.

The *illustrated book* is one that incorporates artistically rendered images alongside text. While the techniques used to make the images are the same ones that printmakers use to make artists' books, the purpose of the book is commercial or educational, rather than a piece of art in its own right.<sup>13</sup> Examples of this medium include deluxe publication of books that incorporate

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<sup>12</sup> Drucker, *The Century of Artists' Books*, 94.

<sup>13</sup> *Ibid.*, 5.



hand-printed elements or specialty binding. Although an illustrated book may contain exceptional artistry, it still may not be considered an artist's book unless it conceptually engages with the elements of bookness. William Blake, having apprenticed and made a career for himself as an engraver, was often commissioned to provide illustrations for medical textbooks. For example, Blake was hired to engrave plates for the English edition of Johann Caspar Lavater's *Essays on Physiognomy* (1789). This example shows how overlapping the categories of artists' books and illustration practices can be, while also further entangling the connections between artists' books and the institution of medicine.

The closest model to Fluxus artists' books is what we now refer to as *zines*, short for magazines. The significance of zines draws from their uncensored expression, quick printing, and potential for broad distribution. Zines began and continue to be used as activist publishing because of their inexpensive nature and immediacy within subcultures and political groups. Zines utilize hand-drawn or collaged content while keeping the form rather consistent: a single softcover folio, editioned by Xerox or Risograph copiers, and bound using a pamphlet stitch or staples. Artists' books can be quite different in this regard, where the form itself is highly implicated in the overall meaning of the book.

Medical zines often take on a more educational purpose along with their activism, and are created by and for particular patient communities. Examples of these publications include *Strip AIDS* (1987) out of the UK, *Strip AIDS USA* (1988), or *Diseased Pariah News* (1990-1999), which were used to educate about HIV/AIDS, safer sex practices, share high calorie recipes, and generally to connect a dispersed community around their common experiences. Another notable illness and disability publication is the *Toomeyville Gazette*, whose long run (1955-1998) crowdsourced know-how for altering common household objects to conform with impaired bodies, disability product reviews, job postings, and articles about what it is like to live and work with impairments. Although none of these publications would be considered artists' books, they did print art, creative writing, and comics submitted by their subscribers.

Close relatives to medical zines are *illness comics* and their longer, color printed, and often commercially published cousins *Graphic Medicine* or *Graphic Pathographies*. The familiar narrative layout of comic cells, inclusion of humor, and complexity of deeply personal portrayals of life possible between text + image make this book form particularly prevalent within patient groups and medical education. Like artists' books, illness comics emphasize the social impacts of living with a diagnosis or disability, written by the patient or family member rather than the medical perspective. Giving authority to patients to define their own lived experiences in these accessible, graphic formats "could therefore be seen as seizing power away from the 'official' iconography that informs society's notion of an illness."<sup>14</sup> The overlap between artists' books and illness comics can be so vast that it is often the writer-makers themselves that make the final distinction. For example, artist Jenny Lin states that she made two versions of her book, *Skinny Leg* (2012), which portrays and narrates her years-long trauma and recovery after being run over by a truck (See Figure 2.1). One version of *Skinny Leg* digitally reproduces her drawings and text into a single folded and stapled folio, which Lin categorizes as a graphic novel. The other version of *Skinny Leg* is screen printed by Lin, and constructed by hand with pop-ups, foldouts, and is bound within a hardcover.<sup>15</sup> Lin identifies this version of her

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<sup>14</sup> Ian C.M. Williams, "Graphic Medicine: The portrayal of illness in underground and autobiographical comics," in *Medicine, Health and the Arts: Approaches to Medical Humanities*, eds. Victoria Bates, Alan Bleakley, and Sam Goodman (London: Routledge, 2013), 74.

<sup>15</sup> To see more of Lin's work, visit her website: <http://jenny-lin.ca/skinny.html>

narrative as an artist's book because the hand-crafted elements of bookness propel the conceptual content of living with a traumatic injury.



Figure 2.1: Jenny Lin, *Skinny Leg*, Silkscreen, 10" x 7.5," 2012. Image courtesy of the artist.

In spite of the usefulness of a taxonomy to orient a study of artists' books on illness, the issue of what artists' book are, how they should be displayed, and their function as health research is hardly settled—and that's a good thing. As soon as a medium attains a set definition, it limits the kinds of exploration of materials and forms possible. It is also worth cautioning that the commodification and acquisition of artists' books, including their widening appeal in medical library special collections, may limit the topics and uncensored criticality provoked within their pages in favor of what can sell. However, critics of artists' books that cater to an audience like medical libraries must be cognizant of the ever-tightening economic constraints on a sustainable arts practice, which is still recovering from the 2008 recession and will continue to face hardships from the fallout of Covid-19.

### Artists' Books as a Critique of Medical Paradigms

Given their activist roots, it is no surprise that artists' books are still today "conceived of as agents of political persuasion and as vehicles to advocate a change of consciousness or policy in some area of contemporary life."<sup>16</sup> One way artists use the influence of their book creations to advocate for patient-centred care is by appropriating the images and practices of the past and

<sup>16</sup> Drucker, *The Century of Artists' Books*, 287.

reimagining them through contemporary ethics and sensibilities. Artists who appropriate the images and techniques of historical anatomical books in order to re-present them from their own world view are performing a critique of the institution of medicine that was built by and for the white male perspective. The exclusion of women, People of Color, and other marginalized populations from positions of power in medicine have led to biased conceptions how ‘healthy’ bodies look and function. By making and reading artists’ books on this topic, space then opens for a productive critique of such Western medical paradigms.

I situate the longitudinal perspective of medicine’s visual culture against contemporary artists’ books from Joan Lyons and Tagny Duff to show how, although enormous advances have been made towards health equity over the centuries, the foundational power structures of Western medicine continue to hold sway over the lives of patients today. Gendered biases rooted in the Renaissance still put undue pressure on women patients in particular to submit to medical paternalism. The representations of skin color in medical textbooks continue to demonstrate a white bias, and do not reflect the racial distribution of modern society. Such enduring biases lead artists to take up the images and practices of the past in an effort to insert a critical voice, if not directly to medical practitioners themselves, then at least to support others who have felt the pressures of navigating the hierarchies of our healthcare system. In this next section, I demonstrate how enduring visual tropes are appropriated and reframed in artists’ books as a form of institutional critique.

*Joan Lyons: The Gynecologist (1989)*

Joan Lyons’ *The Gynecologist* (1989) is a single folio, soft cover artist’s book whose relatively simple form and staple binding contrast with the depth of conceptual complexities within (See Figure 2.2). Using black and white ink printed with offset lithography on brown paper, Lyons appropriates and reprints images of women’s bodies, organs, and medical devices that were illustrated within landmark anatomical publications over the past 500 years. Whole figures appear on the left-hand side of the page spreads, and disembodied organs float behind text boxes printed on the right-hand pages like uncanny wallpaper. The text narrates an interview with a woman who recounts years of contentious interactions with her gynecologist as he pressures her to have a hysterectomy. Printed together, the peculiar anatomical illustrations, at least to our modern eyes, set against the patient’s own voice highlights historical misconceptions around female anatomy and the pressures women continue to experience within a paternalistic medical paradigm.

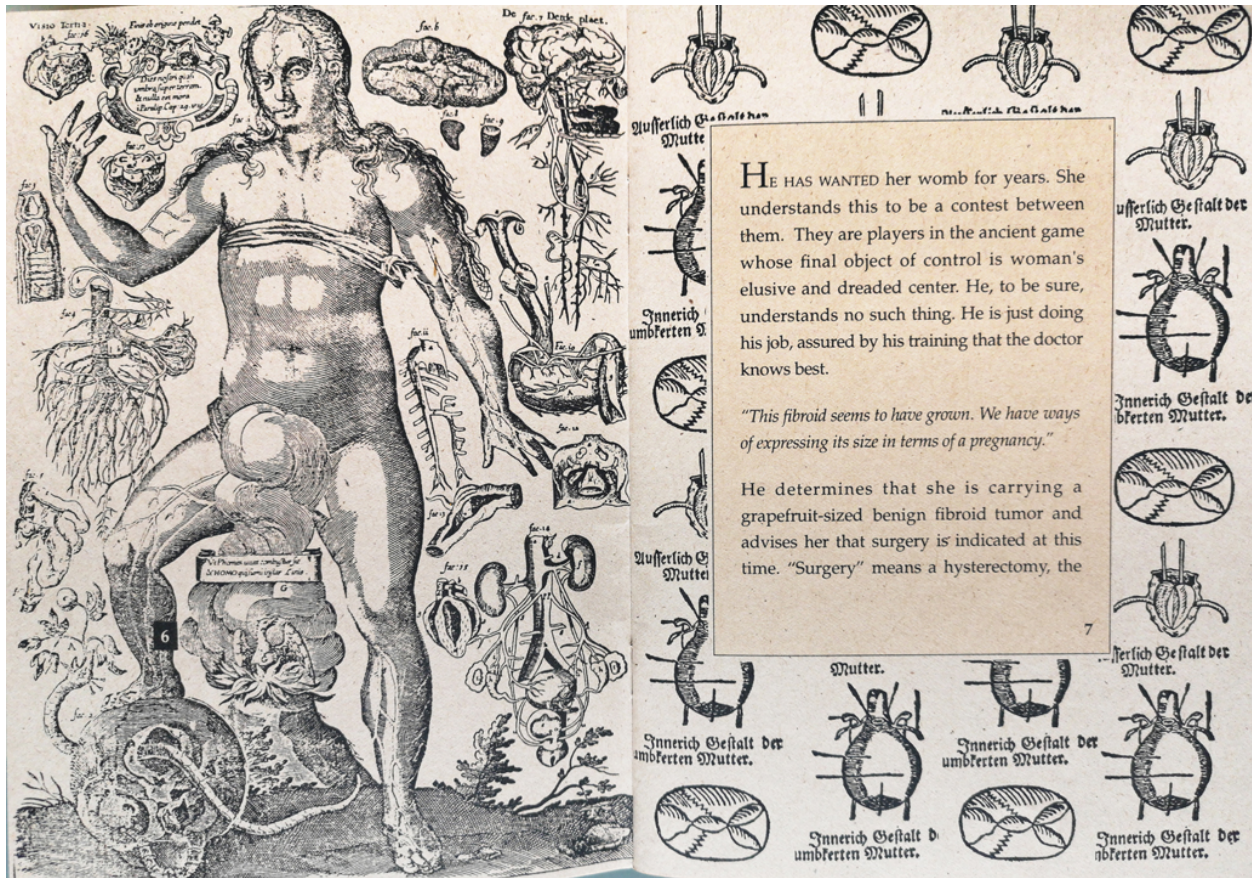


Figure 2.2: Joan Lyons, *The Gynecologist*, Offset lithography, 8.5" x 6," 1989.

The proliferation of medical imagery in the 20<sup>th</sup> century, such as x-rays and affordable anatomical atlases, practically invites appropriation where “artists can openly explore the more troubling, unsettling aspects of bodily phenomena.”<sup>17</sup> Women in particular pick up and re-present these old anatomical illustrations “precisely because they feel that the theories and practices of medicine have exercised disproportionate power over women’s bodies; they want to re-form the representations of the female body in order to affirm the value of women as subjects (including artistic ones).”<sup>18</sup> In their artists’ books, women are empowered to redress the lack of their own first-person perspectives in the formation of healthcare knowledge about them.

The women’s bodies reprinted within *The Gynecologist* reach back into the 1500’s and portray ornate sensibilities that are quite different from contemporary medicine’s illustrative standard of austere objectivity. The Renaissance was a time when art, science, religion, and philosophy could exist together rather than in separated fields, and therefore it was only right that any study of the body would also include visual metaphors to the body’s Creator.<sup>19</sup> For example, anatomical depictions of women’s bodies would often double as biblical allegories for Eve. The first Eve woman reprinted in Lyon’s book is by the German anatomist Johann Remmelin (1583-

<sup>17</sup> Deanna Petherbridge and Ludmilla Jordanova, *The Quick and the Dead: Artists and Anatomy* (Manchester: Cornerhouse Publications, 1997), 101.

<sup>18</sup> *Ibid.*, 112.

<sup>19</sup> Martin Kemp, “Forward,” in *The Physician’s Art*, eds. Julie Hansen and Suzanne Porter (Durham, Duke University Press, 1999), 14.

1632), whose illustrations were then engraved by Lucas Kilian (1579-1637) for the book, *Catoptrum microcosmicum*, first officially published in 1619 (See Figure 2.2). This image portrays a snake with an apple tree branch in its mouth slithering through a skull under Eve's foot. In the background, a phoenix is erupting from a volcano, the ash of which wafts into the foreground to cover Eve's genitals. Themes of Genesis, Greek mythology, *memento mori*, and the promise of life after death present an eccentric array of allegories in this ostensibly anatomical image.

Like Andreas Vesalius' (1514-1564) groundbreaking book of anatomy, *De humani corporis fabrica libri septem* (1543), Remmelin employed the use of flaps to reveal the structures of the human body in the original publication of his book (See Figure 2.3). A reader could lift off the flesh of Eve and, organ by organ, move through the layers of her body. The flap book convention was used throughout the centuries to portray the third dimension of complex bodily spaces within the flat planes of a book. Flaps could also be used to show change over time within the economy of a single page. Edward Tuson's book of midwifery, *Myology* (1828), employs flaps to show how the pregnant body changes throughout gestation, the movement of the fetus through the birth canal, and even the stages of a C-section procedure. One *Lancet* review of *Myology* from 1829 reads, "In the study of these dissected plates, the sense of touch is exercised as well as that of sight; hence their vast superiority over every other description of graphic illustration."<sup>20</sup> The use of flaps were a dimensional, multi-sensory, and temporal method of illustrating and teaching anatomy, albeit quite laborious and expensive to produce. With the inventions of automated publishing techniques, the engaging flaps eventually fell out of favor in anatomy textbooks and are today generally reserved for children's books or artists' books like Lin's *Skinny Leg* (See Figure 2.1).

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<sup>20</sup> *The Lancet* 11, no. 280 (January 1829): 468.



Figure 2.3: Johann Rummelin, *Catoptrum microcosmicum* (flap detail), 1619.  
<https://wellcomecollection.org/works/p2gat3vx/images?id=uqb74t8w>

My purpose in referencing medical flap books from three different centuries is to exemplify how typical it was for anatomists, illustrators, engravers, and publishers to appropriate and copy one another. Publishers cut costs by copying previous work rather than commissioning new illustrations. Indeed, exact copies of Vesalius' plates can be found again and again in anatomical treatises, including Rummelin's aforementioned treatise. Aside from the desire to pirate Vesalius and his illustrator Jan Stephan van Calcar's extraordinarily popular imagery, including the plates, portraits, and anatomical notions of forebears was also a method of paying homage to a lineage of medical thinkers. Vesalius himself faced some professional backlash for *de Fabrica* when he broke with conventions and excluded most of the, albeit false, conventions of Galenic anatomy established all the way back in the 2<sup>nd</sup> century AD. Ideas of how the body works and what it looks like become engrained as medical fact when the same plates are reprinted through the centuries, each new publisher depending on the accuracy of the former, even when those images are demonstrably inaccurate. This explains why the same tropes and misinformation of female anatomy appear again and again—effectively cementing them into the visual culture of medicine.

By reprinting images of female genitalia from 500 years of medical illustration, Lyons shows how biased or even false anatomical representations come to be standard thinking. For example, the idea that the female reproductive organs are more or less undescended, internal penises was established in the Renaissance and severely influenced how they were illustrated for centuries. A phallic bias was able to take root because the male body was understood as the standard, representative body, except when specifically depicting obstetrics. Even in this field, however, direct parallels were made between men and women's genital structures and bodily fluids, so that maleness could be understood as universal and femaleness as stunted or deviant.<sup>21</sup> These phallic uteruses are re-printed throughout Lyon's pages, and are meant to exemplify the lack of accurate knowledge when it comes to female bodies.

The depictions of women in anatomical treatises are also meant to reflect their ideal roles in society. While their faces and breasts remain alluring, intact, and unscarred by the anatomist's scalpel, women's abdomens are cut open to reveal either a fetus or a hollow gut cavity awaiting to be filled. Male cadavers, on the other hand, could be depicted in any state of exposed musculature, veins, viscera, or ossification. Visual tropes such as this reinforce the idea that a woman is valued by her beauty and potential to be mother, and nothing in-between.

The artists and anatomists of these publications played on the voyeurism of their male audiences by displaying female anatomy in erotic fashions. Under the guise of science, it was socially acceptable to view an exposed woman, "legitimizing [the] frame through which the naked female body could be viewed, at a time when most displays of nudity were highly regulated."<sup>22</sup> Perhaps this is no more apparent than within the common visual trope of many anatomical treatises' title pages, known as *ex libris* pages, which depict a nude female figure laying on the dissection table at the center of an anatomy theatre: breasts and face intact, abdomen flayed open, and surrounded by crowds of well-dressed men. Lyons has reprinted one of these title pages from another one of Vesalius' publications, *Epitome* (1540), within her artist's book (See Figure 2.4). "Sexuality here has been taken to its ultimate, and possibly fetishistic depths of penetration into the female body—beyond anatomy, beyond 'science,'"<sup>23</sup> and into, as conceptualized by Foucault's writing on the dominating medical gaze,<sup>24</sup> the realm of social control. As with so many of Vesalius' plates, the composition of this *ex libris* was evoked over and over in artistic renderings of medicine throughout the subsequent centuries, reiterating the idea that a woman's role in medicine is, at most, that of object of study and never of medical authority.

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<sup>21</sup> Petherbridge and Jordanova, *The Quick and the Dead*, 63.

<sup>22</sup> Joanna Ebenstein, *The Anatomical Venus* (London: Thames and Hudson, 2016), 122.

<sup>23</sup> Petherbridge and Jordanova, *The Quick and the Dead*, 90.

<sup>24</sup> Michel Foucault, *The Birth of the Clinic* (London: Routledge, 1976), 84.

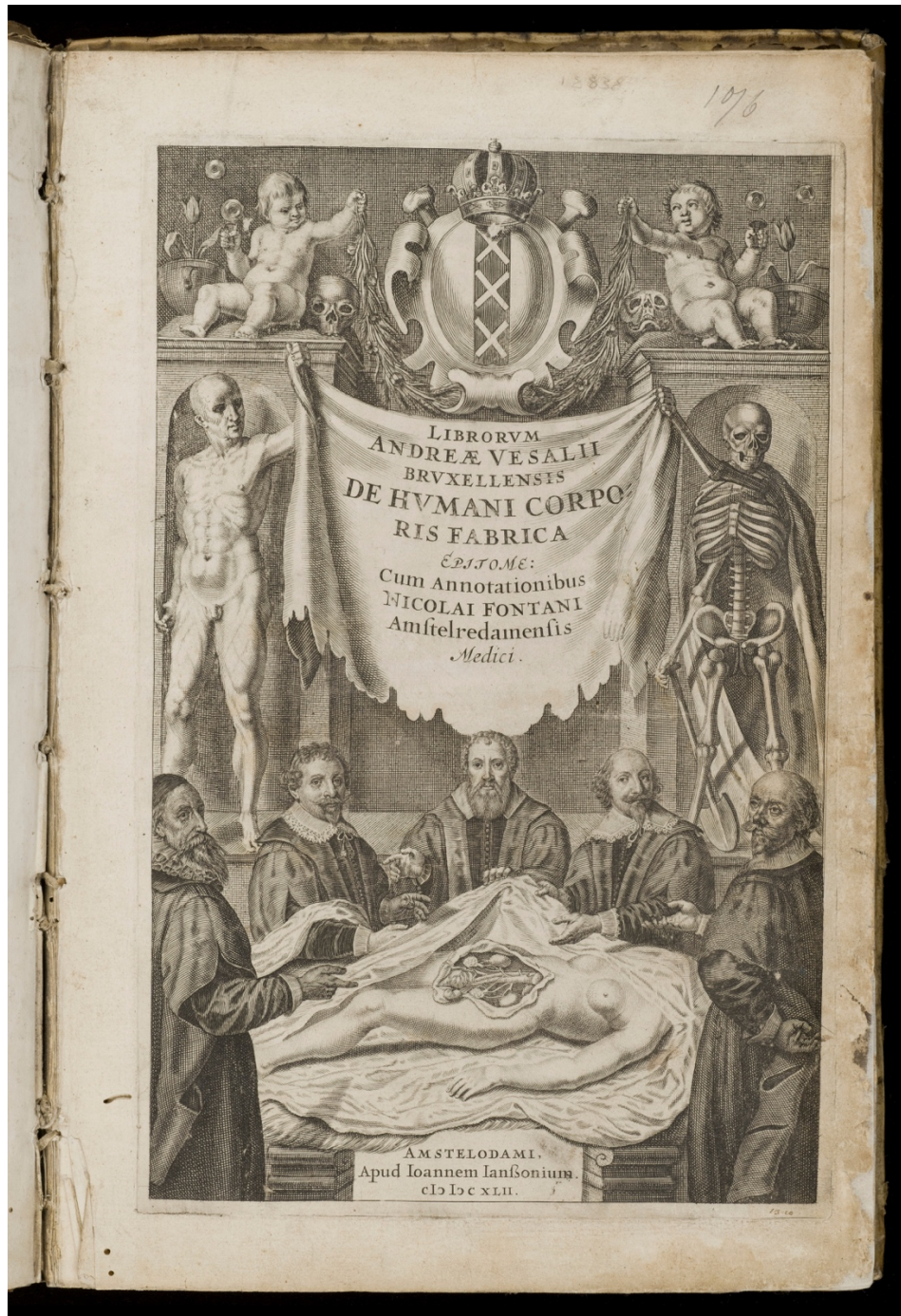


Figure 2.4: Andreas Vesalius, *De humani corporis fabrica epitome*, Ex libris page, 1540.  
<https://wellcomecollection.org/works/vnwfgcqj/images?id=w9apauyv>

Lyons longitudinally traces this *ex libris* visual trope within *The Gynecologist* by also including much more recent examples of the female body laying supine in the center of many finely dressed medical men, such as the photograph, “Howard Atwood Kelly About to Operate” (1897), and the advertisement for surgical supplies, *Great Moments in Medicine* (1945) by Lejaren a Hiller. We must remember that the original illustrations reprinted in *The Gynecologist*



were products of a time when women held very little power in the way of healthcare knowledge. Given that women (and people of color) were generally shunned from attaining medical degrees and practicing medicine until 1960's, it may be no wonder that this composition held fast as one of the quintessential visual representations for the art of practicing medicine.

Lyons' appropriation and reprinting of medical images portray the development of female anatomical knowledge in the absence of women's voices. In her *Afterword*, Lyons explains that "while modern medical practice has removed the horns from its anatomical description of the uterus and no longer insists on a phallic representation of female genitalia, the mythic elements that informed these representations lives on in the still largely patriarchal practice of gynecology."<sup>25</sup> However, as the feminist artist collective subRosa also point out, even contemporary representations of female genitalia in medical textbooks remain "amazingly inaccurate, misogynistic, and outdated... , made by some of the first male doctors and gynecologists, [and] still permeate contemporary scientific and medical literature and practice."<sup>26</sup> The convention of reprinting the same anatomical images again and again, either as an honorific or cost saving measure, have resulted their continued biased influence over new generations of physicians.

In an effort to include women's voices, rather than solely their inert bodies, in gynecological discourse, Lyons has transcribed an interview with a woman who felt coerced by her physician to undergo a hysterectomy. Lyons likens their debate to two "players in the ancient game whose final object of control is the woman's elusive and dreaded center."<sup>27</sup> In the course of the artist's book, we read the physician pressure his patient by instilling fears that her benign uterine fibroid may become cancerous in the future, the higher risks of surgical complications and blood loss if she decides to wait, and even potentially contracting AIDS through multiple blood transfusions. He also attempts to bate her with the promise of a permanent form of birth control, no longer having menstruation cycles so she can perform at top levels "like [his] other patients—lawyers," and "be like everybody else."<sup>28</sup> The pressure tactics and belittlement of the narrator's chosen career as an artist do not deter her, and she continues to ask questions that champion her long-term health outcomes from a total removal of her hormone-producing organs, rather than submit to medical paternalism.

To propel the activist feminist message of this book, Lyons editioned this work to the high number of 800, which allows it to have a relatively low purchase price. This decision aligns with the 'democratic multiple' model of artists' books for a wide distribution. Although this work is about one woman in particular, Lyons has transcribed a paternalistic narrative that many patients can relate to. In the space of her artist's book, Lyons seeks to "inform women and thus give them back, if not control over their own bodies, at least support for negotiating rather than submitting to medical authority."<sup>29</sup> The juxtaposition of inaccurate historical depictions of female anatomy and submissive women's bodies set against an inquisitive woman's voice exemplifies the tension many patients feel when questioning medical authority. While the artist's book does not reveal whether the patient does ultimately receive a hysterectomy, it is clear her resilient self-advocacy in the midst of such medical pressures led her to feel more informed and at ease with

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<sup>25</sup> Joan Lyons, *The Gynecologist* (Rochester: The Visual Studies Workshop, 1989), 23.

<sup>26</sup> subRosa, "Common Knowledge and Political Love," in *Tactical Biopolitics: Art, Activism, and Technoscience*, eds. Beatriz da Costa and Kativa Philip (Cambridge: MIT Press, 2008), 231.

<sup>27</sup> Lyons, *The Gynecologist*, 7.

<sup>28</sup> *Ibid.*, 19.

<sup>29</sup> Joan Lyons, quoted by Johanna Drucker, *The Century of Artists' Books* (New York City: Granary Books, 1995), 293.

this decision.

*Tagny Duff: Cryobook Archive*

Like Lyons, artist Tagny Duff engages with the medium of artist's book as a space for critiquing the dominant power of medicine over the body; however, rather than engage with internal anatomy, Duff focuses on the surface. The *Cryobook Archive* (2010-present) presents a series of four hand-sized books that are bound with fleshy materials (See Figure 2.5). Upon reading Duff's artist statement, the viewer is informed that the book covers are in fact made from animal and human flesh. The books contain folios of blank paper and are sewn to the cover using black surgical sutures. The books are presented in a wooden cabinet behind triple sealed glass, which sits upon a freezer unit that keep the books in a cryogenic stasis at  $-80^{\circ}\text{C}$ .



Figure 2.5: Tagny Duff, *Cryobook Archives*, Human and animal flesh and paper, 2010-present. Image courtesy of the artist. [tagnyduff.com/projects-current/cryobook-archives/](http://tagnyduff.com/projects-current/cryobook-archives/)

Duff's work is meant to bring attention to the very real bodies behind the sterilized digital and illustrated images that portray medical research, because "we often forget that information is made from physical bodies."<sup>30</sup> Although the human flesh was ethically donated to Duff's project, the books are also meant to evoke historical practices of "grave robbing," or the unscrupulous and nonconsensual acquisition and dissection of cadavers, as well as contemporary black market trading of human organs and tissue. Duff calls on us to consider the "status and

<sup>30</sup> Tagny Duff, "Cryobook Archives\_Tagny Duff," filmed February 7, 2011 at the Science Gallery, Dublin, video, 2:44, <http://tagnyduff.com/projects-current/cryobook-archives/>.

instrumentalization of bodies in the pursuit of knowledge and information”<sup>31</sup> by presenting flesh excised from their original bodies and bound into the iconic symbol of learning: books.

The significance of skin has risen, fallen, and risen to prominence again in the arch of Western medical thinking. As the porous membrane where fluids could enter and excrete, the flesh was a vital interface in Medieval and early Renaissance medical practice for balancing the four humors. It was also thought that a learned medical man could read the subtle signs of moles and hue that manifested on the skin to diagnose an internal malady. By the late Renaissance and into the Modern Era, medicine became influenced by new theories on how the universe worked. Philosophers like Newton, Descartes, and Hobbes came to see that “the fundamental components of life might not be humors but particles, and the body might be refigured materialistically as a machine, a matrix of pipes, pumps, and levers,”<sup>32</sup> which could be excised, replaced, or repaired by surgical intervention. Therefore, skin fell from prominence as it became a mere barrier to anatomical discoveries of below.

As is shown on the *ex libris* pages of anatomical treatises like N. Highmore's *Corporis humani disquisitio* (1651), flesh was often illustrated as the substrate material for the title and front matter text (See Figure 2.6). The implication here being that the flesh, like the cover of this book, must be opened to gain knowledge of the body within. However, by peeling back the flesh and ‘revealing’ the unseen, what are these illustrations subsequently obscuring? Without the identity that flesh provides, cadavers could be reimagined into any character that the anatomist desired and that social decorum required.

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<sup>31</sup> Tagny Duff, “Cryobook Archives,” accessed November 4, 2020, <http://tagnyduff.com/projects-current/cryobook-archives/>.

<sup>32</sup> Barnett, *The Sick Rose*, 24.



Figure 2.6: N. Highmore, *Corporis humani disquisitio*, Ex libris page, 1651.  
<https://wellcomecollection.org/works/gu486jnj/images?id=t6rzmrhj>

In contrast to the typical imagery within anatomical treatises that depict Adam and Eve figures, cadavers dancing through the Italian country side, or posed next to exotic animals, the great advancements to our modern knowledge of the body and medicine was made, quite literally, on the backs the poor, the enslaved, and those subjected to capital punishment. Great Britain's Murder Act of 1752 stipulated that convicted murderers could be further sentenced to *anatomization*, that is, medical dissection, in order to humiliate the corpse and deny an intact

Christian burial.<sup>33</sup> Although the images produced for medical treatises were expensive and grand affairs whose figures are characterized as upper-class members of society or even holy figures, the origins of these cadavers belonged to those on the fringes of society over whom the medical institution could exert its total control.



Figure 2.7: *Burke's Skin Pocket Book*, 1829. Photo via Surgeons' Hall, Edinburgh.  
<https://museum.rcsed.ac.uk/the-collection/key-collections/key-object-page/pocketbook-made-from-burkes-skin>

One such case study is the crimes and curious afterlife of William Burke (1792-1829), who engaged in the black-market procurement and sale of corpses to eager schools of anatomy in Edinburgh. When Burke and his accomplice were found to have murdered sixteen people over a two-year spree in order to sell the bodies for medical education, he was sentenced to hang and, in a kind of symmetrical justice, also sentenced to anatomization at the University of Edinburgh by anatomy professor Alexander Monro III.<sup>34</sup> Monro then used Burke's excised flesh to create at

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<sup>33</sup> Sarah Tarlow and Emma Battell Lowman, *Harnessing the Power of the Criminal Corpse* (London: Palgrave Macmillan, 2018), 84.

<sup>34</sup> Sarah Tarlow, "Curious Afterlives: The Enduring Appeal of the Criminal Corpse," *Mortality* 21, no. 3 (2018): 216.

least two calling-card holders (what we might deem today as business-card holders) and, most pertinent for this analysis, a pocket book (See Figure 2.7). This small, dark brown folder, which would have been used to carry loose papers and notes, is imprinted with the gold leaf title, “Burke’s Skin Pocket Book” on the front, the date of his execution on the back, and boasts loops for conveniently holding writing utensils. While Highmore only illustrated the title of his book on a cadaver’s flesh, Monro’s series of objects made from Burke’s leather hide takes the intersection of bookmaking and medical objectification to the most extreme.

The practice of turning human flesh into books, known as *anthropodermic bibliopegy*, while rare, was also certainly not unheard of. In most cases, the cadaver’s flesh was used to bind books of their murderous crimes or hold copies of anatomical treatises. Brown University counts a human-skin-bound copy of Vesalius’ *de Fabrica* among its collection. These items became valuable collectables, which is one of the reasonings behind such a morbid practice. Other reasons include posing as a deterrent for felonious crimes or lending a certain authenticity and gravitas to an anatomical textbook. A final justification for turning human flesh into books, I posit, is to continue one’s corporeal punishment long after death.

Historian Constance Classen relays that schoolmasters would beat their students in order to make “what one learnt part of one’s innermost bodily experience,”<sup>35</sup> as it was thought that the memory of the painful beating would cement the day’s learning along with it. For Burke and others like him, could there be a more fitting capital punishment than having his skin bound into the cover of a book—the iconic symbol of societal knowledge and authority that the criminal so disregarded in life? Certainly, a lesson has been learned in the transformation from body to book.

In the aftermath of Burke’s crimes and sensational trial, Great Britain passed the Anatomy Act of 1832, which stipulated that *any* unclaimed corpse, not necessarily those of criminals, could now be acquired by anatomy schools in order to undercut the black market for corpses. This act effectively shifted the cache of cadavers from executed criminals to the extremely poor: those who remained unclaimed in the morgue or whose family could not afford a burial. Although the more fanciful images of anatomy were being replaced by austere and ‘objective’ illustrations by the mid-19<sup>th</sup> century, like those found in Henry Grey’s *Anatomy* (1858), behind the figures in all of these medical treatises and textbooks, within the very foundations of our modern understanding of pathology and anatomy, lies an inextricable practice of state power being exercised over the bodies of criminals, the poor, and those on the fringes of society.

In America and other European colonial establishments, medical knowledge was further built upon the bodies of People of Color. The institution and legacy of slavery in America meant that the bodies exploited for medical knowledge were disproportionately Black.<sup>36</sup> For example, the so-called “Father Modern of Gynecology” J. Marion Sims (1813-1883) honed his experimental techniques on Black slaves who had no rights to resist. However, the physician “hid his subjects’ race and even illustrated reports of experiments on Black slave women with illustrations of bourgeois white matrons.”<sup>37</sup> An application of medical knowledge garnered from the exploitation of Black bodies for the benefit of White bodies necessitates the obliteration of

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<sup>35</sup> Constance Classen, *The Deepest Sense: A Cultural History of Touch* (Urbana: University of Illinois Press, 2012), 19.

<sup>36</sup> Barnett, *The Sick Rose*, 38-39.

<sup>37</sup> Harriet A. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (New York: Harlem Moon Broadway Books, 2006), 59.

identity that the skin provides.

When Black people *were* portrayed in medical textbooks and print media in the 16<sup>th</sup> through 20<sup>th</sup> centuries, they were often accompanied by racist stereotypes and negative connotations. In humoral medicine, madness was diagnosed as the overabundance of black bile, which had the ability to darken a person's soul along with their skin—indicating the totality and permanence of the humoral imbalance that ultimately pervaded one's outward appearance. This, along with the iconography of small black demons biting the heads or leaping from the mouths of the Mad, formed the commonplace association between Madness and Blackness.<sup>38</sup> The evolution of illustrating Madness culminated in the 18<sup>th</sup> century with the publication of pseudoscientific phrenology and physiognomy textbooks, where dispositions and intelligence could be read through cranial shapes and facial features, respectively. The founder of phrenology Franz Joseph Gall (1758-1828) and his book, *On the Functions of the Brain and of Each of Its parts* (English translation published in 1835), concluded that the facial features of those from African descent were most closely linked with criminality and Madness. Thus, attributions of “Black, murderer, and madman become interchangeable...”<sup>39</sup> This pathology was employed to justify the dehumanization and enslavement of Black people and continued to influence systemic racist ideas like eugenics into the 20<sup>th</sup> century.<sup>40</sup>

Due to economic disparities, Black people were at the highest risk of anatomization in many parts of America until the Uniform Anatomical Gift Act of 1968, which enabled the wide practice of consensual anatomical donation. However, still to this day, “the legacy of this ‘postmortem racism’ survives in policies that continue to appropriate the bodies of ‘friendless paupers’ such as the homeless—a disproportionate number of whom are Black—for medical purposes.”<sup>41</sup> Even though the number of Black persons who are anatomized outpaces their population ratio, Blackness remains underrepresented in medical illustration and textbooks. A recent survey found that the most common textbooks and anatomical atlases used in medical schools today disproportionately portray light skin tones relative to population proportions, even though certain diseases, like skin cancer, can appear strikingly different on darker skin.<sup>42</sup> Therefore, “a lack of attention to race/ethnicity in case examples reinforces whiteness as the assumed norm,”<sup>43</sup> to the detriment of health outcomes experienced by People of Color.

Duff's *Cryobook Archive* brings skin to the forefront of our attention as a site where knowledge is formed, history is etched, and identity is recognized. In this work, human flesh is not discarded to reveal the internal body within, nor is it re-presented in illustration or writing, but becomes the material focus entirely. These one of a kind books certainly fall into the category of auratic object, and appeal to the idea that each person contains their own particular history and life experience. Duff means to preserve the notion that flesh remains a rightful site of subjectivity and identity by preserving this particular skin in a cryogenic cabinet and evoking the archival nature of books.

Although the viewer of these books is not permitted to take them out of cryogenic stasis to hold them, the visceral quality of the flesh covers, including their lumpy texture, visible yellow fat, and suture piercings, provokes an empathetic sense of touch and gut reaction. This

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<sup>38</sup> Sander Gilman, *Seeing the Insane* (Lincoln: University of Nebraska Press, 1996), 2.

<sup>39</sup> *Ibid.*, 111.

<sup>40</sup> Eelco Wijdicks, “The Galling and Gifted Franz Joseph Gall,” *The Lancet: Neurology* 19, no. 10 (2020): 812-813.

<sup>41</sup> Washington, *Medical Apartheid*, 118.

<sup>42</sup> Patricia Louie and Rita Wilkes, “Representation of race and skin tone in medical textbook imagery,” *Social Science & Medicine* 202 (2018): 39.

<sup>43</sup> *Ibid.*, 39.

response links to a phenomenological flesh that produces sensory feedback even in the absence of direct engagement. Duff's work takes up anatomical practices of the past and returns it with new sensibilities of consent and reciprocity. Unlike previous examples of anthropodermic bibliopeggy or forced anatomization, Duff attained full consent from a living donor whose flesh was explanted during a cosmetic surgery. The *Cryobook Archives* thus reverse the domination and appropriation of flesh from the past and engenders a feeling of ethical intercorporeality between the patient and viewers of her books.

### **A Reunion of Art and Medicine**

As illustrated by the exquisite images anatomical treatises, artists were integral members of medical institutions for centuries. Their draftsmanship and ability to translate anatomy into to visual language of printmaking was essential to disseminate medical thought, while the deft inclusion of allegory and philosophy made these images meaningful and significant to their contemporary audiences (for better or for worse). Artists were fixtures within the anatomical theatre and worked closely with physicians and anatomists to represent their work. However, as photography, medical imaging, and illustration began to specialize, artists were edged out of medicine. The role of artists then shifted to critical outsiders who visualize their critiques of dominant medical paradigms that objectify and subjugate patients.

In an effort to move well away from harmful medical biases and promote *reflexivity* within the institution of medicine, theologians, ethicists, and philosophers began promoting the humanities alongside of clinical training in the 1960's.<sup>44</sup> Reflexivity "involves constantly examining your own position in the research endeavor, including your assumptions, feelings, and decisions."<sup>45</sup> In such institutional introspections, the dominant and dehumanizing metaphor of 'body as machine' is found to result in depersonalization and dissatisfaction from patients and practitioners alike. To promote a more holistic view of medical practice, these advocates focused on adding and integrating the study of arts and humanities back into medical education, which, while admirable, were ultimately mired in continuous challenges from the institution to justify the the transfer of resources, time, and prove the efficacy of such curriculum changes.<sup>46</sup> The field of medical humanities has had difficulty finding widespread integration because of these debates ever since.<sup>47</sup>

Advocating for partnerships between the arts and medicine shifts artists from critical outsiders and back to integral co-researchers. Collaborating interdisciplinary perspectives allow for ambiguity and reflexivity, within which an open-ended and continuous questioning of how health knowledge is constructed and upheld can take place. Medical and health humanities proponents challenge the institution to recognize that the historical visual cultures of medicine "were little more than tools used to justify the domination of white European (and American) males over colonized populations, women, and People of Color," which have resulted in lingering biases to this day.<sup>48</sup> By analyzing these images, reading patient narrative, studying artworks, *making* artwork, and many other forms of humanities interventions, reemerging art and

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<sup>44</sup> Jane Macnaughton, "Medical Humanities Challenge to Medicine," *Journal of Evaluation in Medical Practice* 17, no. 5 (2011): 927-932

<sup>45</sup> Patricia Leavy, *Method Meets Art: Arts-Based Research Practice* (New York City: Guilford Press, 2015), 282.

<sup>46</sup> A closer look at these debates and difficulties with providing evidence-based justifications for the intrinsic value of art is provided in Chapter 4 of this thesis.

<sup>47</sup> Macnaughton, "Medical Humanities Challenge to Medicine," 934.

<sup>48</sup> Thomas Cole, Nathan Carlin, and Ronald Carson, *Medical Humanities: An Introduction* (Cambridge: Cambridge University Press, 2014), 5.



medicine is a strategy of turning the dominating medical gaze on itself in order to become more conscious of the power exerted over patients and the ways medical paradigms suppress the natural emotions that come with practicing medicine.

Like all political art, there is debate on the effectiveness of artwork to instigate meaningful change if it remains unnoticed by those who hold the most power. Until very recently, artists' books, graphic novels, and zines were not circulated within medical education and thus had little influence on those populations.<sup>49</sup> However, with the surge of interest in these materials in medical humanities courses and special collection libraries, the union of patient voices and complex, subjective imagery within artists' books is beginning to find an audience *within* medical institutions.

One promising example of artists returning to the anatomical theatre is provided by New York University School of Medicine's long-term artist in residence, Laura Ferguson. Ferguson leads weekly anatomy drawing classes of the cadavers the students dissect during their medical degrees. She concludes that the close looking involved in drawing from life fosters the students' ability to more accurately recognize the subtle structures of anatomy. As well, the meditative, durational time of drawing also gives students space to process the brutal and emotionally laden act of dissection, which may otherwise negatively impact mental health.<sup>50</sup> The act of attentive care it takes to accurately record anatomical structures "is part of a growing movement in medicine that encourages a more empathetic attitude towards patients and recognizes the value of listening to their voices, especially through the expressive power of arts."<sup>51</sup> Spending time drawing a cadaver, or reading patients' artists' books, has the power to reverse dehumanizing detachment, acknowledge the emotions of medicine, and provide the time to *be with* their patients.

## Conclusion

Those who possess books, and to a much greater extent, those who make books, hold the power of knowledge representation. In the long arc of medical illustration and books, elite institutions and their members have defined what being ill or well looks like until very recently. Advances in printing technology have transitioned that power from the upper classes to that of any citizen. The opportunity for self-representation within the authority of the books has never been so accessible. I argue that the very act of creating a book, to seize the authority contained within *The Book* as an icon of knowledge, is in itself a radical act of self-advocacy. When artists' bookmakers appropriate the images and practices of medicine that are meant to categorize and even control them, the authority over defining health is flipped from specialized medical knowledge to the patients' own lived experiences. This flipped hierarchy enables a critique of engrained paternalistic and patriarchal healthcare paradigms, represented and reinforced within medical textbooks throughout modern history, from the patients themselves—pressed and preserved in ink.

The way to alert readers to the overt and subtle bias of biomedical images is to continuously critique their origins and methods of influence. As Finley states, "if arts-based researchers actively create a body of work that tells the stories of local groups and individuals,

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<sup>49</sup> Johanna Drucker, "Bound to Speak: Accounts of Illness in Artists' Books," *Journal of Medical Humanities* 41, no. 1 (2020): 86.

<sup>50</sup> Laura Ferguson and Katie Grogan, *Art & Anatomy: Drawings* (San Francisco: University of California Medical Humanities Press, 2017), 15.

<sup>51</sup> *Ibid.*, 12.

while it exposes the injustices people have experienced as subjects to the tyranny of the majority, and in which diverse forms of art are used as a means to draw attention to the citizens' articulations of oppression, arts-based research can retrace and expose the common threads of racism, sexism, and discrimination that form social contract."<sup>52</sup> The artist's goal in appropriating images and practices of bygone medicine is to take power over the image, then alter, transform, and return it with renewed attention to the lived, sensing body. In addition to providing support for those with similar patient experiences, these critiques are beginning to be incorporated within medical institutions in the form of pedagogies and partnerships that do not shy away from the challenges presented by artists. Either through the patient voice reprinted in Lyons' artist's book, the ethical reciprocity of flesh by Duff, and the other artists detailed in the following chapters, feminist artists present a challenge to the patriarchal and paternalistic paradigms of medicine by asserting their authority within the politic of health.

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<sup>52</sup> Susan Finley, "Arts-Based Research," in *Handbook of the Arts in Qualitative Research: Perspectives, Methodologies, Examples, and Issues*, eds. J Gary Knowles and Ardra L. Cole (Los Angeles: Sage Publications, 2008), 78.

## Chapter 3

### *Field Notes: How to Be With*

#### **Introduction**

*Field Notes: How to Be With* is the artist's book I created as a research-creation method and output of my investigation at the intersection of art and health. This chapter is framed through a close reading of this artist's book, as it amalgamates the interviews, archival research, and artistic collaborations conducted to examine how arts-based research is conducted within the health humanities today. *Field Notes* brings together two embedded positions I held during my fieldwork: first as a Visiting Scholar in the University of Kent Medical Humanities Program, and then as the Artist in Residence at the McGill University Fertility Research Laboratory. I was drawn to conduct a portion of my fieldwork in the UK because of what I perceive to be the highly developed level of scholarship surrounding arts-based research in healthcare. I was also most interested in collaborating with Dr. Stella Bolaki, who is the Director of the University of Kent's Medical Humanities Program and has published chapters and articles on the potentiality of artists' books in healthcare research. In this collaboration, I was also able to study the University of Kent's Prescriptions Collection: a distinctive archive of artists' books dedicated to topics of bodily concern. These books enabled me to investigate the various methods artists communicate their encounters with medicine, and how, as part of university's library archives, they are employed as primary health research material. I was interested to discover the kinds of sensory or tacit knowing that generally elude written narrative, but that can be uniquely communicated by handling artists' books. Throughout this chapter, I will position the artists' books from this collection that I found to be especially poignant for my arguments on the communicative aspects of bookness, and which ultimately influenced the final formation of *Field Notes*.

While in the UK, I took this geographical opportunity to meet and formally interview over twenty scholars working at the nexus of humanities and health, including artists, writers, physicians, historians, librarians, and philosophers. My goal with these interviews was to discover the most emergent themes and arguments in contemporary health humanities, medical humanities, and critical medical humanities, as well as if and how research-creation is being employed as a research methodology. Portions of these interviews have been transcribed and rearranged in *Field Notes* as if these researchers were sharing in a discourse with one another in order to portray the interconnectedness of thought around these topics.

The second portion of my fieldwork was conducted as the first Artist in Residence at the McGill University Fertility Research Laboratory. For three months, I shadowed two scientists during their daily experiments and held numerous informal conversations with them about their research. My first aim in this residency was to better understand the process of generating original medical knowledge, and how the scientist's body is implicated in, or is displaced from, embodied perception. My second objective for this residency was to use aesthetics as a nexus between science and arts-based research, and bridge the lacuna between the images produced in a laboratory and the how end users of medicine (i.e., patients) re-present their own imaged bodies in artists' books. Many of the images included in *Field Notes* emerged from a collaborative printmaking process I developed with these two scientists.

The purpose of *Field Notes* and this accompanying chapter is to argue for research-

creation artists' books as original health humanities scholarship. The unique contribution of artists' books to the field is their ability to express lived experience and form intercorporealities with the reader through the intertwining engagement of the sensory, text, and image. The neglect of this kind of embodied scholarship within healthcare is of growing concern, as biomedical imaging and other technologically mediated ways of examining the body contributes to a sense of depersonalization—leading to dissatisfaction from both patients and healthcare providers.<sup>1</sup> The multivalent modalities of artists' books challenge healthcare researchers to de-center linguistic narrative and third-person case studies as the modus operandi of illness research, and “forge new alliances with the arts and humanities in order to remain pluralistic and experimental.”<sup>2</sup> Returning attention to sensory ways of knowing enables a phenomenological practice of understanding illness, fostering empathy, and promoting artistic practices as creative care.

Although the research-creation outcome is accompanied by this written thesis, I consider *Field Notes* to be equally rigorous and potentially more eminent due to its economy of means, sensory engagements, and intimate impact with readers. As well, I believe that the compact nature and conversational tone of the text that generally avoids jargon is capable of speaking to a wider range of audiences than may be possible with this written component. *Field Notes* is more than a thesis that weaves together facets of arguments from preeminent scholars of the field. It is more than a collaborative ethnographic piece of fine art. It is more than research about art-based research. It is best described as research-creation on the process and outcomes of research-creation—thoroughly investigated through archive holdings, expert interviews, and embedded residencies to analyze how artists' books embody and generate new ideas. This is different than the largely auto-ethnographic research-creation that occurs in most artists' books about illness, where makers seek to materialize and communicate an inscrutable phenomenon about themselves, as is the general aim of the books I encountered in the Prescriptions Collection. Although these books are also textual and multi-sensory investigations of illness, *Field Notes* goes a step further to embed artists' books within a wider discourse about the state of arts-based research in healthcare, who employs it, and who would benefit from doing so. It is a meta-book on the process and outcomes of making books.

Given the transcendental nature of books, that is, the medium's long history in our society that has cultivated certain norms and expectations of what a book is and does, closely analyzing artists' books concludes with the impossibility of reading them in isolation. Artists' books depend on a culturally engrained knowledge of how to read a book in order to turn such standards on their head. Subverting our preconceived notions for bookness is a core method for artists to illuminate lived experiences that counter our preconceived notions of health and illness. Therefore, the artists' books cited here portray entangled perspectives that are at once far reaching and intensely personal, variable and dependent upon a multiplicity of potential interpretations from each successive reader. To create a potential meaning that illuminates some aspect of the artists' experiences, I employ a phenomenological practice of sensory description and material hermeneutics. While acknowledging the subjectivity of the medium, artists' books are an *experience*, of which this is mine.

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<sup>1</sup> Drew Leder. *The Distressed Body: Rethinking Illness, Imprisonment, and Healing* (Chicago: The University of Chicago Press, 2016), 44.

<sup>2</sup> Stella Bolaki, *Illness as Many Narratives: Arts, Medicine, and Culture* (Edinburgh: Edinburgh University Press: 2016), 7.



Figure 3.1: Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.

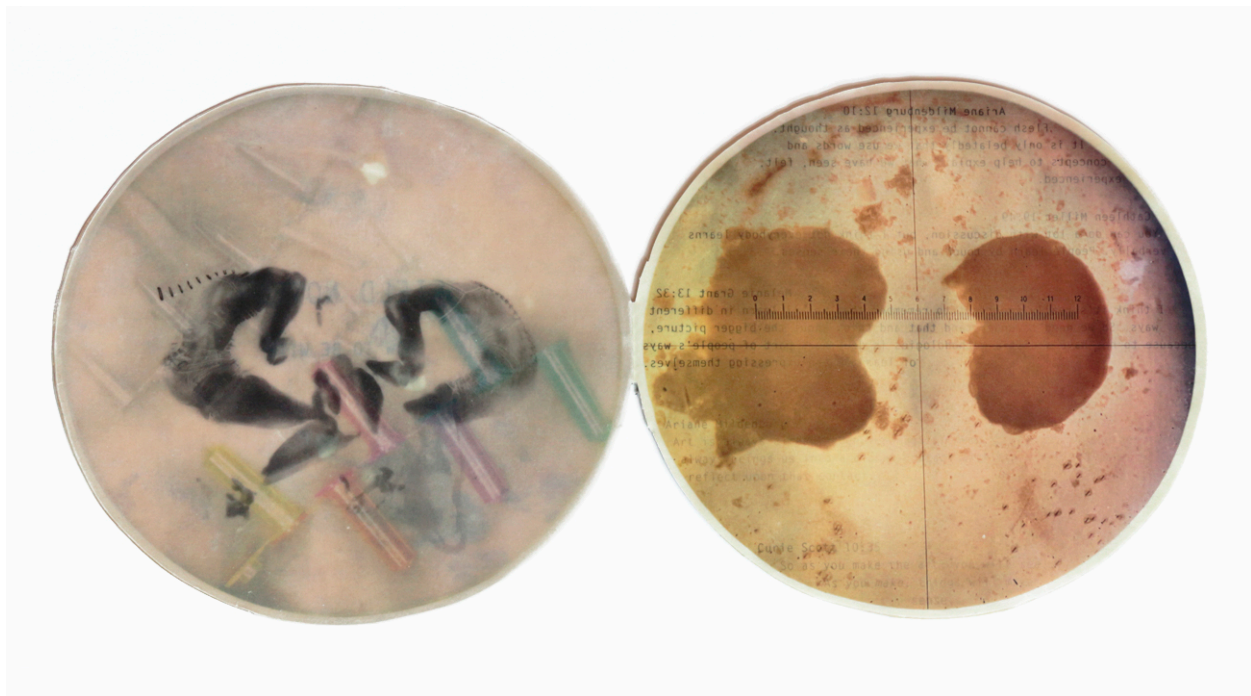


Figure 3.2: Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.

### **Preface**

When closed, *Field Notes: How to Be With* is an eight-inch round book and about one-fourth of an inch thick. Across the center one can read the title, *Field Notes: How to Be With*, in

an unadorned sans serif font (See Figure 3.1). Around the outer edge of the cover is a golden ring, which joins on the left-hand edge of the book. The book is bound at this juncture with golden thread in a Japanese or stab-stitch binding. Beneath the binding one can see a golden stencil of the metal hardware that tightens an embroidery hoop. This detail gives some context for the unusual shape, though its inclusion is unobtrusive enough to evoke many other interpretations for the round cover.

The book's shape is immediately arresting because it subverts the typical rectangular book form. It's roundness not geometrically perfect, and therefore feels more natural in origin, like a planetary body or cross-section of a tree. The cover shifts hues between uneven layers of warm ochres and umbers—reminiscent of deer leather. In some places, especially on the back cover of the book, there is a topography of shallow bumps, bubbles, and crags. These features make the leathery cover appear burned or afflicted with some kind of skin condition. Overall, the cover is easily understood as the skin of book-body—be it human or nonhuman in origin.

The multiple interpretations of this cover initiate the idea that all objects belong within networks of meanings, associations, and histories, the circle being perhaps the most fundamental shape in human consciousness. This assertion is based on the Stratford's book, *Echo Objects*, which argues that the human brain solicits common shapes and patterns in order to make sense of the world. What could be a more recognizable shape than the round eye of a loved one or gazing upon the moon? In fine art, the simplest geometric forms, like the circle, are often the most meaning-full compositions because our culture has called upon their geometry over and over again. As Stafford attests, “this graphic grammar, composed of discrete character or cipher combinations, allows us to generate a range of denotative and connotative meanings from elementary forms.”<sup>3</sup> More specifically for the topics of this book, the circle connotes the scientific composition of the body (parts) seen through the microscope, fluoroscopy scan, or surgical cameras. This, along with the potentially pathological looking skin of the cover, alerts us to medical themes to come.

Opening the front cover (See Figure 3.2), the book becomes a diptych. Splitting the circular book and forming a binocular view of the book-body alludes to all the partnerships that have informed this research: art and science, myself and my sister, objects and subjects, health and illness. The ways in which all of these themes are intimately intertwined comes into focus as the reader lifts each translucent page to place it upon its opposite.

The first section of pages contains two small figures curled towards each other in the fetal position. Only the very surface of figures' torsos is shown, which gives the impression of a planar slice from an MRI or CT scan. The appearance of spines and other anatomy furthers the associations with biomedical imaging technologies. These two figures are seen nestled within two larger kidney-bean shapes. Flipping the page, the figures are lifted away to join the multi-colored testing vials on the left side of the diptych. The presence of crosshairs and a measuring guide across the shapes clue us in that they may be very small organs if we are viewing them through a microscope. They are in fact mouse ovaries.

This visual introduction of *Field Notes* exhibits the two major visual collaborations that occurred in the making of this book: between myself and my sister, and between myself and two fertility scientists at McGill University. *Field Notes* is the latest iteration of my long-term collaborative art practice with my sister, Devan Stahl, who is a hospital chaplain, Professor of Medical Ethics at Baylor University, a chronically ill person with multiple sclerosis, and was

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<sup>3</sup> Barbara Maria Stafford, *Echo Objects: The Cognitive Work of Images* (Chicago: The University of Chicago Press, 2007), 20.

struggling with infertility during the course of this research. I began making artwork about Devan's symptoms of MS and sharing them with her in 2012 because I found the topic of disease and all the implications it had for my sister's life too difficult to acknowledge directly. By creating these works and gifting them to her, I was able to *show* her my care in a way that my words had failed. This artistic gesture inspired Devan to write more narratives about her lived experiences of illness and procure copies of her MRI scans to share with me. She thought we could creatively expand these singular purpose images to also communicate the impacts of illness on her daily life. Through the layering and additive processes of printmaking and bookmaking, I merge her MRI scans with impressions of my own skin in an attempt to provide shelter to her imaged viscera. This blending of our bodies are the two figures that appear in the beginning *Field Notes*, and they embody the creative caretaking I share with my sister.

After years of semi-annual MRI scans and participation in demanding clinical trials, Devan's experiences under the medical surveillance became compounded during her years-long effort to become a mother. She had to discontinue her MS medications, as their potential effects on a fetus are unknown. This put her health in a state of constant precarity, and she felt an incredible amount of pressure to become pregnant quickly—which did not happen. My care for Devan continued to include a reimagining of her medicalized body, which now incorporated time-lapsed fluoroscopy stills of contrast being injected into her uterus, and eventually, the first ultrasounds of her son. Representing the complexity of illness is one of the main goals of this research-creation, and although there is no research that links MS with infertility, it would be wrong to say they are unrelated. Forgoing vital medications for years in the hopes of conceiving a child is not an easy choice to make, and these decisions were also interrogated by her physicians, particularly in light of her “advanced maternal age.” The inclusion of Devan's medical scans exemplifies for the readers the pressures patients face, particularly for women, to lead the life of their choosing while also being ill.

The mouse ovaries and various assemblages of medical ephemera printed throughout the book are the result of my second fine art collaboration with two scientists at the McGill University Fertility Research Laboratory, Karen Carvalho and Sofia Granados. Acknowledging my lack of knowledge about such topics, I sought out this residency in order to understand current and future fertility treatment possibilities that may go on to help people like my sister. I was also curious about the people constructing primary scientific knowledge, as this perspective was generally absent from my health humanities research thus far. My research questions at the center of this artist residency ask, “What is at stake when the images of medical and scientific research contain so much specialized knowledge that they become indecipherable by the person they represent? How can these images be deconstructed and contextualized in ways that refocus on lived experience?” And finally, “How might aesthetics form a bridge between scientists and those who seek healing?”

To engage these questions, I performed what design anthropologist Sarah Pink defines as “sensory ethnography,” which is “an emplaced ethnography that attends to the questions of experience by accounting for the relationships between bodies, minds, and the materiality and sensoriality of the environment.”<sup>4</sup> To know a place, it is best to experience it through prolonged presence, touch, smell, and sound. To know the practices of a person who operates within that particular space, such as this laboratory, ideally the researcher performs the practice alongside the practitioner's expertise. In this position alongside, each person contributes her own situated

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<sup>4</sup> Sarah Pink, *Doing Sensory Ethnography* (Los Angeles: Sage Publishing Ltd., 2015), 28.

knowledge into a potentially collaborative environment.

My sustained presence in the lab established trust and rapport with the scientists. I could ask probing questions about the process and implications their research in the midst of its occurrence—creating a far richer sensory understanding than typical sit-down interviews. I asked questions like, “What was each experiment hoping to discover? How does it feel to conduct research using the ova of mice versus the ova of humans? How might what you are doing today impact patients in the future? What is your experience as a woman in science? What are the future plans for this research, and for yourself?”

What I had not anticipated were the emotional stakes of conducting scientific research. My own preconceived notions of hushed, antiseptic environments and stoic objectivity were completely upended. When real people donate their harvested ova or mice have been specially bred and sacrificed for dissection, the pressure to successfully carry out experiments is incredibly high. I also learned that, in spite of its advanced robotic or technological portrayals in popular media, much of the procedure for scientific experiments is conducted through carefully orchestrated embodied movements. I observed, most notably, how they pulled their breath through a rubber tube connected to a hand-crafted glass pipette (which they fired and pulled themselves) to carefully lift a single mouse ovum from a Petri dish and place it into the experiment’s chemicals, all while only viewing this minute action through a microscope. Finally, it became abundantly evident the depth of creativity needed to even begin formulating an experiment, how to conduct it using incontestable scientific methods, and then accurately imaging and interpreting its results in order to inform the next day’s experiment. By the end of my residency, I found the laboratory to be a space where sensory engagement and creativity thrives, which I believe makes sustained art/sci collaborations all the more possible.

To form a true collaboration rather than one-way transmission of knowledge, I invited the scientists into my art studio to discover how aesthetics can bridge our disciplines, and potentially, form new knowledges at a nexus of art and science. We first gathered the daily tools of their research, like colorful syringes, nitrile gloves, and biohazard bags, to create aesthetic assemblages on the photo bed of a scanner. I then taught them my encaustic printmaking technique, which allowed us to layer and merge our Xerox scans with images from the history of medicine or the scientists’ microscopy. Although I was not permitted to photograph the mice in the laboratory, I stitched their visages into the prints as a way to include their bodies in this research-creation.

The method of collaging these images together, as Kathleen Vaughan states, “with its overlappings, juxtapositions, and shifting centers and margins—can be seen as a transborder practice with epistemological implications.”<sup>5</sup> For example, the scientists’ motivation for collaboration was to connect what they do in the laboratory with the communities they serve, and demystify the scientific process for a general audience. Especially in this current political climate of science skepticism or denial, making science scrutable to non-experts is an essential strategy to convey the importance of their research. I argue including the images and practices of science as artwork that invites the viewer to activate and become a part of its meaning is a productive way to form inclusive alliances. Translucent artists’ books can be seen as participatory collages, as the layers of image and voice are seen through, pulled apart, read individually, then placed back into their seat. Ultimately, the narrow and big-picture applications of the scientists’ findings are made more apparent through the layered and collaged pages of *Field Notes*. This method of

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<sup>5</sup> Kathleen Vaughan, “Pieced Together: Collage as an artist’s method for interdisciplinary research,” *International Journal of Qualitative Methods* 4 (2005): 32.



meaning-making implicates both artistic and scientific epistemologies, and portray the mass amount of labor, materials, and creativity necessary to produce the images of our shared research.

From the beginning of this residency, my goal was to understand how the narrow results of an experiment link within networks of discoveries that finally go on to impact people like my sister, the real-world receivers of treatment. In short, capturing the bigger picture. Given the embodied methods of the scientists' research, the outcome of this residency, *Field Notes*, is similarly understood by the sensing body. Binding the images of science into an artist's book destabilizes and abstracts their original, narrow meaning so new associations can emerge. The movement of transparent bodies across a spine keeps the images suspended, and the ambiguities of scale and origins of body parts sustain such instabilities. The corporeal fluidity of *Field Notes* disrupts the boundaries between human and nonhuman and layers them back onto the other as mutually constitutive. This stratification connects the restricted space of the laboratory with the impacts of scientific research on patients, families, and the researchers themselves. This is how *Field Notes* is able to bridge the epistemological divides of art and science, and how it will continue to question the current and future practices in health humanities.



Figure 3.3: Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.

**Ariane Mildenburg 12:10**

Flesh cannot be experienced as thought. It is only belatedly that we use words and concepts to help explain what we have seen, felt, experienced.

**Cathleen Miller 19:49** You can do a lot with discussion, but I think not everybody learns verbally. People learn by touch and using their senses.

**Melanie Grant 13:32**

I think it's really important to remember that we all learn in different ways. So we need to

understand that and think about the bigger picture, because to not have artistic methodologies is denying a part of people's ways of learning and expressing themselves.

**Ariane Mildenburg 7:47**

Art is always already phenomenological. For in one way or another, art always brings us into a closer contact with the world and makes us reflect upon that contact.

**Curie Scott 10:36**

So as you make the art, you will *see*. As you *make*, things will make sense.

**Sensory Meaning-Making in Artists' Books**

The first text included in *Field Notes* alerts the reader to the sensory aspects of this artist's book and how the senses are implicated in learning. The materials of *Field Notes* are meant to work together and provide meaning in excess of its imagery and text. As Classen points out, "many feelings are difficult to put into language, they are too subtle or too powerful or too complex. The anthropology of the senses sensitizes us to the mutable ways in which humans communicate and express themselves through nonlinguistic modalities."<sup>6</sup> The value of this kind of expression is to challenge normative styles of scholarship, like written theses, which can be inaccessible and unintelligible to non-specialist audiences. The academic reliance on text neglects sensory ways of knowing—a gap that artists books are exceptionally suited to fill.

Apart from the visual and haptic description provided above, a reader may first notice that the book feels heavier than it appears. This is due to the density of wax that is imbued into each page. The most significant sensory contribution of the wax, however, is its exhalation of aroma. The material used to make the fleshy cover contains dissolved sugars, a sweet caramel scent that is further nuanced by a covering of beeswax. In addition to this scent, many of the internal pages of *Field Notes* are covered in a wax medium that uses turpentine as its mineral spirit, whose exceptional pine perfume remains embedded in the wax long after the spirit has evaporated. The touch and smell of this book remind the reader of its materiality by surprising the senses at every turn.

Scent is a method to connect with the reader's memories and emotions. Verbeek and Campen explain that "more than any other sense, smell can instantly determine an atmosphere or a mood, almost independent of the context."<sup>7</sup> The pleasant scents of *Field Notes* have the potential to calm the reader during what may otherwise be an uneasy read on illness. Sweet scents as care for the body is an ancient idea, as the dominant pre-modern concept for how diseased traveled was through *miasma*, or vaporized matter that carried disease via stench. Therefore, a strategy for staving off disease was to overpower it with pleasant aromas.<sup>8</sup> During instances of plague in London, Classen relays that "amid the strength of disease and death, lavender, juniper and cinnamon were burnt in the streets and houses to 'cleanse' the air of infection."<sup>9</sup> The fragrances of *Field Notes* thus intertwine past and present conceptualizations of bodily care.

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<sup>6</sup> Constance Classen, *The Deepest Sense: A Cultural History of Touch*, (Chicago: University of Illinois Press, 2012), xvii.

<sup>7</sup> Caro Verbeek and Cretien van Campen, "Inhaling Memories: Smell and Taste Memories in Art, Science, and Practice," *Senses and Society* 8, no. 2 (2013): 137.

<sup>8</sup> Steven Connor, *The Book of Skin* (London: Reaction Books Ltd., 2004), 213.

<sup>9</sup> Constance Classen, *The Museum of the Senses* (London: Bloomsbury Academic, 2017), 112.

In addition to promoting sensory wellbeing, the strong scents of *Field Notes* elicit memories for the reader, a phenomenon that occurs “largely independent of personal will, breaking into the conscious mind unbidden and at unexpected moments.”<sup>10</sup> What does the aroma of caramel evoke for you? What emotions rise to the surface when surrounded by the scent of pine? Memories provoked by scent are typically tied to some of our oldest impressions, they are often non-lingual, and they may induce stronger emotions than viewing images alone.<sup>11</sup> Scent is strategy to make present and personal all the various meanings and interpretations of this artist’s book based upon each reader’s personal history. At the very least, the scent of this book ensures a reader cannot engage with it and remain unaffected.



Figure 3.4: Erin K. Schmidt, *The Unfinished Blanket*, Crocheted cotton yarn, inkjet-printed ribbon, inkjet-printed silk. 10” x 7.5” x 3,” 2016.

Many of the over seventy artists’ books within the Prescriptions Collection engage multiple senses as a strategy to tacitly communicate deeply emotional topics that elude verbal expression, and perhaps none more so than Erin K. Schmidt’s *The Unfinished Blanket* (See Figure 3.4). It is a white, fuzzy, delicately crocheted book comprised of a single ‘sheet’ and that is folded into thirds. It is so soft and light in fact, that it almost feels like I am touching nothing but air. Perhaps this lack of real touch is my first entry point into this book on loss. Opening the covers, we first see a clumped strip of crimson yarn, then a scattering of fastened pink text-printed ribbons, and finally, a much smaller silk book fastened inside. This second internal book

<sup>10</sup> Verbeek and Campen, “Inhaling Memories: Smell and Taste Memories in Art, Science, and Practice,” *Senses and Society* 8, no. 2 (2013): 135.

<sup>11</sup> *Ibid.*, 140.

is printed with sonograms and text; however, I do not need to read the text to already comprehend that this book concerns the grieving of a miscarriage.

According to Schmidt's artist's statement, "the text describes the joy and excitement of a new pregnancy, followed by the worry of a possible complication, and finally the deep sadness at the loss of not just one baby, but of twins due to a molar pregnancy."<sup>12</sup> Inside the smaller second book, phrases like "Three Copies of Chromosome 18// Antenatal loss// Rare"<sup>13</sup> are printed boundlessly around page. Schmidt explains that "the words don't seem to make sense, but float on the page much the same way that confusing medical terminology and jargon seem to hang in the air without meaning when speaking with doctors during times of distress."<sup>14</sup> The ineffectual words from her physicians are visually communicated through their unmoored composition.

The extreme privacy of a miscarriage in our culture makes this relatively common occurrence nevertheless unutterable and even taboo to mourn publicly. It is no wonder, then, that Schmidt chooses to circumvent a written narrative in favor of poetic and sensory meaning-making methods. Holding the unoccupied swatch of blanket places the reader in a close relation with Schmidt, as the sadness of the event is made tangible. The soft touch of the page brings the reader (and hopefully, Schmidt herself) a bit of comfort amidst the mourning of its origins.

One of the unique qualities of artists' books in healthcare research is their innate shareability, which further counters the pressure for silence around topics like infertility and miscarriage. In a materialized form, the emotions of grief can be tacitly felt, held, and dispersed over a community of readers who may be similarly impacted with struggles to build a family or those comprehending the emotional impact of such an event on others for the first time. Leder attests to the healing qualities of handmade objects shared with others. "Such objects thus embody not only divine love but that of the community.... Care and healing are made tangible... Here the touch of the shawl or quilt re-presents—makes present, over and over—a communal embrace."<sup>15</sup> Unlike machine produced books, there is a tangible sense of the hands that craft the page. It is as if we are able to touch and be touched by the maker even over vast distances simply by holding their creation. This phenomenological engagement of bodies encourages intercorporeality and can act as a form of empathy creation. Leder agrees that "unlike other sensory modes, touch unfolds through an impactful reciprocity between the toucher and the touched. For the ill person this can serve to establish human connection and assist therapeutic chance at the prelinguistic level."<sup>16</sup> The intercorporeality of haptic books like *The Unfinished Blanket* encouraged me to likewise engage the sense touch and *Field Notes*, and demonstrate the effectiveness of non-linguistic research-creation to form intimate, emotive communication between subjects.

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<sup>12</sup> Erin Schmidt, "The Unfinished Blanket," accessed June 12, 2020, <https://www.erinkschmidt.com/theunfinishedblanket.html>.

<sup>13</sup> Erin Schmidt, *The Unfinished Blanket* (University of Kent: Prescriptions Collection, 2016).

<sup>14</sup> Erin Schmidt, "The Unfinished Blanket."

<sup>15</sup> Leder, *The Distressed Body*, 76.

<sup>16</sup> *Ibid.*, 9.

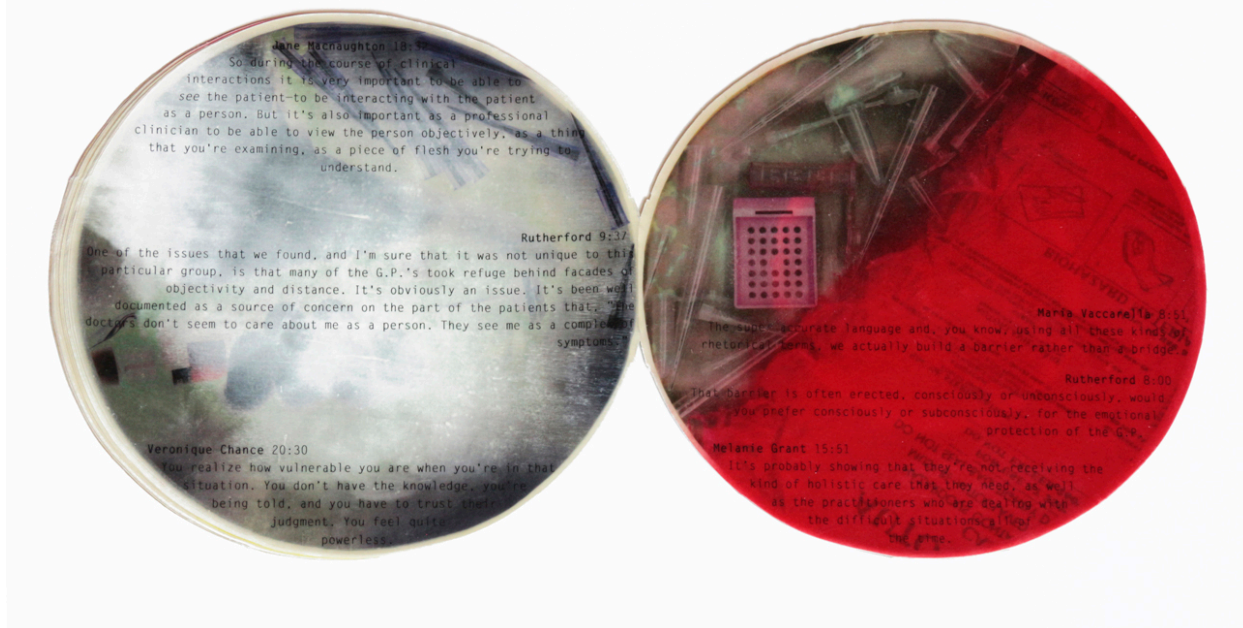


Figure 3.5: Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.

**Jane Macnaughton 18:32**

So during the course of clinical interactions it is very important to be able to *see* the patient—to be interacting with the patient as a person. But it's also important as a professional clinician to be able to view the person objectively, as a thing that you're examining, as a piece of flesh you're trying to understand.

**Rutherford 9:37**

One of the issues that we found, and I'm sure that it was not unique to this particular group, is that many of the G.P.'s took refuge behind facades of objectivity and distance. It's obviously an issue. It's been well documented as a source of concern on the part of the patients that, "The doctors don't seem to care about me as a person. They see me as a complex of symptoms."

**Veronique Chance 20:30**

You realize how vulnerable you are when you're in that situation. You don't have the knowledge, you're being told, and you have to trust their judgment. You feel quite powerless.

**Maria Vaccarella 8:51**

The super accurate language, and you know, using all these kinds of rhetorical terms, we actually build a barrier rather than a bridge.

**Rutherford 8:00**

That barrier is often erected, consciously or unconsciously, would you prefer consciously or subconsciously, for the emotional protection of the G.P.

**Melanie Grant 15:51**

It's probably showing that they're not receiving the kind of holistic care that they need, as well as

the practitioners who are dealing with the difficult situations all of the time.

### **Texts in Artists' Books**

The text in *Field Notes* serves to explicitly address the most emergent debates in field of health humanities. One of which is the perceived damage or benefits of objectifying patients during the course of a clinical interaction (See Figure 3.5). While this sense of being seen as a “piece of flesh” can be detrimental to patient satisfaction, critical medical humanities professor and MD Jane Macnaughton asserts that objectification is necessary for the practitioner to carry out her medical examination. Other medical humanities professors like Rutherford and Maria Vaccarella point out that objectification may be an emotional coping strategy for physicians who may not be receiving adequate mental health support during the course of their duties. One of these strategies is the use of medical jargon and other ‘objective’ language, which, as Schmidt previously documents, can be difficult for the patient to comprehend even in the best of circumstances. The language and labeling of medical records furthers the sense of depersonalization, as “the ‘disembodiment’ of the clinical text reaches its limit: the person-as-ill is translated into a series of numbers.”<sup>17</sup> This lack of linguistic connectedness is actively redressed in the space of artists’ books, where makers appropriate instructional media or transcribe verbal commands from healthcare workers that are meant to regulate the patient body. When physicians’ words are reprinted in combination with patient narrative, images, and other sensory engagements, new understandings of the impacts of objectivity become possible.

The text-based artist’s book from Emma O’Connor, *S:ST298.402*, which is also her assigned patient number, complicates seemingly straight-forward exchanges with her physicians by contextualizing their significance against O’Connor’s life beyond the hospital doors. Concerning her pre-cancerous genetic testing and the possibility of life-altering stomach removal surgery, O’Connor writes, “the surgeon and his staff were excellent at dealing with the medical aspects of stomach removal but not the family and psychological matters which are important for the rest of your life.”<sup>18</sup> These are matters like the guilt her father feels over passing on cancerous genes to his daughter and the socio-economic factors of healthcare that have impacted her treatment. Even with the promise of future genetic therapies, the artist’s book notes that “the financial cost of genetic medicine will result in rationing of public resources, whereas the rich will be able to pay their own way.”<sup>19</sup> O’Connor’s narrative is an example of how artists’ books are able to fill gaps in awareness about the costs of illness, both financial and emotional, from the patient’s perspective.

Illness narratives have become an important resource in sociology, psychology, and medical anthropology because of the way they relate illness to subjective bodily experience and the social world of an individual. However, one must ask, “Whose narratives are excluded from the genre because they do not fit within the strict confines of commercial publishing?” Narratives like O’Connor’s, which may otherwise be labeled as ‘too short,’ ‘too personal,’ or ‘too image-based’ to be commercially viable, are nevertheless able to gain an audience within a fine arts context. Artists’ books do not need to be neat and tidy. In fact, much of their impact comes from the unedited and uncensored testaments of lived experience. As Ducker notes, “the usual mediation of publishing [is] stripped away, and gone with it [are] the modifications of bare, blunt

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<sup>17</sup> Leder, *The Distressed Body*, 96.

<sup>18</sup> Emma O’Connor, *S:ST298.402* (University of Kent: Prescriptions Collection, 2015).

<sup>19</sup> *Ibid.*, 30.

statement into bromides of politeness.”<sup>20</sup> The narratives in artists’ books can be raw, emotional, immediate, episodic, poetic, mysterious, and unsatisfying, which may ultimately reflect the authentic experience of the illness itself.

While narrativizing an experience of illness has been lauded by many for its positive effects on the sense of agency and meaning-making for the writer,<sup>21</sup> I also argue that the productive tension between that text *in combination with image* opens the genre of illness narrative to abstraction and poetics. Such openness to a subjective reading then empowers the reader to also engage in the meaning-making process. This reciprocity between maker and reader increases the potential of establishing intercorporeality. As well, a multitude of writing styles and modes can, as Bolaki states, “create a more inclusive illness narrative canon that de-centers the literary form as the paradigm for understandings of this genre and draws connections between different illness perspectives.”<sup>22</sup> This inclusivity keeps the medium of artists’ books experimental, broadly applied, and resistant to normalization.



Figure 3.6: Mary Rouncefield, *Mr. Darcy's Advice to the Hip Patient*, Watercolor and ink, 2013.

A book in the Prescriptions Collection that poetically joins text and image is Mary Rouncefield's satirical *Mr. Darcy's Advice to the Hip Patient* (See Figure 3.6). Rouncefield illustrates a fanciful nude woman flirting with the prim *Pride and Prejudice* character Mr. Darcy across different settings, each of which flagrantly disregards the instructions on preventing post-operative hip injury printed at the bottom of the page. Although the woman in the illustrations appears to enjoy breaking the rules, Rouncefield points out the visual metaphors of this figure in

<sup>20</sup> Johanna Drucker, "Bound to Speak: Accounts of Illness in Artists' Books," *Journal of Medical Humanities* 41, no. 1 (2020): 85.

<sup>21</sup> Rita Charon, "Narrative Medicine: A Model for Empathy," *JAMA* 286, no. 15 (2001): 1897-1902.

<sup>22</sup> Bolaki, *Illness as Many Narratives*, 3.

regard to her own experience as a hip patient: “The illustrations show the female patient quite naked, emphasizing her complete vulnerability and status as ‘patient’ and ‘victim.’”<sup>23</sup> The nakedness of the female figure compared to the fully suited man also evokes the similar visual trope of *ex libris* pages in historical anatomical treatises presented in the previous chapter. Under the veil of humor, the tension between the text and images presented to the reader by Rouncefield point to exposure and danger one may feel, especially as a woman, to submit to various states of undress throughout the operating and recuperation procedures.

Rouncefield was a bed-bound patient imaginatively fulfilling the desire to do the exact opposite of what her body necessitates and what she has been told (not) to do. *Mr. Darcy’s Advice to the Hip Patient’s* larger format, expansive negative space, bright illustration, and lessons-to-be-learned feel enforce a link with children’s books, which emphasizes the sense of medical paternalism present in the textual commands. Although she must follow ‘doctor’s orders’ in order to avoid further injuring herself, her wish for willfulness is safely satisfied within her artist’s book.

Re-presenting text in an artist’s book and contextualizing it against imagery and other sensory engagements expands the potential membership to critical dialogues, an accessibility consideration that is also one of the main goals for *Field Notes*. For *Field Notes* in particular, the conversational tone of the text, resulting from piecing together transcripts of my interviews rather than quoting their published work, avoids didactic medical or overly academic jargon. It may also lower the specialized knowledge necessary for the reader to join the discussion and layer in their own views on the topics brought up. As I will detail in the next section, the same reclamation and gestures toward inclusivity can also be performed for the images of medicine.

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<sup>23</sup> Mary Rouncefield, “Mr. Darcy’s Advice to the Hip Patient,” in *Prescriptions: Artists’ Books on Wellbeing and Medicine*, eds. Stella Bolaki and Egidija Ciricaite, (London: Natrix Natrix Press, 2016), 83.





Figure 3.7: Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.



Figure 3.8: Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.

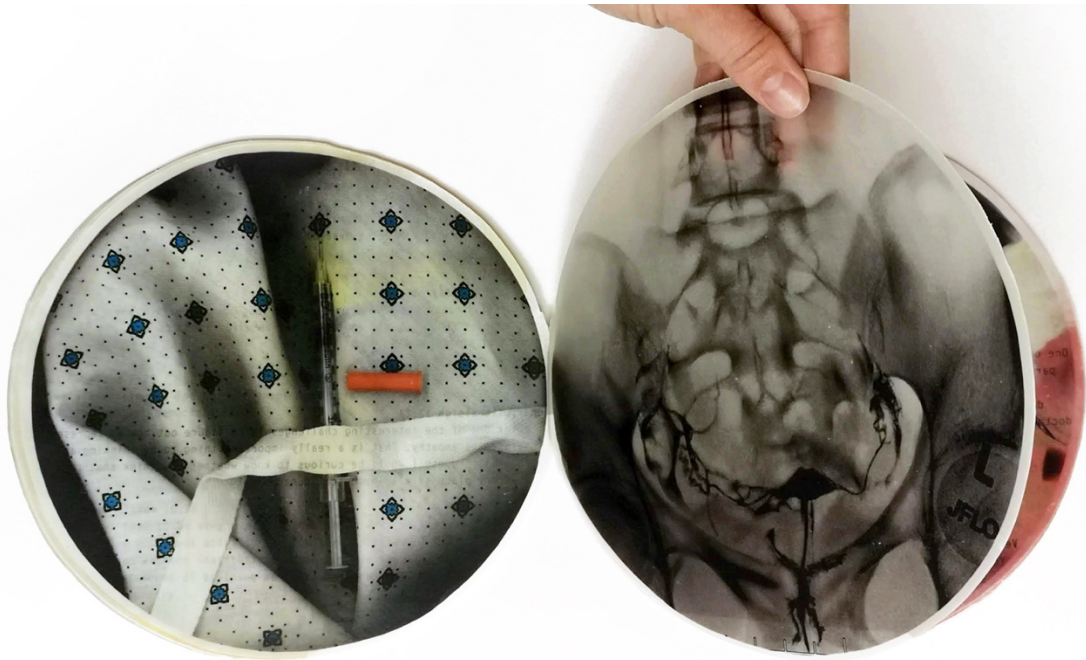


Figure 3.9: Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.

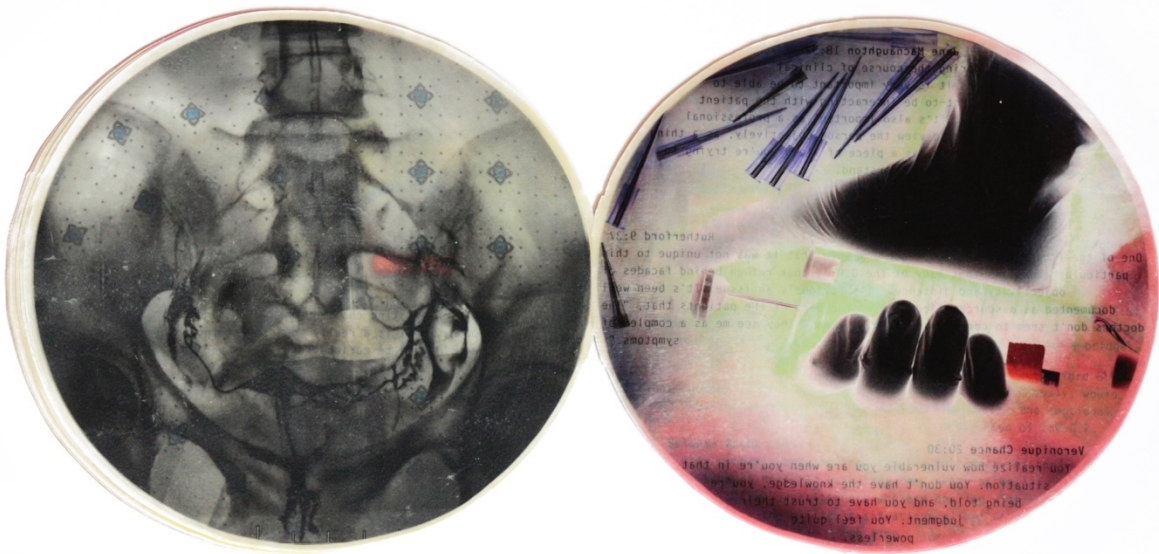


Figure 3.10: Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.

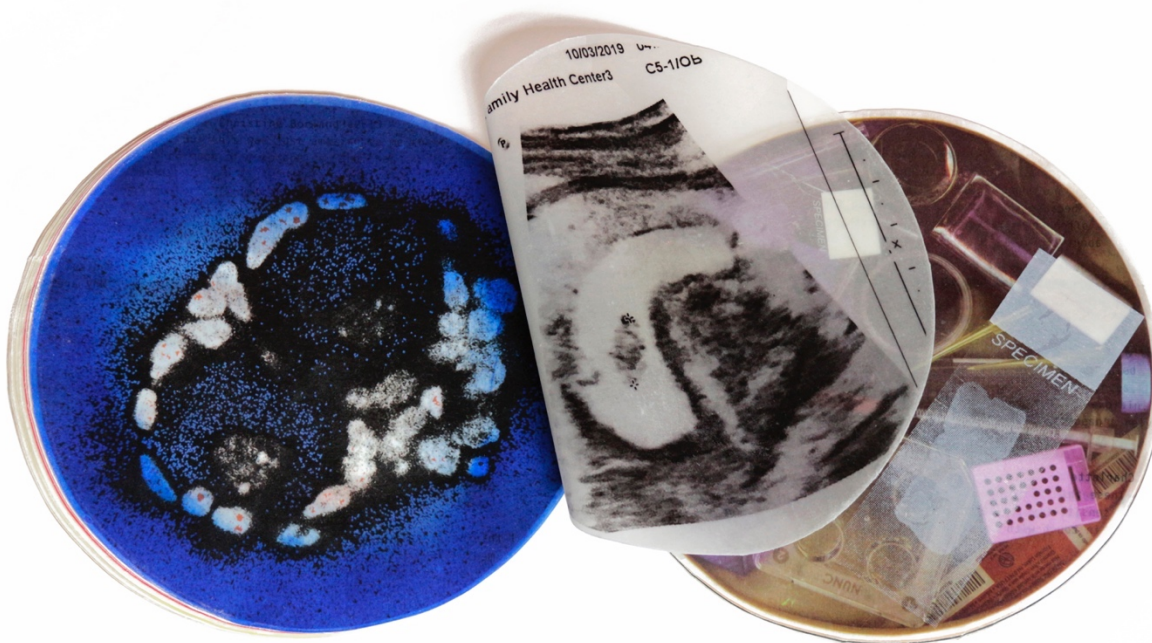


Figure 3.11: Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.



Figure 3.12. Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.

**Katherine Rawling 38:40**

So we've got these historical pictures of patients and their bodies are on display, but we are also understanding them and viewing them as an embodied experience.

**Claire Jones 23:38**

We in the history of surgery, of course, we very much look at images. We think about objectivity and think about, actually, that these are stylized—these are in a particular kind of artistic tradition. They don't necessarily represent the body as it looked.

**Katherine Rawling 36:03**

I always feel a little uncomfortable with people just posting up historical photos of patients.

**Fiona Johnstone 21:45**

Medical culture is increasingly visual, if you think about medical imaging and also data visualizations. And we are increasingly interested in art-science collaboration and working with visual artists. I think specifically *visual* medical humanities becomes very important.

**Katherine Rawling 35:00**

Does that mean that we then have the right to do whatever we want with those images?

**Jane Macnaughton 13:55**

We are, as clinicians and as the general public, charmed by the power of the image. But what we don't understand that I think is extremely complex is the technological processes that have gone into generating that image.

**Katherine Rawling 18:09**

And this idea of the doctor putting the patient in another uncomfortable or painful position, perhaps a harmful position, just to take a photo? Is that compromising their role as a doctor? But then, are they fulfilling part of the other world of being a doctor by producing medical knowledge?

**Rutherford 3:19**

Reflect on and consider the possible significance of both the nature of the individual elements contained or recorded within the photograph, and more importantly, their arrangement, composition, or juxtaposition in terms of what that might suggest about things that are of concern to the person who made the photograph.

### **Biomedical Images in Artists' Books**

The objectification felt by patients may be no more acute than when the physician gazes into their medical scans. As Foucault asks in his conception of the medical gaze, “to look in order to know, to show in order to teach, is not this a tacit form of violence, all the more abusive for its silence, upon a sick body that demands to be comforted, not displayed?”<sup>24</sup> Following this thinking, I ask in this section, “If flesh is the site of subjectivity, identity, and the primary medium of engaging and perceiving the world, then what happens to the person’s conception of self when her flesh is erased by biomedical imaging technology? How can a physician retain a sense of humanity for her patients when the primary analysis of their bodies is conducted through scans and machinery? In the pursuit of visibility, what is subsequently obscured?” Here I explore the consequences of transparency, and how an artistic re-presentation of medical scans in artists’ books reclaims a sense of agency over how the body is viewed.

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<sup>24</sup> Michel Foucault, *Birth of the Clinic* (London: Routledge, 1976), 84.

The technological evolution of biomedical imaging has increased the physician's power to transform the entirety of illness into a singular, detached image. With biomedical imaging, the body can now be read and diagnosed far from of the patient's body. As Leder explains, "the X-ray, MRI, or CT scan results are permanent, reproducible, open to inspection by anyone and everyone, and thus have come to seem the most authoritarian elements of the workup."<sup>25</sup> In light of Foucault's concept of the medical gaze, scholars like Leder, Jackie Stacy, Catherine Haase, and Rosemarie Garland-Thomson expand on Foucault's the notion that an imaged body is a dominated body.

Although patients can be seen as a kind of 'collaborator' in the making of biomedical images,<sup>26</sup> a severe hierarchy is emplaced when a patient must submit to the regimes of medicine in order to receive their benefit. Clearing the bowels, fasting, ingesting foul laxatives, or being injected with contrast causes considerable discomfort and can be emotionally taxing—not just in the process itself, but also in the anticipation of a diagnosis. All of the biomedical images included within *Field Notes* originate from Devan's body. MRI scans of her brain (Figure 3.8), intrauterine fluoroscopy scans (Figure 3.9), and ultrasounds of her womb (Figure 3.11) are a visual testament to her long history of submitting to the medical gaze.

The power differentials between the imager and the imaged ensure these seemingly 'objective' sights into the body are nevertheless shaped by economic priorities, politics, cultural values, and power. At its worst, one's submission to imaging can be met by those who would take advantage of a patient at her most vulnerable. In Devan's own illness pathography, she recounts such a situation:

After filling out my preliminary intake forms, I am asked to undress and put on a hospital gown, two if the gown is flimsy. Better safe than sorry. I have found the standards for the clothes I can wear during the exam vary depending on the lab. I once had a rather awkward conversation with a radiology technician about my bra. He was an older, slightly grizzly looking man who introduced himself by asking where I bought my bra. In my vulnerable position, I did not immediately ask why he wanted to know. I assumed he was a professional with a point. Apparently, Victoria Secret bras use a plastic underwire, which is perfectly fine in the MRI scanner. Regardless, he informed me, a metal underwire, like the metal zipper and button on my jeans, would vibrate during the exam, "which some women rather enjoy." This comment left me in the rather awkward position of having to decide whether I should leave my clothes on and allow this man to think I was "enjoying" the exam, or take them off and feel cold for the next two hours.<sup>27</sup>

In addition to this overt account of sexual harassment, an exchange with her neurologist in the moment of her diagnosis further demonstrates the objectification of Devan's body in the imaging process, albeit in a more covert manner:

"It's MS!" he declared.... My rather insensitive physician pushed a box of tissues my way without taking his eyes off the computer screen containing my MRI scans. "How can you be sure?" I managed. He looked confused. "I'm not sure what you are seeing in those

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<sup>25</sup> Leder, *The Distressed Body*, 95.

<sup>26</sup> Maud Radstake, *Visions of Illness: An Endography of Real-Time Medical Imaging* (Utrecht: Eburon Delft, 2007), 57.

<sup>27</sup> Devan Stahl, *Imagining and Imagining Illness* (Eugene: Cascade Books, 2018), 2.

pictures,” I followed up. “I’m a specialist” he assured me, in his most proud and patronizing tone. “I know what I am looking for.”<sup>28</sup>

Reaching for the chart, avoiding eye contact, and not answering questions reinforces the sense that the images of the body are more useful and important than the patient herself. In her own account of physicians viewing her internal body during the course of treatments, Jackie Stacey also finds that “the copy speaks more urgently and with more authority than the opaque and occluded ‘original body.’”<sup>29</sup> The issue of authority, that is, who has the right to capture, print, and interpret internal anatomy, is key to the reclamation of agency experienced by those who appropriate and re-print the imaged body in their artists’ books.



Figure 3.13: Veronique Chance, *In the Absence of Running*, Inkjet on Japanese paper, 2015.

My understanding of power exerted by the medical gaze, especially over women’s bodies, was expanded by the Prescriptions Collection artist’s book, *In the Absence of Running* by Veronique Chance (See Figure 3.13). This book consists of two large sheets of paper, about 2 x 4 feet each, which depict a gridded series of round video stills from her arthroscopic knee surgery. In her essay on the making of this book, Chance describes how, although long distance running is a crucial aspect of her personal health and professional career as an artist, her physician did not

<sup>28</sup> Stahl, *Imagining and Imagining Illness*, 5.

<sup>29</sup> Jackie Stacey, *Teratologies* (London: Routledge, 1997), 158.

recommend restorative knee surgery due to her middle age and, Chance suspects, her gender.<sup>30</sup> Chance states, “My experience made me realize how vulnerable one is as a patient and how much those in positions of power can influence decisions and outcomes in treatment.”<sup>31</sup> Only after returning to the doctor’s office with the support of her male partner was she authorized for surgery.

In *Field Notes*, the vulnerability of the patient’s body is most profoundly displayed in Figure 3.9. Here, a cropped view of a hospital gown cradles an orange capped syringe. On the right-hand side, a pelvis is displayed. A dark substance permeates the center of this anatomy like a drop of ink in water. In reality, this is a fluoroscopy video still of Devan’s uterus, which the doctor has injected with contrast to check for blockages in her fallopian tubes that may determine the cause of her infertility. Lifting this page, its transparency causes the reader’s hand to become a part of the pelvic composition. On the following spread (See Figure 3.10), a gloved hand grasps a large injection instrument, surrounded by sharp needle caps. These images look scary, invasive, and uncomfortable, and evoke the feelings Devan experienced at the time.

Like Chance’s arthroscopy stills, Devan’s fluoroscopy images are captured in round compositions. And like Chance’s images, one may garner many associations from gazing into the body through a dark, circular scope. Looking feels extraordinarily intrusive here, like these images are captured by spying through a door’s peephole. The circular view also recalls observing the rodent ovaries through the microscope shown on other pages of *Field Notes*, likening the patient to a specimen. For Chance, this the round compositions recall not only “portholes into the body but also a time-sequence of planets or moons, an abstract painting or a stained-glass window.”<sup>32</sup> Finally, the roundness could also recall a telescopic view, securing the notion that the medicalized body can be made present for viewing even from a great distance.

In all of these associations, the lived body is abstracted by instruments. While the sense of self is typically constructed through perceiving the body, in this case, it is also influenced by viewing the visceral through technological mediation—a premise of perception that was largely neglected by the founders of the phenomenology like Merleau-Ponty. A *postphenomenological* practice addresses the ways the body is altered, abstracted, or reduced when it is translated or perceived through instruments. The interpretations of these bodily abstractions are, as Cathrine Hasse explains, “from this perspective not a subjective reading of an external representation, but a lived embodied experience forming perceptions of the material worlds.”<sup>33</sup> This understanding of how one interprets imaged bodies acknowledges the ways our own sensory perceptions, environment, cultural histories, and personal ways of being-in-the-world impact our multivalent interpretations of the person those images represent, which “gives way for an understanding of perception as polymorphic.”<sup>34</sup> Postphenomenology gives us a framework for understanding that even ‘objective’ medical scans are still open to interpretation. Therefore, space is made for radically different uses and meanings of these images by artists.

Reclaiming the images of medicine and re-presenting them in artists’ books is a strategy for the makers to not only communicate the wider impacts of medical surveillance to their

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<sup>30</sup> Veronique Chance, “In the Absence of Running: From Injury and Medical Intervention to Art,” *Journal of Medical Humanities* 41, no. 1 (2020), 65-80.

<sup>31</sup> *Ibid.*, 70.

<sup>32</sup> *Ibid.*, 77.

<sup>33</sup> Cathrine Hasse, “Postphenomenology: Learning Cultural Perception in Science,” *Humanistic Studies* 31 (2008): 57.

<sup>34</sup> *Ibid.*, 45.

readers, but also critique the medical gaze itself. Taking medical scans, manipulating them, expanding them, rearranging them, layering them with other images, and re-printing them according to one's own subjective experience of the encounter is an act of defying the regimes of medical imagining. Such artists' books "challenge the 'mastery' of the surgeon's singular view into the body from a single camera lens or screen"<sup>35</sup> when they disseminate medical scans as subjective imagery. As an innately shareable medium, artists' books invite others to view the internal body beneath the flesh of the cover. The *invitation* to look is crucial here, as it flips the conditions of the dominating medical gaze and places agency with the maker to determine the parameters of visibility. Instead of gawking or objectifying, readers become ethical viewers in their "capacity to vivify human empathy through bearing visual witness."<sup>36</sup> In the intimate space between reader and book, the artist destabilizes the exclusivity and hierarchies of the medical gaze through the open provocation to reinterpret the imaged body, and entangle all the fleshy, interpersonal, economic, and identity impacts of that image.

The readers of *Field Notes* are likewise invited to witness the transformation of medical scans from image to icon, filled with allegory and symbolism of lived experience. As Garland-Thomson explains, "the representational trajectory from Devan as medical specimen—naked before the doctor, entombed in the MRI machine, curled like a fetus on the examining room floor—to Devan as icon,"<sup>37</sup> is a method for her to view her diseased anatomy as "one she can live in and live with, one that is not broken but beautiful, one fit to behold as a sacred object."<sup>38</sup> For Devan, seeing her body transformed into an artists' book so that it may be read and re-interpreted by others exemplifies how the particularities of her experience can grow to encompass multiple subjectivities. She states, "Allowing another person to reshape my body allows me to see the images as universal—they exceed me and invite others to see themselves reflected in [Darian's] art."<sup>39</sup> The intercorporeality of artists' books thus transforms an isolating and vulnerable event into a vehicle for shared understanding and empathy.

Keeping medical images unstable and polymorphic is essential for continually raising new questions about their purposes and impacts. In *Field Notes*, the transparency of Devan's medical scans ensures they are continually complicated by the text and images that appear beneath them and all the unpredictable associations this may hold for the viewer. Even as one lifts the page to view the scans in isolation, the visual presence of the reader's own hand through the transparent scan implicates their body in a renewed meaning of this pathology. The essential vitality of artist's books as mediations between embodiments enables a particular diagnosis, like a miscarriage, stomach cancer, knee pain, MS, or infertility, to become a part of a network of associations and questions that simultaneously expand and personalize the complex meanings of illness.

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<sup>35</sup> Chance, "In the Absence of Running," 77.

<sup>36</sup> Rosemarie Garland-Thomson, *Staring: How We Look* (New York: Oxford University Press, 2009), 188.

<sup>37</sup> Rosemarie Garland-Thomson, "Forward," in *Imaging and Imagining Illness: Becoming Whole in a Broken Body*, ed. Devan Stahl (Eugene: Cascade Books, 2017), xi.

<sup>38</sup> *Ibid.*, xii.

<sup>39</sup> Stahl, *Imagining and Imagining Illness*, 111-112.



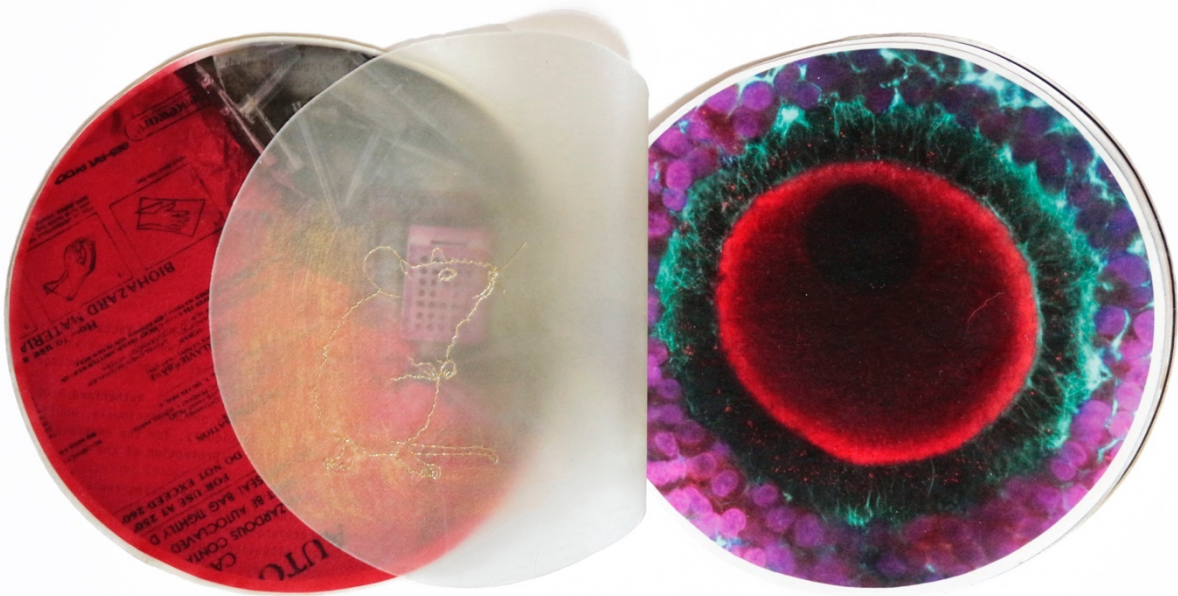


Figure 3.13: Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.

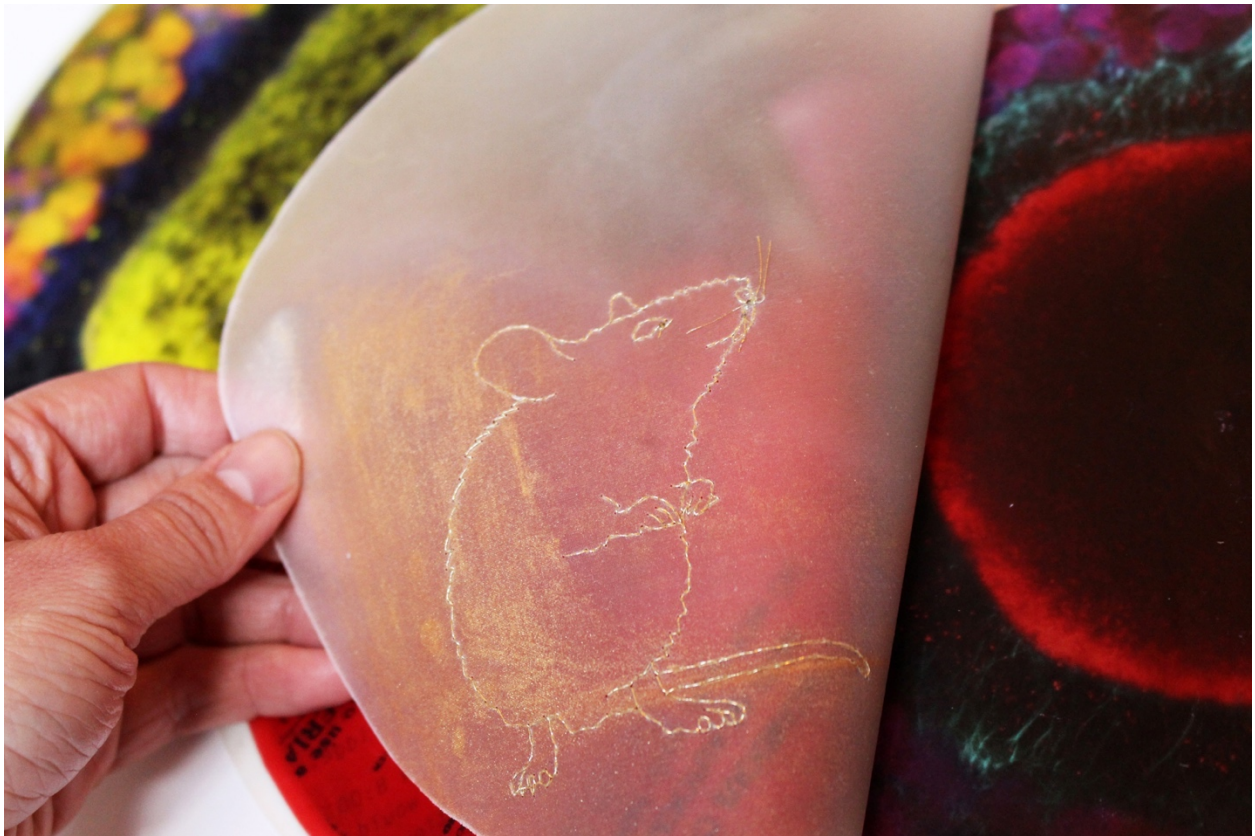


Figure 3.14: Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.

### More-than-Human Bodies in Artists' Books

Whereas the previous sections document the transformation of patient into specimen via medical imaging, this section details the transformation of specimen into patient. The use of animal surrogates to stand in for human bodies is a long-standing practice in pursuit of medical progress. Lisa Cartwright likens Foucault's medical gaze to that of scientists gazing into animal anatomy. She states that "the laboratory visual culture is, after all, a culture of human corporeal supervision and discipline, even in cases where the human body is not directly studied... The animal body is a symbolic site where human corporeal regulation is carried out."<sup>40</sup> Imaging isolated specimen organs, like the ovaries and ova of mice printed in *Field Notes*, disguises their animal origins, which makes it all the more palatable to apply the findings of the laboratory onto human bodies.

The most abstract biomedical images in *Field Notes* come from the internal bodies of mice (See Figure 3.13). The frequent presence of whole rodent bodies and microscopy of their internal structures in this artist's book concerns one of the most controversial subjects in medicine, animal testing, a topic which is often overlooked in contemporary health humanities dialogues. The high emotions of conducting research on the ubiquitous dissected bodies of mice was a constant topic of concern with my scientific collaborators in the Fertility Research Laboratory. However, animal bodies were broached only once in my over twenty interviews with health humanities scholars in the UK, from science and technology professor Charlotte Sleigh:

**Charlotte Sleigh** 17:24 I think one of the interesting challenges is to figure out how we represent interspecies empathy. That is a really important thing to be thinking about, as well. I guess I would be curious to know whether you think that that has any place at all in medical humanities?

Figure 3.14 depicts a stitched outline of a life-sized mouse on a translucent fleshy page in mid-journey across the spine of the book. The thread used to embroider this rodent is gold, and a light wash of gold pigment casts a shadow behind the small mammal. Beneath the mouse on the left-hand page depicts a bright red biohazard bag that includes diagrammatic instructions for properly picking up potentially hazardous materials (like dissected mouse bodies) using the bag. On the right-hand side of this spread is a radiant, technicolor ovum image of concentric circles, with bursts of blues and pinks emanating from a bright red and velvety black center.

The use of gold thread and pigment that outlines the mouse sits against the red warning of the biohazard bag. This placement points to the tension between the mouse being invaluable to scientific research but also disposable once the ova are dissected. Seen in isolation, we are to understand the mouse ova as approximate, even a substitute for, the ova of humans—now made readily available and genetically modified to glow under the microscope's lasers. The radiant microscopy images of the internal structures of ova are almost otherworldly enough to make one forget about the very real bodies put forward as experimental source material. However, within the space of *Field Notes*, the thickness of the gold thread embosses into the waxed center of the imaged ovum beneath, ensuring that the mouse's palimpsest remains visible after it's body has been removed. The artist's book's re-contextualization of animal imaging opens the possibility to engage with animal testing in a new way, one where the care of the researchers and sacrifice of

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<sup>40</sup> Lisa Cartwright, *Screening the Body: Tracing Medicine's Visual Culture* (Minneapolis: University of Minnesota Press, 1995), 93.

the mice is more openly be acknowledged and respected.

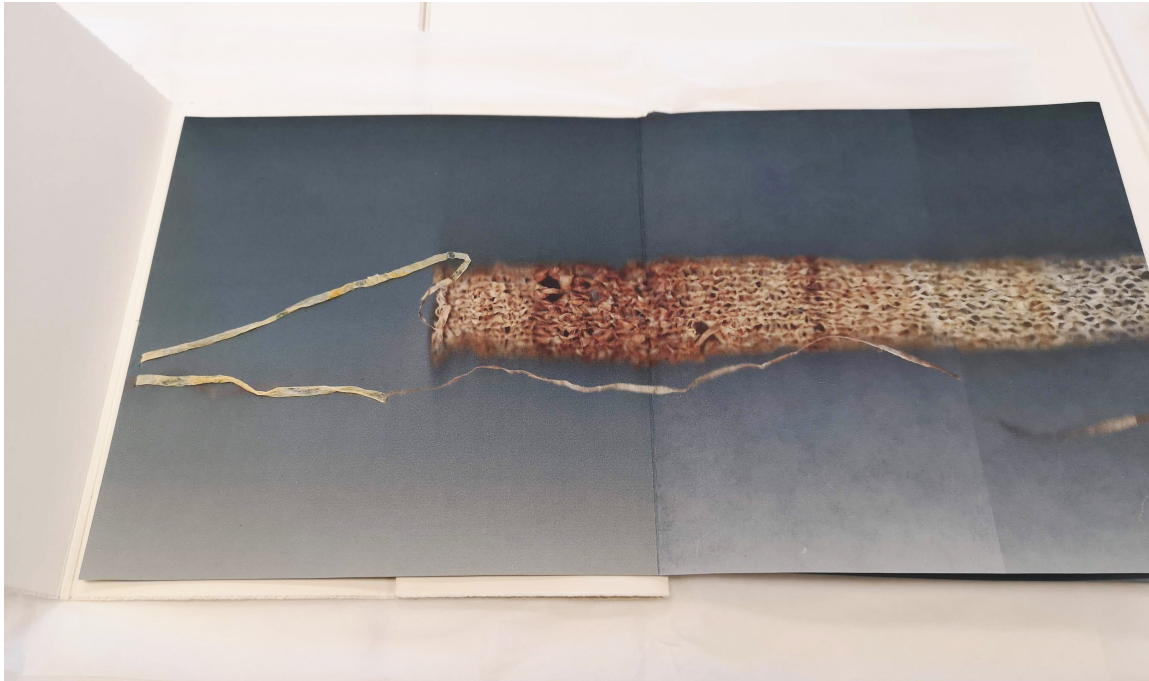


Figure 3.15: Amanda Couch, *Entrail Troyan*, Double sided inkjet print on variety of Japanese papers and weights, with salami skin collage and threads, bound in 300 gsm. Waterford folio with wax seal, 2016.

Another artist who complicates the relation between animal and human bodies in her Prescriptions Collection artist's book is Amanda Couch. Pictured above in Figure 3.15, *Entrail Troyan* depicts a long, knitted tube sculpture that has been Xerox scanned and printed along the length of her concertina book. On the final page, the 'thread' used to knit this sculpture leaps off the page then weaves back through the opposite cover to bind the book together around a red wax seal that is embossed with an anus insignia.

Couch's article in the *Journal of Medical Humanities* reveals that the sculpture is formed from knitting together pork sausage casings cut into thin strips, so that the sculpture both connotes and is formed with literal entrails.<sup>41</sup> Couch also discloses her struggles with irritable bowel syndrome—a notoriously mysterious condition. Couch fulfills her wish to better understand her vexing guts by materializing them through an animal proxy. Couch uses her "fingers, palms, arms, breasts, legs, wherever a tome was placed, . . . [to] enact a corporeal connectivity through the haptic."<sup>42</sup> Bowels that are typically hidden in her bodily depths but nevertheless profoundly impact her food and traveling choices can now be engaged with in a way that is meaningful for the author and readers of this artist's book.

The use of animal bodies in art and science continues to draw further parallels to patient experiences. Feelings of being treated 'like a lab rat' or 'guinea pig' extend the all-too-easy comparisons between the ill and rodents into our common vernacular. In *Field Notes*, the distinctions between animal and human parts is obscured as it contains microscopy images of

<sup>41</sup> Amanda Couch, "Reflections on Digestions and Other Corporealities in Artists' Books," *Journal of Medical Humanities* 41, no. 1 (2020): 13.

<sup>42</sup> *Ibid.*, 8.

*both* human and mouse ova that were used in the scientists' experimentations. Without making distinctions between the two, this blending of bodies materializes the extraordinarily complicated issues of consent, ethics, and innovation when it comes to animal testing. The subsequent goals for raising these controversial issues are to bring attention to the emotional toll of conducting medical research on human and animal bodies, the psychological impacts of oscillating between subjectivity and objectivity for the ill, and finally, the ways an artistic practice can form reflective time and space to consider more-than-human bodies within the realm of the health humanities.

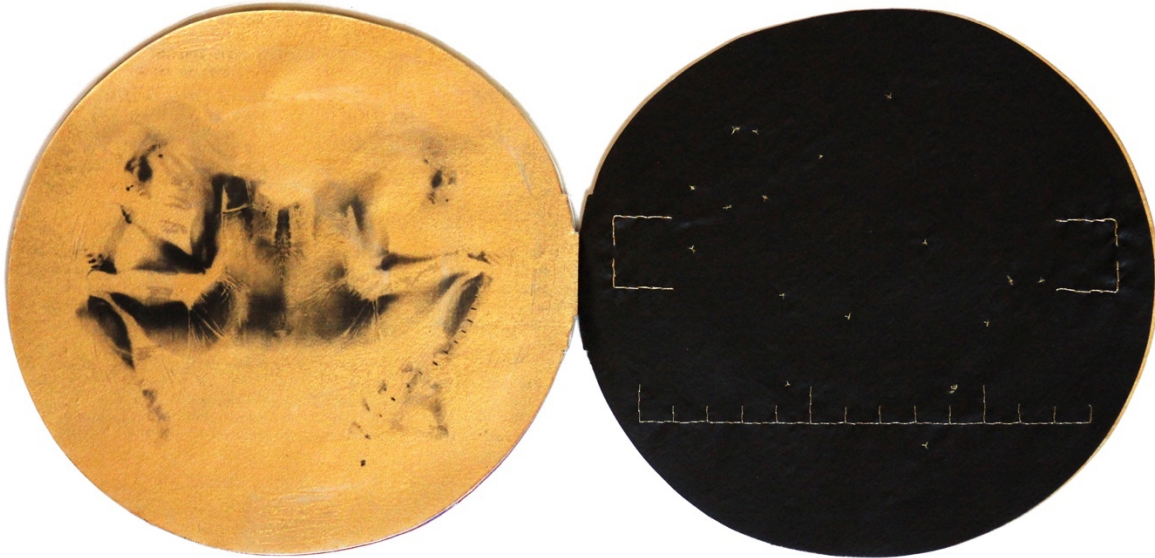


Figure 3.16: Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.

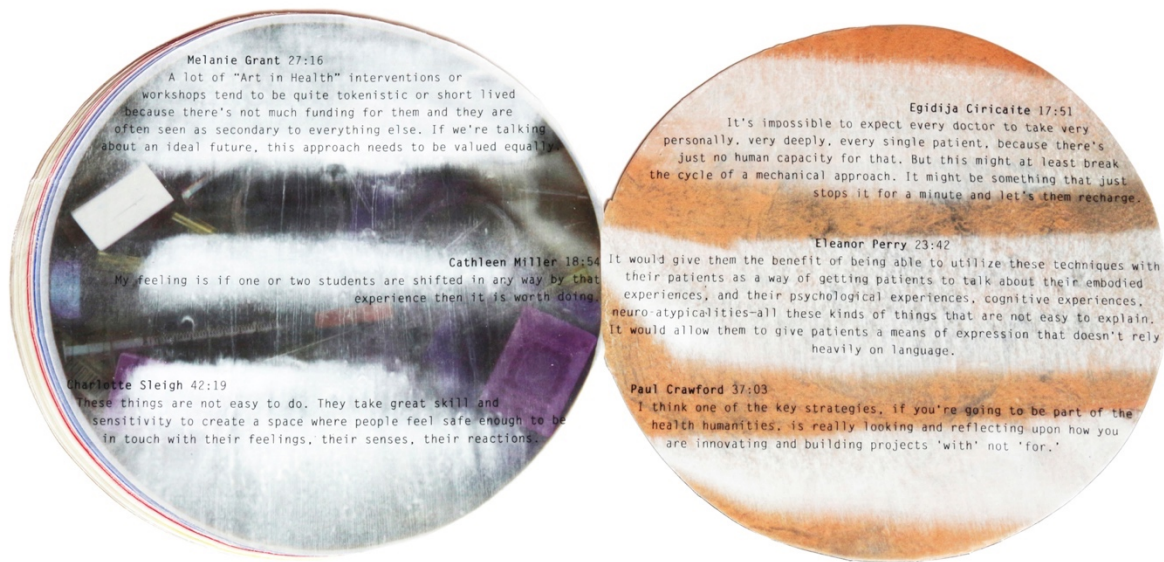


Figure 3.17: Darian Goldin Stahl, *Field Notes: How to Be With*, 2020.

**Melanie Grant 27:16**

A lot of “Art in Health” interventions or workshops tend to be quite tokenistic or short lived because there’s not much funding for them and they are often seen as secondary to everything else. If we’re talking about an ideal future, this approach needs to be valued equally.

**Cathleen Miller 18:54**

My feeling is if one or two students are shifted in any way by that experience then it is worth doing.

**Charlotte Sleigh 42:19**

These things are not easy to do. They take great skill and sensitivity to create a space where people feel safe enough to be in touch with their feelings, their senses, their reactions.

**Egidija Ciricaite 17:51**

It’s impossible to expect every doctor to take very personally, very deeply, every single patient, because there’s just no human capacity for that. But this might at least break the cycle of a mechanical approach. It might be something that just stops it for a minute and lets them recharge.

**Eleanor Perry: 23:42**

It would give them the benefit of being able to utilize these techniques with their patients as a way of getting patients to talk about their embodied experiences, and their psychological experiences, cognitive experiences, neuro-atypicalities—all these kinds of things that are not easy to explain. It would allow them to give patients a means of expression that doesn’t rely heavily on language.

**Paul Crawford 37:03**

I think one of the key strategies, if you're going to be part of the health humanities, is really looking and reflecting upon how you are innovating and building projects 'with' not 'for.'

### **Conclusion: Intertwinings**

The debates raised at the end of *Field Notes* concerning the effectiveness of incorporating artistic practices into the foundations of medical learning is a topic for in the next chapter. In the artists' book itself, there are no final answers to the many debates raised between its covers because the purpose of art, like the practice of phenomenology, is not to instruct but to continually question. The only guidance going forward is provided by health humanities professor Paul Crawford, who encourages a democratic and diverse representation in health humanities scholarship, so that any new pedagogies and practices will be formed “‘with’ not ‘for.’”<sup>43</sup>

The final image-based spread shown in Figure 3.16 points to the purpose of this artists' book, which is to merge disciplines through research-creation and the intertwining of text, image, and the sensory within a shareable, intimate medium. Like the first page of *Field Notes* detailed the beginning of this chapter, the image on the left-hand side is a merging of two bodies around a spine, eluding to the joining of art and medical discourses across the spine of this book. The perceived dualities of art and science, patient and doctor, human and nonhuman, and subjectivity and objectivity are portrayed here as two halves of one body.

On the right-hand page, we are presented with an almost entirely black image. Across the dark surface twinkle golden embroidered stars, while the microscope's measurement ruler at the bottom of the page alludes to a viewpoint much closer to home. An astronomically-inclined reader may notice the arrangement of stars on this page make up the constellation Gemini—another allusion to the twinning and intertwining of epistemologies presented in *Field Notes*.

Paradoxically, by cropping and simplifying images, their capacities to entangle manifold knowledges grows. The artist's book becomes a vibrant being whose polymorphous interpretations will inevitably shift across individuals and disciplines. The ability to speak to many different knowledge holders creates a nexus point where distinct aesthetics and language may speak to one another on common ground. Like connecting stars into constellations, the purpose of *Field Notes* is to connect the most critical topics in health humanities, complicate them, and expand them through the unexpected manifestations between pages.

*Field Notes* has always been, at its core, a discourse on scale. The scales of medicine are never constant, but slip through microscopic, internal, animal, human, interpersonal, and population perspectives. *Field Notes* fluctuates between ambiguous scales in each spread, while constantly reminding the reader of the whole, three dimensional bodies portrayed on the flat pages before them. From the microscopic disturbances of synapses that cause disease, to the division of cells that initiate a new life, to the hands that craft tools to surveil bodies from afar, and finally, to the interstellar journey of atoms that make up our being, this artist's book aims to collapse corporeal scales back into one another.

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<sup>43</sup> Paul Crawford, interview with author, February 26, 2019, in *Field Notes: How to Be With*, ed. Darian Goldin Stahl (2020).

## Chapter 4

### Artists' Books in the Clinic and Classroom

"I make books so I won't die." –Martha Hall

#### Introduction

In May of 1989, Martha Hall received a telephone call from a physician she did not know. "'You have breast cancer and you better decide quickly whether you're going to do something about it here [Dartmouth Hitchcock Hospital in Hanover, N.H.] or in Portland [Maine, the nearest major hospital to my home].' With that threat, he hung up."<sup>1</sup> She was thirty-nine years old, had been married for 18 years, and had two elementary school-aged daughters at the time of this first diagnosis. After studying English at Smith College and receiving a certificate in art education in 1972, Hall made several careers for herself in the subsequent years as an English teacher, weaver, and a weaving supplies small business owner.<sup>2</sup> To expand her marketing skills, she attained an MBA from Dartmouth College in 1989 and transitioned into a career in corporate management. Three years after a second diagnosis of breast cancer, Hall returned to her artistic roots by enrolling in papermaking and bookmaking courses at Haystack Mountain School of Crafts in Deer Isle, Maine in 1996.<sup>3</sup> This last shift in vocations would ultimately shape Martha Hall's legacy.

After initially deciding not to create art about her diagnosis, poetic text and imagery about living with cancer nevertheless "came to [Hall] spontaneously," and she felt compelled to materialize and her long-term illness experiences as artists' books. Hall's artist statement explains that making artist's books "uncovered or *brought to light* emotions [she] had not previously acknowledged. ... The process of making books has been a powerful part of [her] healing."<sup>4</sup> Hall invested in her arts practice and graduated with a BFA from the Maine College of Art in 1998. After crafting dozens of artists' books about her lived experiences with illness, sharing them with her family and physicians, exhibiting them in galleries across the U.S., and depositing them in numerous academic libraries, Hall died from her disease in her beloved home on Orr's Island, Maine, in 2003 at the age of 54. Hall ensured her artist's books would continue to speak volumes in her absence. Archived and employed within medical institutions as pedagogical resources, these works continue "to effect change in the way medical professionals interact with their patients."<sup>5</sup>

This chapter follows the unique life of Hall's artist's books: from creation, to activation in the clinic, to archive, and finally, to their mobilization in medical classrooms. Hall's bookmaking practice and patient activism serve as a case study for the potentiality of artists'

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<sup>1</sup> Martha Hall, "Artist Statement," in *Holding In, Holding On: Artist's Books by Martha A. Hall*, eds. Martha Hall and Martin Antoinette (Northampton: Mortimer Rare Book Room, Smith College, 2003).

<sup>2</sup> "Martha A. Hall collection, 1971–2011, undated," Maine Women Writers Collection, University of New England, accessed December 18, 2020, <https://library.une.edu/mwwc/collections/collections-a-z/martha-a-hall-collection-1998-2003/>.

<sup>3</sup> Ibid.

<sup>4</sup> Hall, "Artist Statement."

<sup>5</sup> Ibid.

books within medical contexts. Employed in the examination room, an artist book presents a destabilizing ‘flipping of the script’ on the typical doctor-patient encounter that may ultimately lead to more productive communication and a sense of holistic care. Within a medical or health humanities classroom, a thorough investigation of artists’ books focuses a reflexive lens onto the systemic injustices of Western medicine, such as disparate priorities of time, knowledge hierarchies, and dehumanization. Following Hall’s lead, I also argue for further integration of the medium into medical humanities pedagogies because artists’ books not only give an authoritative account of what it is like to be chronically ill that is otherwise absent from medical textbooks, but they also provoke critical dialogues that scrutinize the Western medical paradigms at the root of patient and practitioner discontents alike.

Throughout this chapter, it will become evident the extent to which artists’ books are a time-based medium. Beyond the duration of reading an artist’s book, they also engage with concepts of time as a tool for capturing an event or memory, enduring time in an archive, and resisting the forward momentum of time and mortality as a capsule of lived experience that persists beyond the author’s lifetime. Finally, holding another’s autobiographical artist’s book transports the reader into a moment of time with its maker. Giving space to reflect on the narrative present within artists’ books acknowledges that time is the paramount medium of being-with and dignity.

### **The Practice of Martha Hall**

The focus of this investigation into Hall’s practice is not only the positive impacts bookmaking had on her sense of wellbeing while living with the shadow of cancer for fourteen years. This chapter also examines the unconventional ways she activated her books within the clinical setting. Although Hall initially made books to help communicate with her family, she also “put a huge amount of importance on using the books to communicate with [her] physicians, and [her] nurses, and the medical community in general.”<sup>6</sup> Finding success in this endeavor, Hall sought to make her artists’ books available to future generations of health professionals within university archives, namely the University of New England, where they could continue to generate vital dialogues around effective patient care.

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<sup>6</sup> Martha Hall, *I Make Books*, directed by Jennifer S. Tuttle, Portland: Maine Women Writers Collection, 2004.



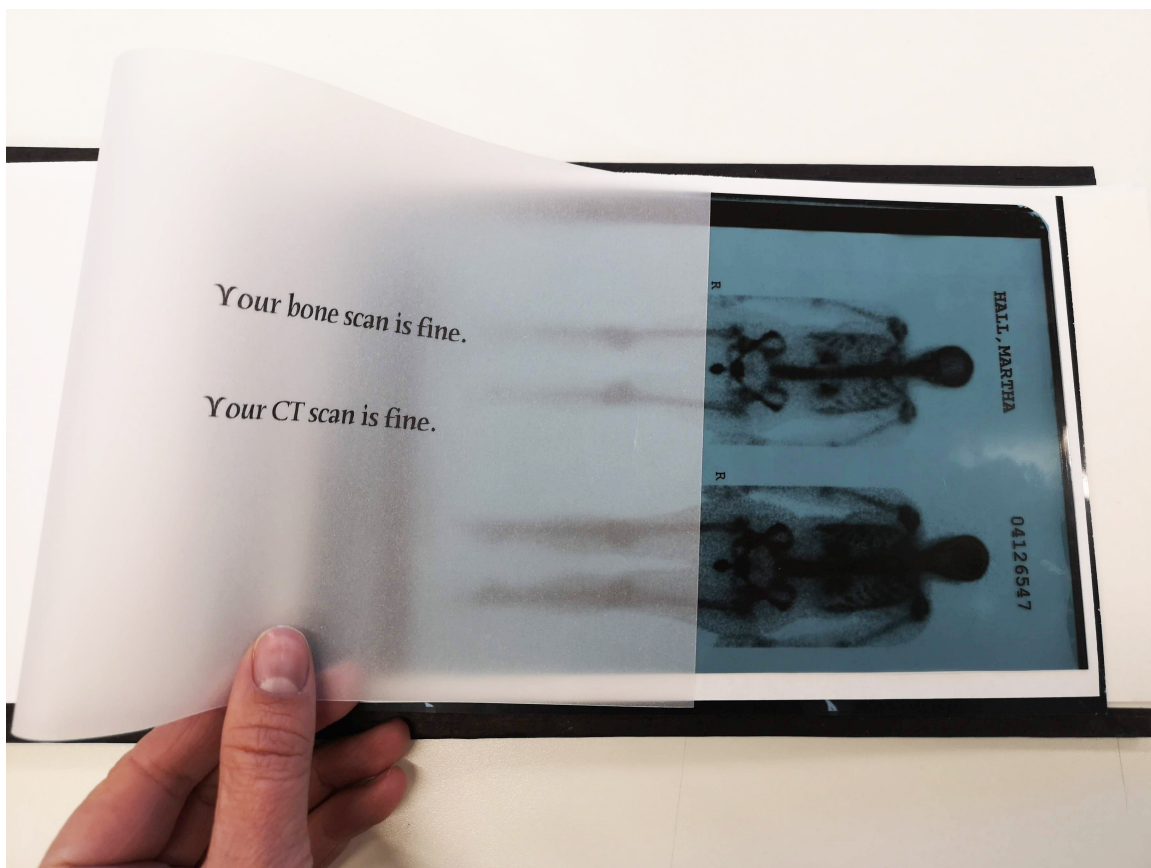


Figure 4.1: Martha Hall, *Voices: Five Doctors Speak*, 1999. This image shows a hand lifting a transparent page of a book with the text, “Your bone scan is fine. Your CT scan is fine.” Underneath are two full-body CT scans printed on blue film.

One prominent example of Hall’s unconventional employment of her artist’s books in medical contexts is demonstrated within *Voices: Five Doctors Speak* (See Figure 4.1). For this book, Hall transcribes the conversations she had with five of her physicians during an unexpected recurrence of cancer. Each of her physicians is distinguished using a different typeface, although the sentiments they provide are strikingly similar. The first text reads, “Let’s find a place to talk,” foreshadowing the grim news on the next page that can already be seen through the semi-transparent paper. The following pages describe the treatments, side effects she will endure, and a prognosis of living between six months and six years. The final set of translucent vellum pages are glued together to collapse several conversations into a single hazy memory. Through the atmospheric paper, we can just make out the voices describing her treatment, which was not successful: “We failed. You failed.”<sup>7</sup> At the end of the book, she writes the names of her doctors using their respective typefaces, as if to credit the co-authors of this moment in her life.

The images in *Voices* include full body medical scans of Hall that have been re-scanned and sized to fit within this hand-held medium. These images present us with a scan of a scan of Hall, or met-scan: an image that is reflexive on itself so that the distinctions between observer

<sup>7</sup> Martha Hall, *Voices: Five Doctors Speak*, 1999.

and subject become blurred. The scans made into art, along with the transcription of voices from her doctors, turn the tables on who exactly is being examined here.

Hall brought this book into each of her five doctors' offices during her appointments in order to communicate with them how it felt to be diagnosed with cancer again, and how painful it was to hear the words, "You failed." Hall narrates this interaction in the documentary, "I Make Books," which was produced by the University of New England's Maine Women Writers Collection (MWWC) in 2004:

[Reading from *Voices*] "I didn't want to believe you'd failed. The bone marrow transplant failed. You were responsive to chemo. We failed. You failed." The last thing I want to hear is I "failed." And he was using it in a very medical terminology sense—it meant that, "that treatment failed for you." But it came across as I as a person failed and he as a physician failed. And it wasn't until we really had a chance to talk about that that it softened somewhat for me. But for a long time that, "I failed—We failed" has been a pain.<sup>8</sup>

In another instance, Hall used this book to express her priority for in-person meetings to discuss a diagnosis rather than over the phone:

[Reading from *Voices*]: "Do you want to speak to me on the phone or in person?" When I sat down with him and we read this page, I said, "That's you. That's what you said to me." And he goes, "Yeah... so?" And my response was, "It was so important to me to see you in person." And he said, "You don't understand, most people do not want to see me in person. It is too hard to have that difficult emotional time with this person who is somewhat of a stranger. It is very unusual for somebody to want to talk to me in person."<sup>9</sup>

Hall's artist's book initiated a dialogue on the perceived differences in her sense of ethics (that cancer diagnoses should be delivered in person) and her physician's past experiences (that most patients prefer to be counseled over the phone). Her physicians also validated the significance of her arts practice by asserting "that the books [she] was creating were more than a form of art therapy and that the books themselves had an intrinsic value."<sup>10</sup> Part of this value was the way in which they helped Hall and her doctors find the common ground to rebuild their relationships going forward.

Although there are clear positive impacts for Hall to activate her artists' books within clinical appointments, one could rightly ask, "Why not just voice these concerns outright? Why go through the trouble of making an artist's book to have this conversation?" First, as I have posited before, artists' books can be used as a productive "stepping-stone" to cross the lacuna between two people and begin a difficult conversation. Sharing this book as the object of attention surely lifted the pressure of initiating a critique of her physician's language, which may have felt too confrontational otherwise. I further argue that the authority of *The Book* as a symbol of knowledge gave Hall the courage to broach these concerns with her physicians. Conceiving the book and laboring it into being requires the maker to spend reflective time formulating a response to the perceived slight in a creative way that feels accurate and assertive.

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<sup>8</sup> Martha Hall, *I Make Books*.

<sup>9</sup> Ibid.

<sup>10</sup> Hall, "Artist Statement."

Hall herself recognized that the books were “pushing [her] to communicate a strong message,... they are a way [she] can have a voice in the world.”<sup>11</sup> It is no easy task to question the experience and immense specialized knowledge of someone who is charged with saving your life, even when his actions or misconceptions result in distress. Impossible to misread as a passing concern, Hall committed her disquiet to ink, which then became the vehicle to hold and share her truths. Hall’s books enabled her to re-orient the agenda of the medical appointment towards her own primary concerns.

The imbalance of power and the vulnerability experienced by the patient during a clinical encounter is the reason why artists’ books form a vital tool for rearranging expressive authority. As Bolaki attests, “if medicine is associated with a particular kind of authority and expertise to which the patient often needs to surrender, book artists... claim a different kind of authority in articulating lived experiences that are not to be found in x-rays, laboratory studies and pathology reports through their work.”<sup>12</sup> In sharing the artists’ book with her doctors, Hall is providing the material to be discussed, rich with metaphor, sensory expressiveness, and inclusive of the impacts of disease that fall outside of the strict delineations of the personal and the medical, such as the impact of doctor-patient relationships and her sense of wellbeing. Artists’ books in the clinical encounter thus shift the study of the body to a study of embodiment.

Artists’ books are probably something very new for the physician, and any subsequent uncertainty they evoke is key to opening the imagination and understanding his patient’s particularities anew. Like the practice of phenomenology, Hall’s books prompt her physicians to reassess their habituated responses to what are, for them, common situations. Hall recounts that being confronted with their own voices in her artist’s book “elicited responses of denial, disbelief, discomfort”<sup>13</sup> from her doctors. However, taking the time to read this book together provided Hall’s physicians with more insight into her experiences, and they were then able to become better partners in her care. Caroline Wellbery attests that the greatest outcome of Hall’s practice was to equalize her relationship with her physicians. Respecting Hall’s wishes to engage with her art during a clinical appointment confirms that a “doctor who lets go of those tools that support his or her superiority in the encounter—for example the superiority of medical knowledge—becomes more of a partner than a doctor.”<sup>14</sup> Within an unstructured meeting over an artist’s book, agendas are set aside, unanticipated insights emerge, and being with becomes possible.

In the final pages of *Voices*, there is a much smaller book tucked into a pocket. It is titled *Legacy*, and it depicts joyous dancing skeletons and a conversation with one doctor about the lasting impact of her books. This small book foreshadows Hall’s wish that her practice continue to enable intercorporealities in her absence, even after her death, and provoke productive pedagogies in medical education as part of university archives.

### **Archiving a Legacy**

The second life of Hall’s books began after their acquirement by medical institutions across the US and UK, including Dartmouth, Smith, and Wellesley Colleges, Harvard

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<sup>11</sup> Hall, “Artist Statement.”

<sup>12</sup> Stella Bolaki, “Contemporary Artists’ Books and the Intimate Aesthetics of Illness,” *Journal of Medical Humanities* 41 (2020): 33.

<sup>13</sup> Hall, “Artist Statement.”

<sup>14</sup> Caroline Wellbery, “Inter-Face: Artists’ books as mutual inquiry,” in *Prescriptions: Artists’ books on wellbeing and medicine*, eds. Stella Bolaki and Egidija Ciricaite (London: Natrix Natrix Press, 2017), 20.

University, and the University of Kent. The largest collection of Hall's work resides with the University of New England's Maine Women Writers Collection (MWWC). Hall wanted her books in these archives because she thought they would be able to reach her target audience of medical learners and researchers. The head outreach archivist for the MWWC, Cathleen Miller, states that "by providing wide access to Hall's artist's books in both the classroom and the archives, the MWWC has answered Hall's call for conversation and consciousness-raising among current and future health care providers."<sup>15</sup> I conducted archive fieldwork at the MWWC and the University of Kent in order to witness the fruition of Hall's legacy. I wanted to experience the books firsthand and speak with their respective librarians about the special considerations of archiving such unusual books, their own efforts to integrate them into coursework, and the reactions they see from students who engage with them.

Artists' books are attractive to medical archives because they offer an experience very different to a typical illness memoir. Poetic, sensory, and generally able to be read within a single sitting, this medium provides a means to engage with illness narratives within an already over-booked medical curriculum. The accessible nature of creating an artist's books, especially compared to writing and publishing a memoir, also has the potential to diversify the voices represented in library collections. Artists' books enable a breadth of artistic illness expression that does not rely on narrative 'completeness' or text at all, for that matter. The head of artists' books acquisition for the Wellcome Trust in London, Melanie Grant, states that the reason they began collecting artists' books in 2014 was to make space "for the ways in which people were expressing themselves creatively, and talking about their lived experience that wasn't necessarily in a traditional kind of memoir."<sup>16</sup> Finally, the stability of a book-object lends permanence and authority to self-published narratives, while other forms of emergent narratives like social media or blog posts can be quickly buried. In archival form, artists' books demonstrate that the lasting impact of illness narratives is not only constructed by what the author says, but the very medium through which we read them.

This niche for artists' books enables more women to occupy shelf space in medical and academic institutions, whose holdings traditionally privilege the white male perspective.<sup>17</sup> In our interview, Miller expresses her interest in collecting artists' books by women, who also tend to make the majority of artists' books on topics of medicine and illness. Perhaps this is no coincidence. In a situation where one has very little control over the most profound matters of one's life, like the diagnosis and treatment of cancer, it may be no wonder that women seek out an authoritative medium like artists' books to express these experiences. Artists' books may also be particularly salient for women due to their history of circumventing male-dominated gallery and publishing systems, the bodily closeness and intimacy the medium provides, as well as the inclusivity of typically women's media like sewing, scrapbooking, or journaling.<sup>18</sup>

Artists' books are also an avenue to include more minority perspectives on illness within university archives. The narrow confines of peer-reviewed commercial publishing

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<sup>15</sup> Cathleen Miller and Jennifer Tuttle, "'I make books so I won't die': Artists' books in the archives and in the classroom," in *Prescriptions: Artists' books on wellbeing and medicine*, eds. Stella Bolaki and Egidija Ciricaite (London: Natrix Natrix Press, 2017), 11.

<sup>16</sup> Melanie Grant, interview by Darian Goldin Stahl, March 27, 2019.

<sup>17</sup> Claire Hooker and Estelle Noonan, "Medical Humanities as Expressive of Western Culture," *Medical Humanities* 37, no. 2 (2011): 83.

<sup>18</sup> Stella Bolaki, "The Material Power of Artists' Books: How books can speak about illness and care," in *Prescriptions: Artists' books on wellbeing and medicine*, eds. Stella Bolaki and Egidija Ciricaite (London: Natrix Natrix Press, 2017), 6.

disproportionately neglect BIPOC (Black, Indigenous, and People of Color) writers,<sup>19</sup> despite well documented evidence that membership to racial minority communities negatively impacts health outcomes.<sup>20</sup> To counter this representational gap, Grant states that the library curator must constantly question whose voices are missing within a their holdings, “and then try and figure out where those voices are, and start to bring them into our collections.”<sup>21</sup> Another librarian seeking equitable archives is Jane Ann Carlin at the University of Puget Sound, who is attempting to decolonize the archives by collecting artists’ books by BIPOC authors for its Race and Pedagogy Institute. Carlin states that “artists’ books offer the library the opportunity to build collections that represent distinct points of view and contribute new voices to scholarly discussions.”<sup>22</sup>

Although artists’ books are known as a democratic medium because of their low barriers of entry, librarians must nevertheless be vigilant to the ways institutional archives stubbornly uphold Western settler perspectives.<sup>23</sup> These librarians highlight that forming equitable collections is an ongoing practice of interrogating who makes archives, who is included in the holdings, who has access to holdings, and who does not. University archives are often out of reach to the general public or are not well-equipped for accommodating people with impairments, such as audio recitations. While Hall wanted her books in medical libraries so they could reach medical students in particular, it would be a disservice to her work to constrain them to strictly professionalized contexts. With regards to who has access to these books, it is also worth scrutinizing the ways archives exclude certain illness or disability populations at the same time they attempt to represent them.

For researchers like me who already possess substantial privileges to conduct fieldwork within institutional spaces, the process of viewing archived artists’ books was not straightforward. At the University of Kent, I had to attain a Visiting Scholar title with library access, identify and email the correct librarian, choose only ten books to view per day from limited pictures on its online catalogue (though any imagery is a rarity for online catalogues), find the small viewing room within the sprawling library, leave all of my belongings in a locker, and finish looking at the books within a predetermined timeframe. Although making artists’ books has a high level of accessibility, viewing them presents what may be insurmountable hurdles to most. For her part, the special collections librarian at the University of Kent, Joanna Baines, acknowledges that these artists’ books have untapped potential to positively impact people who would not be able or willing to go through the effort to visit these books.<sup>24</sup> She hopes to enact future programming in which the artists’ books will be taken into hospitals, where they can fulfill Hall’s wish to “to touch the hearts of people who themselves are battling cancer or a life-threatening disease.”<sup>25</sup>

However, with concerns over damage, especially for books whose materiality may not

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<sup>19</sup> Amos Paul Kennedy Jr., “Social Book Building,” in *Talking the Boundless Book: Art, Language, and the Book Arts*, ed. Charles Alexander (Minneapolis: Minnesota Center for Book Arts, 1995), 51.

<sup>20</sup> Susan Merrill Squier, “Beyond Nescience: The intersectional insights of health humanities,” *Perspectives in Biology and Medicine* 50, no. 3 (2007): 345, Project Muse.

<sup>21</sup> Grant, interview.

<sup>22</sup> Jane Anne Carlin, “Artists’ books as catalysts for social change,” *Art Libraries Journal* 44, no. 1 (2019): 2.

<sup>23</sup> For further dialogue on the topic of decolonizing archives, see: Stephanie Springgay, Anise Truman, and Sara MacLean, “Socially Engaged Art, Experimental Pedagogies, and Anarchiving as Research-Creation,” *Qualitative Inquiry* 5, no. 1 (2019): 1-11.

<sup>24</sup> Joanna Baines, interview by Darian Goldin Stahl, January 31, 2019.

<sup>25</sup> Hall, “Artist Statement.”

fall within a book restorer's typical repertoire, it can be difficult to balance public access with the desire to preserve an artist's book. Another way librarians are attempting to broaden access to artists' books is to provide more detailed photographs and searchable keyword catalogues. However, the variable size, shape, and navigation of each artist's books makes effectively photographing them particularly challenging.<sup>26</sup> As well, the feel, weight, smell, time, and other sensory information that make up a large portion of the book's overall meaning is lost. Artists' books demand to be touched in order to fulfill their pedagogical purpose. Democratizing this access may mean letting go of the pristine and prioritizing how these books can be made present and useful in the present tense, rather than perfectly preserving them in perpetuity. Finally, as artists' books continue to be collected by archives, the types of book-objects considered archivable will also need to expand significantly. If only artists' books that adhere to comfortable codex forms, fit on a shelf, or are constructed with materials that will not change over time, then the collections will inevitably exclude certain sensory knowledges.

One final concern for the librarians is how to choose which artists' books to acquire given tightening budget restrictions. For arts-based researchers like Leavy, the outcomes of such creative endeavors must not be judged primarily on the level of craft achieved, but on the *usefulness* of the artworks for "communicating information about the experiences associated with differences, diversity, and prejudice."<sup>27</sup> The librarians I spoke with agree. The value they find in these books is not necessarily how 'good' they are in the aesthetic sense, but if and how they fill gaps in knowledge within the library's collection. Grant attests, "if an artist's book is saying something important, that's maybe not being said somewhere else, even if it's not necessarily the most successful artists' book you will come across, then it still has some value to us." The aim of these collections for medical learning places priority on the breadth of illness perspectives over subjective standards of aesthetics. On the other hand, if artists' books on illness are to be taken seriously as objects worth collecting and viewing, then it is important that they contain sufficient artistic merit to attract and engage the reader, and not simply appreciated that they were created at all. These artists' books must be alluring enough to entice audiences inside and outside of medical contexts if they are to enact challenges to dominant (mis-)conceptions of illness.

From the perspective of the artists, an institution's investment in their books may also feel like their labor, point of view, and even their lives have been given value. As Hall states,

In leaving a legacy, they are helping me to feel that my life has value. ...What makes me feel like all that I do has value is knowing that there will be some students who are going to be pursuing medical careers, in the medical profession in one way or another, who will have access to these books and will have a way to react to them.<sup>28</sup>

### **Mobilizing Artists' books in Medical and Health Humanities Pedagogies**

As a part of university archives, Hall's books are being mobilized in medical and health humanities classrooms. In the education of medical students in particular, the goals for integrating such arts-led<sup>29</sup> pedagogies are diverse, and include increased comfort with ambiguity, observation and communication skills, and empathy. While these qualities are important, a focus

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<sup>26</sup> Egidijia Ciricaite, "On Photographing Artist's books," *Journal of Medical Humanities* 41, (2020): 81.

<sup>27</sup> Patricia Leavy, *Method Meets Art: Arts-Based Research Practice* (New York City: Guilford Press, 2015), 24.

<sup>28</sup> Martha Hall, *I Make Books*.

<sup>29</sup> "Arts-led" pedagogies here connotes using artworks as research evidence, not necessarily making new artworks.

on the utility of medical humanities to improve physician and patient interactions risks neglecting the ways humanities methodologies can form a criticality around more systemic issues in the institution of medicine. A more critical wave of medical humanities scrutinizes the peripheral instrumentalization of the arts to ‘soften the edges’ of medicine rather than their potentiality to provide the time, space, and permission for a reflexive critique of dehumanizing Western medical paradigms. Jeffery Bishop’s provocatively titled essay, “Rejecting Medical Humanism,” calls out what he deems to be superficial medical humanities pedagogies that merely obscure the hierarchies of power within medicine without taking measures to dismantle them.<sup>30</sup> Bishop argues that it is only when physicians forgo the push for efficiency, reclaim the time of being with their patients, and invite those with lived experiences of illness to become co-creators of healthcare knowledge that the medical humanities will succeed.

To meet such aims, the *critical medical humanities* has emerged in the past decade within the UK, and begins with the conclusion that the medical humanities are not risky, consequential, or critical enough to instigate the paradigm changes needed to achieve healthcare equity. Rather than setting therapeutic goals for medical students by practicing the arts and humanities, like elective creative writing courses to alleviate stress and burnout, this more critical perspective challenges the institution to reflexively investigate the reasons why so many students experience burnout in the first place and then remodel such harmful learning environments, which may ultimately include the integration of humanities and arts methodologies. M.L. Jennings reports that “the epidemic of medical student burnout can be attributed to a technocratic paradigm that fails to value medical students as persons with human needs and limitations.”<sup>31</sup> The suppression of natural emotion, overwhelming workloads, and push for more technologically mediated ways of interacting with patients are all found to cause feelings of detachment, which result in “elevated rates of depression, anxiety, suicidal ideation, and overall poor mental health as compared to themselves at matriculation and to their age-matched peers.”<sup>32</sup> A strong rationale for integrating the humanities is to carve out time, seemingly inefficient time, within the demanding pace of medical education to practice being with. I posit that spending time with first-person artists’ books, hearing their stories, allowing oneself to feel the emotions they brings up, and engaging the sensing body as a co-creator of their meanings is a potentially transformative practice to counter the depersonalizing effects of practicing medicine.

Critical medical humanities proponents out of the University of Durham, like Jane Macnaughton, Havi Carel, and Angela Woods, question the kinds of narrow modalities that are typically employed in medical humanities classrooms, which are currently dominated by the study of Narrative Medicine.<sup>33</sup> An inclusive approach to practicing being with must acknowledge that narrative is inadequate for communicating experiences that seem to elude language or resist representation, such as ‘invisible’ conditions like mental illness or especially difficult topics like dying.<sup>34</sup> To help fill the epistemic gap, University of New England medical humanities and English professor Jennifer S. Tuttle partners with Miller to teach their health science students about patient experiences by mobilizing Hall’s artist’s books. These reflexive, multi-sensory

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<sup>30</sup> Jeff Bishop, "Rejecting Medical Humanism: Medical Humanities and the Metaphysics of Medicine," *The Journal of Medical Humanities* 29 (2008): 22.

<sup>31</sup> M.L. Jennings, "Medical Student Burnout: Interdisciplinary Exploration and Analysis," *Journal of Medical Humanities* 30 (2009): 253.

<sup>32</sup> *Ibid.*, 253.

<sup>33</sup> Angela Woods, "The Limits of Narrative: Provocations for the Medical Humanities," *Medical Humanities* 37, no. 2 (2011): 76.

<sup>34</sup> Bishop, "Rejecting Medical Humanism," 22.

artworks ignite a dialogue on systemic concerns in Western medicine, most notably, the hierarchies between doctors and patients, managed time, and the suppression of emotion.

### *Hierarchies*

Although there are numerous forms of hierarchies that can be found within the practice of medicine, for this discussion around artists' books, I will focus on the disparities between expert medical language and the patient's attempts to narrate their own lived experience. Such disparities in knowledge and language may ultimately construct barriers in the doctor-patient relationship. Hall writes that the "mysterious language of medicine" left her frustrated and angry, which she expressed in her artist's books as "terse sentences, irony, humor, color, [and] images that cannot be understood."<sup>35</sup> Carel explains that the perceived status of being able to accurately recount symptoms using medical terminology can lead to a form of epistemic injustice, wherein the patient is at a disadvantage in articulating their experiences.<sup>36</sup> If an ill person, for example, improperly applies medical jargon, they "are more vulnerable to testimonial injustice, because they are often regarded as cognitively unreliable, emotionally compromised, or existentially suspect."<sup>37</sup> This injustice is also confirmed in Christina Lammer's experience of documenting radiology technicians, who privately mock a patient's misuse medical language, because "the patient's attempt to make him/herself understood is seen as a foreign intrusion into the language of medical expertise."<sup>38</sup> To right this injustice, patients must be seen as the experts of their own experiences, and deference must be applied to meet ill persons where they are and the types of communication they employ.

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<sup>35</sup> Martha Hall, "Artist Statement."

<sup>36</sup> Havi Carel, *The Phenomenology of Illness* (Oxford: Oxford University Press, 2016), 183.

<sup>37</sup> *Ibid.*, 182.

<sup>38</sup> Christina Lammer, "Bodywork: Social somatic interventions in the operating theaters of invasive radiology," in *Visual Interventions: Applied Visual Anthropology*, ed. Sarah Pink (Oxford: Berghahn, 2007), 128-129.



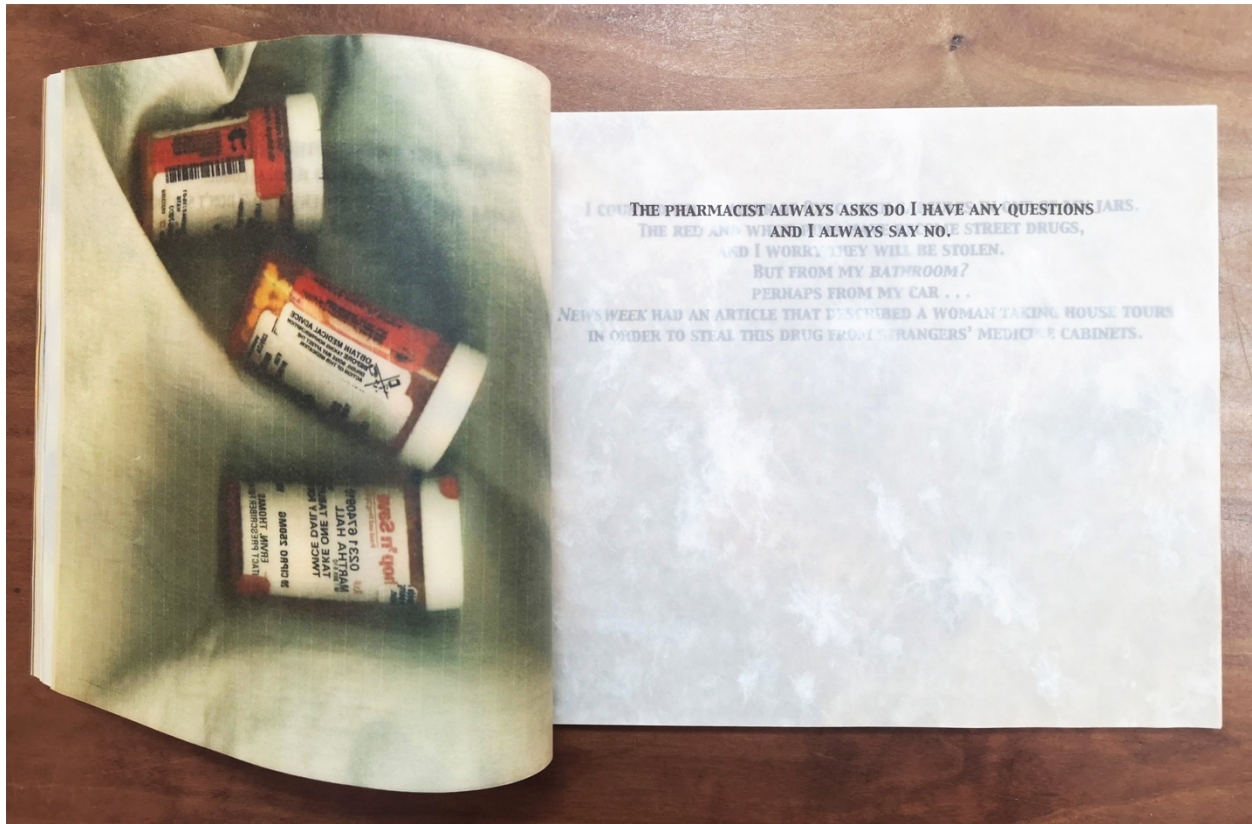


Figure 4.2: Martha Hall, *Prescriptions*, Toner on vellum, 8” x 10,” 2003. This image of an artist’s book shows a Xerox scan of three orange pill bottles on the left-hand page, and text that is printed on transparent white pages on the right. Text descriptions are reprinted below.

The authority of printed and bound books as vehicles for the transference and preservation of knowledge inherently gives credence to the voices inside. A close read of Hall’s books by medical students repositions her from a non-expert to a primary resource of illness knowledge that is novel, expansive, and meaningful. Although these students deal regularly with patients’ recounting of symptoms, they are rarely afforded such an intimate view of how encompassing and world-altering illness becomes, and how such alternations can inhibit the patient’s ability to effectively communicate. As Toombs summarizes in her own study and experiences with multiple sclerosis, “illness represents a distinct way of being in the world—a way of being which is characterized not simply by bodily dysfunction but by a concurrent disruption of self and the surrounding world,” that is, a “global sense of disorder.”<sup>39</sup> Hall’s books provide a glimpse into this other world.

For a patient with as much outgoing self-advocacy, education, and even English teaching experience like Hall, changes to her sense of global order took the form of mental confusion and verbal incoherence during acute periods of cancer treatment. She encapsulates this experience in her artist’s book, *Prescriptions* (See Figure 4.2). In it, Hall writes, “The pharmacist always asks if I have any questions and I always say no.” This response is then immediately contradicted with numerous lingering questions on the following pages:

<sup>39</sup> S. Kay Toombs, “The Body in Multiple Sclerosis: A Patient Perspective,” in *The Body in Medical Thought and Practice*, ed. Drew Leder (London: Kluwer Academic Publishers, 199), 134.

Why is my oncologist so quick to prescribe a drug? Might there not be something that I am doing or eating or not doing or not eating that I could change? How long did I need to wait to see if the first pills worked? And what if they don't? What was the next prescription to try? How long did I need to wait and see if this one worked?<sup>40</sup>

She goes on to explain that the twenty-two medications prescribed during this round of cancer treatment, scanned and printed into this book, inhibit her ability to respond to her pharmacists' hurried questions. Hall writes that she will "wake up with a foggy brain," a feeling that is visually conveyed to the reader as the semi-transparent pages form a foggy atmosphere over her texts. Tuttle and Miller attest that this book is "humbling for such readers, demanding that they listen to reticence as well as honor questions, using their imagination and empathy in unexpected ways"<sup>41</sup> in order to anticipate their patient's unspoken concerns.

A reflexive engagement with artists' books has the potential to alert the reader to the epistemic injustices that are expressed by Hall's experience, and ultimately, apply more empathetic and accommodating communications with their own patients. In promoting self-critique, Carel attests that the onus of communication is on the physician, not the patient. She prescribes medical professionals to think, "the fact that I don't understand you is not your fault but mine; even your best efforts to make yourself understood are failing, not because of their inarticulacy, but because I am untrained in the appreciation of the sort of articulacy you are using, and this hermeneutical context does not provide me with those resources."<sup>42</sup> The value of the humanities within medical contexts is to promote such entry points into criticality on the modes of expressions we deem valid and useful. It is only within this emotional and intellectual work, prompted by the subtle forms of meaning-making communicated in Hall's work that do not always rely on words, that the hierarchies between medical knowledge and patient experience can begin to be leveled.

### *Making Time*

Perhaps the greatest change to Hall's global sense of order during her cancer treatment was the total management of her time. Hall's artist's book, *The Rest of My Life II* palpably displays how cancer and its treatments overtake every other priority of how to spend time (See Figure 4.3). To create this book, Hall collected every medical appointment card and small prescription envelope she was given for one year and sewed these medical ephemera loosely together end-to-end. The address, date, and time for each appointment is printed on the front, and a fragmented accounting of her decade-long illness narrative is hand-written across the back of these cards:

April 1989. I found a lump in my left breast.// May 1989. I was diagnosed with stage one breast cancer.// July through September 1993. Hospitalized at Maine Medical Center for three rounds, high dose chemo.// September 1999. Cancer in my hips, spine, skull, ribs and liver.<sup>43</sup>

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<sup>40</sup> Martha Hall, *Prescriptions*.

<sup>41</sup> Jennifer S. Tuttle and Cathleen Miller, "Unruly Voices: Artists' Books and Humanities Archives in Health Professions Education," *Journal of Medical Humanities* 41, no. 1 (2020): 57-58.

<sup>42</sup> Carel, *The Phenomenology of Illness*, 188.

<sup>43</sup> Martha Hall, *The Rest of My Life II*, 2000.

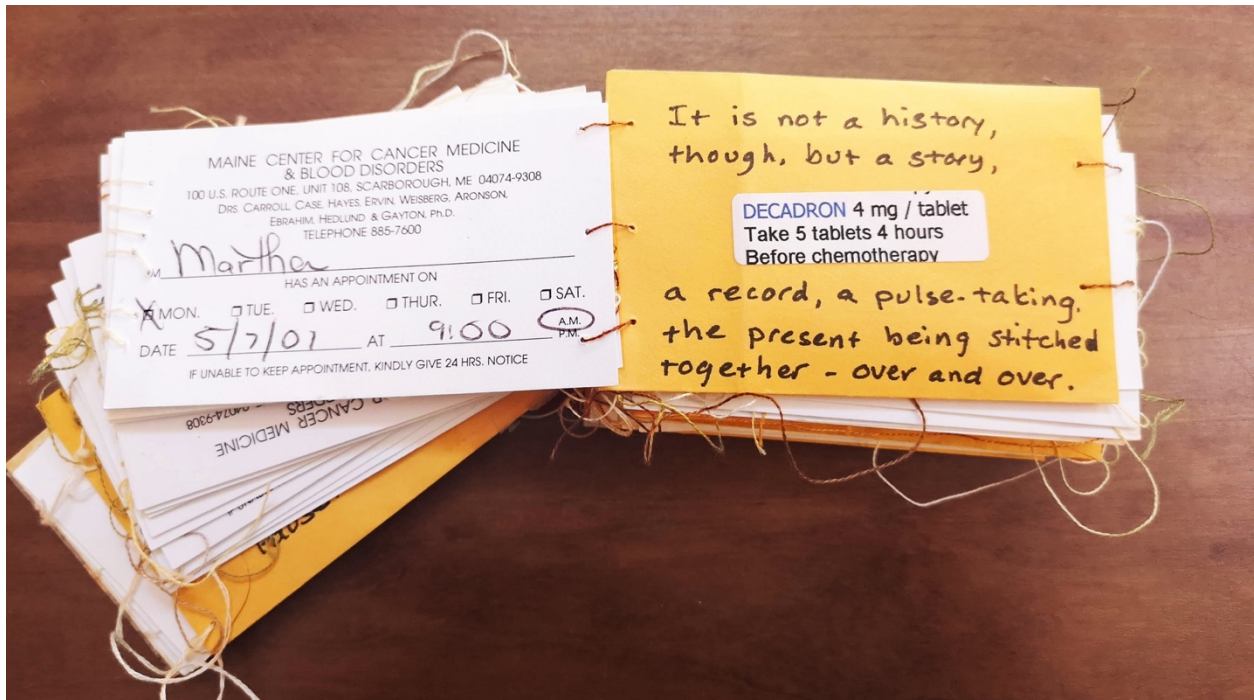


Figure 4.3: Martha Hall, *The Rest of My Life II*, 2000. This image shows a stack of medical appointment cards that have been loosely sewn together into a concertina book. The left-hand page gives Hall’s appointment information, and the right-hand page is a small envelope that once held a dose of medication. On this envelope, Hall as written, “It is not a history, though, but a story, a record, a pulse-taking, the present being stitched together—over and over.”

Hall also records more personal dates that were impacted by her intense treatment schedule: “August 1993. I missed our family reunion.”<sup>44</sup> Finally, Hall projects time into the future tense: “No urn. Wood box. Plant elm tree or lupine field. Party. No organ donation. If any money Haystack or Navajo Nation scholarships to first-third grades.”<sup>45</sup> This one book collapses past, present, and future into a tangible form that weighs so much more than the sum of its materials.

Hall’s text reveals the gravity of her illness, but it is the sheer number of appointment cards that lends this book its expressive heft. Holding them stacked together, one can literally feel the cumulative impact of illness and its domination over how time is controlled by medical treatments. Reclaiming these cards and choosing to spend the time transforming them into book pages enables Hall to gain back some authority over her regulated body and the purpose of her labor. Such an arts intervention challenges where time should be spent as one nears the end of her life. She writes that “the themes are universal and speak to family, friends and strangers living with the fear of dying in order to live, creating to heal myself and others, leaving a legacy, appreciating and living fully each day.”<sup>46</sup> By binding together the printed ephemera that recorded her location on any given day, who she saw there, and how she felt afterwards, Hall is materializing her terminal embodiment, which is confronting its own ephemerality, into

<sup>44</sup> Martha Hall, *The Rest of My Life II*, 2000.

<sup>45</sup> Ibid.

<sup>46</sup> Hall, “Artist Statement.”

something permanent.

In my interview with Miller, she explains that *The Rest of My Life II* “has a lot of impact for students” because of the realization that this tall stack of cards “is only a tiny portion of what she actually experienced.”<sup>47</sup> Another facet of what makes Hall’s books successful for learning about the patient’s experience of time is their transference of something familiar and ephemeral into something iconic. Clinical appointment cards are a common tool of regulating time and ensuring an uninterrupted schedule; but in her appropriation of these cards into an artists’ book, Hall morphs the everyday into the daunting prospect of being ill every day, and all of the physical and emotional demands of such frequent hospital visits. Hall’s transformation of the familiar requires readers to stop, take notice, and to experience the affect of these cards anew. In her invitation to hold and read this book, Hall exchanges the control over her time for that of the readers’—to command the readers’ time for reflecting on her life.

It is no wonder that one of the most impactful aspects of artists’ books is in their capacity as a time-based medium. Medical students are likely to identify with the total management of their time by the institution of medicine, like a pre-set course schedules, heavy rotation itineraries, and eventually long stretches of time on call. After studying Hall’s books, Tuttle and Miller invite the medical students to respond to Hall’s critiques of an apparent lack of care that results from such quick appointments. The instructors report that the “students did empathize... and acknowledge the challenges she faced as a patient, but they also wanted the patient to understand just how difficult it was for them to offer the rigorous, thoughtful, attentive care most beneficial for the patient in the span of time allotted by our healthcare system.”<sup>48</sup> These reflections highlight that in a healthcare system that places upmost value on efficiency, the dizzying speed of face-to-face time between doctors and their patients can leave both parties wanting.

The tensions caused by tight clinical appointment schedules is a discrepancy between feelings of what Arthur Frank terms as “rightness,” or the identification of what is ethical and proper by particular actants within a particular space.<sup>49</sup> For physicians, temporal rightness generally revolves around how many patients they can see and treat in a day. For the patients, rightness may mean taking the time to explain fully explain potential diagnoses and treatment possibilities or recounting impacts of illness on their lives. Both parties feel that their expectations for rightness are being compromised by the other. The differences of temporal rightness make the patient feel as though her (dis)comfort is unconsidered or that her emotions are distantly secondary. In giving primary attention to turnover instead of spending the time necessary for the patient in the room to cover all of her spoken and unspoken questions, that is, “to see certain collateral damage as right,”<sup>50</sup> reveals the depersonalizing systems and pressures in which physicians are trained.

The disparity of temporal expectations between a patient’s ethics of care, or even politeness, and the pressure for clinical efficiency is a systemic cause for much of the dissatisfaction within patient and doctor interactions. Such discrepancies of rightness are already apparent in this chapter through Hall’s accounting of the pressures she felt to not take up too

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<sup>47</sup> Cathleen Miller, interview by Darian Goldin Stahl, July 29, 2019.

<sup>48</sup> Tuttle and Miller, “Unruly Voices,” 61.

<sup>49</sup> Arthur Frank, “Rightness, Place, and Humanistic Health Care Ethics: Fragments of a Moral Inquiry,” *GeoHumanities* 4 (2018): 310.

<sup>50</sup> *Ibid.*, 312.

much time. Either from the vaguely threatening command that she “better decide quickly” where to receive her cancer treatment, her physician’s suggestion of relaying her diagnosis over the phone, or the pharmacist rushing over her potential questions, the speed of medicine is shown to be misaligned with the priorities and abilities of the ill person.

Creating space for meditative reflection in the making and reading of her artist’s books, Hall resists the pressures for speed. Perhaps Hall’s most profound act of countering the efficiency of medicine was to insist that her physicians take the time to read her artist’s book with her. Hall recounts such a demand with a reluctant physician in her documentary:

He was the one who had not seen this book. I would bring it in from time to time and he would say, “I don’t have time. I don’t have this; I don’t have that.” There was one day when he came in and I said, “I am going to be giving a talk on my books, and somebody is going to ask me, because they always do, ‘Have all the doctors seen this book?’ And I am going to say, ‘No. The one who was most black and white and the one who I was most angry at has not seen it.’ And I still have this anger because you won’t look at it. And I am going to tell them that you have not looked at it.” He said, “Alright. Alright. I will look at it.” So he is sitting in his chair, and I am sitting in mine, and we are way too far apart. He is on that side of the little room and I am on this side of the little room. And I said, “If you are going to look at it, let’s move your chair and I will move my chair and you are going to sit next to me. And you are going to look at it.” And we did.<sup>51</sup>

Sitting next to Hall instead of behind a desk, forgoing the schedule, spending time *with* her, and aligning with Hall’s sense of rightness restored their relationship and her trust in him.

In Miller and Tuttle’s classes, taking the time to attentively read Hall’s artist’s books, collectively discuss their significances, and writing thoughtful responses to Hall and her family are acts of giving dignity to the experiences of the subject. What’s more, medical humanities classes such as these provide students with a reprieve from the systemic pressures of productivity, at least for a while. When the currency of dignity is time, providing the space for durational being with is imperative to countering the emotional tolls of an efficiency-based model of practicing medicine.

### *The Suppression of Emotion*

In his case for integrating the humanities with medical education, Alan Bleakley attests that systemic issues of insensibility within Western medical practice results in a spectrum of injustices, which “includes the objectifying of patients, teaching by ritual humiliation, empathy decline, emotional over-insulation, moral erosion and cynicism, intolerance of ambiguity, paternalism, poor self-care and heroic individualism, all of which can lead to medical error.”<sup>52</sup> Jennings also finds that the “suppression of natural emotions on the wards” contributes to the pressure to exhibit stoic detachment. “A medical culture which defines its physicians as heroic and invincible cannot even ‘conceptualize’ a need for physician and student self-care.”<sup>53</sup> Compounding these issues, the de-personalization felt by patients within a profit-driven care system can be felt equally by the physicians, as “the sheer overwork and constant stress, giving

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<sup>51</sup> Hall, *I Make Books*.

<sup>52</sup> Alan Bleakley, “When I Say... The Medical Humanities in Medical Education,” *Medical Education* 49 (2015): 960.

<sup>53</sup> Jennings, “Medical Student Burnout,” 250.

rise to exhaustion, anxiety, pressure, and resentment, may make the new hospital admission seem more like the ‘enemy’ than a focus for one’s compassionate care.”<sup>54</sup> Not providing the space to express or reflect on the inherent emotions of a job as perilous as medicine is antithetical to health and wellbeing. While Hall and the artists discussed in the previous chapter employ artists’ books to reclaim a sense of emotional care for themselves, the rest of this chapter will investigate how similar arts-based practices make space and give permission to students to feel the emotions these artists’ books evoke.

While studying Hall’s artist’s books, Miller recounts that their heavy topics of illness and dying enabled the students to broach emotions within a constructive, low-stakes environment: “There are some students who have been personally touched by cancer in their lives in a close way, and those students connect with the narrative really intensely and emotionally. That anger and the frustration and the things that we’re taught to shove down and put away and not show other people, I think there’s something really powerful in that for students to see—to see that expression of things that are usually forbidden.”<sup>55</sup> Baines additionally attests that the strong emotional impact of artists’ books lies in their multi-sensory expression of illness, which is “very different to just reading a book about it... you can’t *not* engage with it.”<sup>56</sup> The intimacy of holding an artist’s book close to the body and activating our senses to understand its meaning make this art form especially emotive.

In my time in the archives, I found that handling these books was far more emotive than I had even anticipated. I had already read Hall’s statements and watched her documentary, but *touching* these books engaged a level of emotion that had remained untapped before this moment. It was as if these books were a time machine or talisman that transported me alongside her and all the anger, sadness, and love behind these works. The feeling that this object was carefully crafted by the hands of a person who died, who had so little time left but chose to spend it making this object for *you* to experience and learn from, imbued a gravity into every page. The intercorporeality felt by these auratic objects gives them a power to evoke compassion and empathy through time, distance, and mortal planes.

I further posit that employing Hall’s books within medical learning provides an object of attention apart from the students’ own experiences, and that object can then become a kind of emotional lightning rod. Rather than being prompted to speak towards one’s own past experiences, which may be too personal or seen as unprofessional in a classroom setting, a focus on the numerous complex facets of illness that are contained within Hall’s books enables a dialogue around emotions that they may not have been comfortable discussing otherwise. Tuttle and Miller have found that their students ultimately “articulate their thanks for having found in her books a secure place to speak openly about mortality.”<sup>57</sup> Mobilizing Hall’s artists’ books as stepping-stones towards more open and honest discussions about the pressures of medicine was precisely the kind of dialogue Hall was hoping to provoke when she donated her books to the MWWC.

Nevertheless, experiencing artists’ books and reading their uneasy narratives can be an upsetting experience. Hall acknowledges the emotional impact her books will have on medical students she will never meet. She states, “People may not want to ‘touch’ the topics I explore in

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<sup>54</sup> Drew Leder, “Introduction: The Body in Medical Thought and Practice,” *Philosophy and Medicine* 43 (1992): 7.

<sup>55</sup> Miller, interview.

<sup>56</sup> Baines, interview.

<sup>57</sup> Tuttle and Miller, “Unruly Voices,” 59.

my books; yet the books invite handling, touching, interactions.”<sup>58</sup> Hall hints at the intercorporeality inherent in experiencing another’s artist’s book because “they compel not only physical involvement with the book, but also involvement with the ideas expressed in the art and text.”<sup>59</sup> This level of discomfort and vulnerability may be more than readers are willing to handle. Therefore, Baines insists that medical humanities instructors and facilitators must be especially attuned to the emotional states of their students. When she encounters particularly affective reactions, Baines uses this opportunity to form a self-reflective call and response:

Let's talk about this reaction. Let's talk about what this means. Why do you feel like that? What is it that's freaking you out? ... When you're looking at material, when you're looking at the physicality of an object, think about those reactions. They are important, and they're valid.<sup>60</sup>

This kind of questioning and care is vital for reflexive learning that unseats bias and aversion for natural empathetic and emotional responses.

The dialogue brought to the surface while studying these artists’ books is further integrated with learning by Tuttle’s assignments that require students to write term papers about the themes in Hall’s books and hypothetical (or mailed) response letters to Hall’s surviving family. The opportunity for written reflection gives students who may be reluctant to engage in open dialogue the chance to thoroughly reflect on the experience. Tuttle explains that the “students’ letters make clear the emotional and affective impact of Hall’s work and allow future healthcare practitioners to enact the kinds of listening and dialogue that Hall so fervently sought.”<sup>61</sup> These letters exemplify how informal or private writing can be a productive method of processing emotionally challenging situations for the students. Mindful, creative, and time-intensive practices give permission for medical practitioners and learners to slow down, reflect, and reacquaint oneself with the sensing body—a practice which may ultimately aid in sustaining empathy and humanity in their clinical practices.

### **Integrating Humanities**

Considering all of the ways artistic inquiry addresses some of the most systemic concerns in Western medicine, there remains a reluctance to fully integrate the humanities into healthcare education. This is because, although both art and medicine both seek to elucidate the human condition, the methods of doing so rest within fundamentally different paradigms. Whereas medicine sits upon a positivist legacy of uncovering truths about the natural world, “what art seeks is not the discovery of the laws of nature about which true statements or explanations can be given, but rather the creation of images that people will find meaningful and from which their fallible and tentative views of the world can be altered, rejected, or made more secure.”<sup>62</sup> An example of such disparities is provided by Bishop, who notes that the reticence to shift funds and resources to an integrated medical humanities education is because they have yet to prove their effectiveness at improving medical practice in a longitudinal, evidence based, scientific study.<sup>63</sup>

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<sup>58</sup> Hall, “Artist Statement.”

<sup>59</sup> Ibid.

<sup>60</sup> Baines, interview.

<sup>61</sup> Tuttle and Miller, “Unruly Voices,” 58.

<sup>62</sup> Elliot W. Eisner, “On the Differences between Scientific and Artistic Approaches to Qualitative Research,” *Review of Research in Visual Arts Education* 7, no. 1 (1981): 1-8.

<sup>63</sup> Bishop, “Rejecting Medical Humanism,” 23.

Such objective evidence may be impossible to gather for arts-based research, whose impacts to worldview may only tacitly reveal themselves over time. McNiff also encounters the scientific bias for evidence, which ultimately undermines the transformative potential of arts-based research when institutions “insist that all spheres of educational and professional human activity justify themselves by so-called ‘objective’ and measurable outcomes.”<sup>64</sup> Such markers may only be gathered within the utility applications of a humanities practice, such as self-assessed increased tolerances of ambiguity or patient satisfaction ratings, leaving the more intrinsic values of integration essentially unaccounted for. The intrinsic worth of arts-based inquiry is not to increase one’s tolerances for ambiguity, but to interrogate and counter the systemic reasons for *intolerances* of ambiguity. If “every type of thinking must stand before the judgment seat of science,”<sup>65</sup> then the potentiality of the humanities to provoke reflexivity around Western medicine’s divisive history and current hierarchical power structures will be forfeited, and the medical humanities will remain a balm or ‘helpful friend’ to medicine.

Such an undervaluation of arts methodologies was encountered by UK artist and medical humanities instructor Christine Borland, who recounted in our interview that she “was quite personally offended by the attitude of some of the medical staff who would not hesitate to say to students in front of [her], ‘Why are you wasting your time doing something like [art]? You are one of our best students, why are you doing something that you won’t get any credit for?’”<sup>66</sup> A focus on utility, in this case, credit towards a medical degree, demonstrates a misconception for the intrinsic value of the arts and also discounts the role of experts like Borland, who understand not only how and why research-creation and interdisciplinary thinking ought to be integrated with medical learning, but also the history and philosophical reasoning behind such principles.

Medical students have also been shown to demonstrate bias against the humanities. When initiating a study of Hall’s books, Miller must overcome initial balk from students who react with questions like, “Really? This is what we’re doing in this class?”<sup>67</sup> Medical students may resist the open questioning within subjective humanities studies because they believe “medicine is an objective, scientific pursuit based almost exclusively on factual knowledge and technical skills.”<sup>68</sup> Shapiro’s survey of medical humanities students found that they complained of being forced into uncomfortable situations that confront their own vulnerabilities and fears. As well, “many refer to humanities teaching as pointless, boring, worthless, or just plain stupid.”<sup>69</sup> Ultimately, “both anecdotal and investigational data suggest that medical humanities faculty have failed to adequately convince students that the medical humanities really matter to them as future physicians.”<sup>70</sup> Clearly, more investment in how medical humanities is taught, who teaches it, methods of engagement, and clarity on its rationale is necessary to demonstrate the intrinsic value of a medical humanities education.

One strategy to form more meaningful engagement with the humanities is ensuring these courses are led by those who have embedded themselves within the history, practices, and

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<sup>64</sup> Shaun McNiff, “Philosophical and Practical Foundations of Artistic inquiry: Creating Paradigms, Methods, and Presentation Based in Art,” in *Handbook of Arts-Based Research*, ed. Patricia Leavy (New York: The Guilford Press, 2018), 27.

<sup>65</sup> Bishop, “Rejecting Medical Humanism,” 17.

<sup>66</sup> Christine Borland, interview by Darian Goldin Stahl, February 19, 2019.

<sup>67</sup> Miller, interview.

<sup>68</sup> Johanna Shapiro, “Medical Humanities and Their Discontents: Definitions, Critiques, and Implications,” *Academic Medicine* 84, no. 2 (2009): 193.

<sup>69</sup> *Ibid.*, 192.

<sup>70</sup> *Ibid.*, 193.



philosophies of the field. Artists like Borland and librarians like Miller have a clear depth of invested knowledge in their disciplines, which is essential for constructing pedagogies that form productive reflexivity and increase the chance of student buy-in. If humanities and arts experts are not invited to lead or co-lead these pedagogies, then the courses risk becoming a superficial adaptation of artistic methods—ultimately undermining the potentiality of medical humanities and affirming attitudes against their integration.

Co-teaching courses with art and medical experts is one way to form impactful medical and health humanities pedagogies; however, even this model of pedagogy can be fraught with imbalances of workload and compensation. Bleakley points out “the older ‘medical humanities’ for too long have lived off the good will of artists and designers who would provide their labour, intelligence and creative flair for the benefit of medicine or medical education without the medical community giving something back to the arts and design communities.”<sup>71</sup> Charlotte Sleigh also warns of the hierarchies at play within art and medical/science collaborations, which center on, in addition to the above, what are considered legitimate research methods and unequal time investments.<sup>72</sup> The push for integration without addressing such imbalanced partnerships, as critical medical humanities author Patricia Waugh cautions, “may insidiously preserve the knowledge hierarchies of the positivist legacy”<sup>73</sup> in medicine, and ultimately only reinforce disciplinary divisions.

Advocating for balanced interdisciplinary partnerships shifts artists from critical outsiders or helpful friends to integral co-researchers. Tuttle and Miller are not the only ones who have managed to navigate disciplinary divides. There is currently a surge of pioneering co-taught or artist-led medical and health humanities courses. Brown University medical students are offered co-taught cross-listed courses with Rhode Island School of Design students. Collaborating with art students and engaging with the field’s methods, such as regular formative group critiques, the students practice more openly questioning their own methods and outcomes. The medical professor for this course, Jay Baruch, observed that making art encouraged students to scrutinize their discomfort, to “make mistakes, to embrace failure as a valuable and utterly integral part of the learning process.”<sup>74</sup> Another example comes from a photography medical humanities course at Bournemouth University, which was found to productively engage with the high emotions of practicing medicine. Co-professor Rutherford’s expertise in photography enabled him to overcome the students’ initial “degree of hesitation or reticence” for this “touchy feely stuff.”<sup>75</sup> In our interview, he attests, “without somebody who was confidently and knowledgeably and emotionally open to lead them through the process, I don’t think it would have worked.”<sup>76</sup> In this case, Rutherford’s experience navigating arts-based inquiry was critical to promote the buy-in necessary to initiate reflexivity.<sup>77</sup>

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<sup>71</sup> Alan Bleakley, “Transitions in Health Humanities: Towards a ‘Critical’ Health Humanities that Embraces Beauty,” in *Insight 2: Engaging the Health Humanities*, eds. Lianne McTavish & Pamela Brett-McLean (Edmonton: University of Alberta Department of Art and Design, 2013), 12.

<sup>72</sup> Charlotte Sleigh and Sarah Craske, “Nine-Tenths of the Iceberg: Research as the Unseen Component of Artists’ Work,” *Interalia Magazine*, (November 2017): 1.

<sup>73</sup> Patricia Waugh, “Afterward: Evidence and Experiment,” in *The Edinburgh Companion to the Critical Medical Humanities*, eds. Anne Whitehead and Angela Woods (Edinburgh: Edinburgh University, 2018).

<sup>74</sup> Jay Baruch and Kelli Auerbach, “Beyond Comfort Zones: An experiment in medical and art education,” *Journal for Learning Through the Arts* 8, no. 1 (2012): 9.

<sup>75</sup> Rutherford, interview by Darian Goldin Stahl, February 5, 2019.

<sup>76</sup> Ibid.

<sup>77</sup> Rutherford, et al., “Using photography to enhance GP trainees’ reflective practice and professional development,” *Journal of Medical Humanities* 44: no. 3 (2018), 158-164. (Rutherford, et al. 2018)

Tuttle and Miller's sustained teaching and publishing collaboration in the pursuit of integrated art-health pedagogies prove the productivity of dismantling disciplinary hierarchies. Their partnership demonstrates that the model of co-led investigations into artists' books like Hall's are a meaningful and effective method of teaching medical and health humanities. Their expertise of the subject matters and theoretically grounded pedagogies enables their students to practice being with and fostering empathy, all of which evidence the transformative potential of arts-led research. Miller attests that Hall's books have been overwhelmingly successful as primary resources for studying the experience of illness and instigating reflexive dialogue around better patient care. Ultimately, this work honors Martha Hall and the efforts she made to materialize the legacy of her life.

## **Conclusion**

Spending time engaging with patients' artists' books in the medical examination or classroom is a way of giving dignity the subject and reflect on what it means to be ill and live well. Not all doctors will be willing to put aside their agenda for the examination, and not all patients desire to make art or express their vulnerabilities. However, Hall's practice exhibits a kind of holistic care taking in which she invited her physicians to take part. There was ultimately no permanent recovery from Hall's cancer, but by taking the time to sit and be with Hall, to pour over her books together, her physicians provided the care she required.

Inviting reflexivity for the emotional, temporal, and hierarchical facets of illness and medicine may feel uncomfortable or too disruptive to the medical institution, but critique is a practice well established in the process of making art. In donating her artists' books to an archive, Hall hoped to provoke more critique and dialogue about what it is like to be ill in a Western medical system with future generations of doctors. In Hall's words, "My hope in the long run would be that if something is meaningful to someone, or they learn something, or they have a perspective that is different from mine... I would hope that from time to time, somebody would carry on another piece of the conversation."<sup>78</sup> Artists' books' sensory and textual expressiveness, duration, and intimacy make this medium uniquely suited to provoke such dialogues and form the intercorporealities necessary for physicians and patients to work together as partners towards wellbeing.

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<sup>78</sup> Hall, *I Make Books*.

## Chapter 5

### “Book as Body” Artist’s Book Workshop: A Pedagogical Case Study in the Health Humanities

#### Introduction

Beyond the insights into the lived experiences of illness evoked by reading another’s artist’s book, this thesis also investigates how health learners are able to gain insights into their own embodied experiences by *making* artists’ books. To study this phenomenon, I designed and conducted health humanities workshops that teach participants about the historical intersections of books and bodies, examples of patients like Martha Hall who express their lived experiences as artist’s books, and finally, guide participants in the making of their own artist’s books. This chapter focuses on the formation and outcomes of these “Book as Body” workshops as case studies for the potentiality of research-creation within the health humanities context. Ultimately, the workshops critically analyze how the collective creation of artists’ books promotes intercorporealities that enables us understand the body in multi-sensory and relational ways.

This analysis is meant to be a philosophical as well as pragmatic example for those interested in artist-led, collaborative, or co-taught health humanities pedagogies. I situate this workshop as research-creation because it employs “the systematic use of the artistic process, the actual making of artistic expressions in all of the different forms of the arts, as a primary way of understanding and examining experience by both researchers and the people that they involve in their studies.”<sup>1</sup> During my investigations in health humanities, I found a dearth of art-making pedagogies in comparison to other methods like creative writing.<sup>2</sup> Even Tuttle and Miller’s medical and health humanities courses reflect on Hall’s books primarily through writing, and not necessarily by making artists’ books for themselves. Although studying illness art or conducting museum tours to exercise close looking is gaining traction, rarely is *making* a part of the learning program. When arts methods are employed in health contexts, they are far more likely to be conducted with patients rather than healthcare learners and professionals.<sup>3</sup> I hypothesize that there may be structural barriers, a lack of collaboration with artists, or simply not knowing how research-creation could be a valid research methodology that has caused this absence of such art inquiry. I seek to overcome each of these barriers through my “Book as Book” workshops.

The particular structuring of these workshops is meant to demonstrate how research-creation can be thoroughly included in academic and community health humanities contexts alike, and expand notions of what kinds of artistic inquiry are feasible within a standard classroom set up. Acknowledging the inherent structural, safety, and financial obstacles of conducting fine arts outside of specialized arts studios, I have developed non-toxic workshops that can take place in a wide variety of settings and with minimal overhead. I will then investigate specific artists’ books that the participants made, and how these works utilize and

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<sup>1</sup> Shaun McNiff, “Art-Based Research,” in *Handbook of the Arts in Qualitative Research: Perspectives, Methodologies, Examples, and Issues*, eds. J. Gary Knowles and Ardra L. Cole (Los Angeles: Sage Publications, 2008), 29.

<sup>2</sup> Notable exceptions have already been documented in this thesis from Christine Borland, Stella Bolaki, Jay Baruch and Kelli Auerbach, Laura Ferguson and Katie Grogan, and Rutherford. See the Bibliography for details on these resources.

<sup>3</sup> Kimberly Fraser and Fatima al Sayah, “Arts-Based Methods in Health Research,” *Arts & Health* 3 (2011): 110-145.

subvert aspects of bookness to elucidate their own complex lived experiences of symptoms. Finally, I will incorporate the feedback I received to making and interpreting these artists' books into my analysis of the workshop outcomes.

## **“Book as Body” Workshop Outline**

### *Goals*

The overarching goal of this workshop is to investigate how artists' books can foster productive communication and intercorporeality between makers and readers. Under this umbrella, I aim to show how a phenomenological engagement of symptoms enables one to more fully express a lived experience as an artist's book than may have been possible through linguistic means alone. My next goal is to demonstrate the potentiality of translating a symptom into a book as a form of research-creation that critically engages with the wider implications of health and illness. My final goal is to use these artists' books as a catalyst to formulate embodied knowledge—spoken, visual, performative, and tactile—for generative reflections on particular and collective meanings of illness.

### *Methodology*

The primary methodology for these workshops is a feminist-informed phenomenology applied to the making and reading of artist's books. Phenomenology, or the philosophical practice of examining lived experience, is apt for this workshop because it legitimizes the authority to make meaning through one's memories and sensing body. Contemporary feminist phenomenology also overtly addresses how geography, racial background, gender, orientation, and socioeconomic status all impact perception.<sup>4</sup> Although we can attempt to perceive a phenomenon pre-linguistically and without interpretation—as pure feeling—these perceptions will always be framed through the particular background and identity of the subject. Acknowledging such subjectivities opens the possibility for one's symptoms to be interpreted in a multiplicity of meanings with and by others. Therefore, the power to interpret illness is flipped from specialized medical knowledge to each maker's own lived experiences. This inversion of authority enables one to recognize the legitimacy of meanings and significances of illness from others' perspectives.

### *Context*

I conducted three “Book as Body” artist's book workshops within the health humanities context. These workshops were approved by the Concordia University Office of Research to be conducted as research. The first two workshops took place at the University of Kent in Canterbury, England in the Spring of 2019. One was conducted with the members of the University of Kent Medical Humanities Reading Group, which consists of medical professionals, humanities professors, and health humanities students. The other workshop in Canterbury also took place on the university campus, but was open to community members and academics from any discipline. Although I am the lead investigator in these workshops, their structure and content was formed in collaboration with Dr. Stella Bolaki, professor of English and head of the Medical Humanities Program at the University of Kent.

The theme of the workshop was clearly stated in the marketing materials I used, which include digital fliers and an explanatory text emailed to relevant health humanities groups and

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<sup>4</sup> Havi Carel, *The Phenomenology of Illness* (Oxford: Oxford University Press, 2016), 4.

listservs, as well as pointed invitations to local health organizations. Dr. Bolaki reached out to the local Pilgrims Hospices, with whom she has an established relationship. It is important that participants understand the potentially sensitive themes of the workshop prior to attendance, so they have the opportunity to respond with any questions or concerns.

The respondents to the open workshop consisted of healthcare professionals, retired healthcare professionals, medical humanities and arts students, humanities academics, and those who identify as living with a chronic illness or have had an acute but profound illness experience. These categories often overlap. The first workshop with the University of Kent Medical Humanities Reading Group consisted of five participants, and the open workshop had twelve people in attendance.

The third workshop took place at the CHCI Health and Medical Humanities Network Summer School hosted at the Columbia University Global Centers in Paris, France in the Summer of 2019. This annual summer school is part of a larger medical and health humanities conference that proceeds the week-long summer school. The participants of this workshop consisted entirely of those whose graduate research intersects with the health and medical humanities, regardless of their particular discipline. My workshop was a required component for the summer school, and there are eighteen participants in all.

### *Workshop Structure*

A strength of the workshop format is its accessibility. My goal is to demonstrate that anyone can create an artist's book that has aesthetic merit and can be used vehicle for communicating lived experience. I provide a wide range of material choices and methods to populate their books with, because direct drawing can be a barrier for those with anxiety about their 'artistic skills.' As well, the supplies are relatively inexpensive, highly mobile, low mess, water soluble, and easily stored at home. The artist's books we create don't require specialized equipment, onerous safety considerations, or ventilation systems. Further, the compact size of artists' books ensures the materials can fit into a backpack or carry-on suitcase if the participants have traveled to attend the workshop.

The room set up and supplies are consistent across all three workshops. Before the workshops begin, I spread the copious amounts of bookmaking and artistic supplies across the table(s). I arrange the room to consist of one long table or tables connected in a 'U' formation. In my experience, I find students rarely stand up to explore the room's supplies and tend to only use the materials that are directly in front of them. Therefore, this unifying room layout ensures that everyone can see the wide variety of materials to work with. As well, they can easily observe others' variety creative solutions and receive ongoing feedback from their neighbors to inform and enhance their own ideas.

The first workshop took place in three hours, the second in four hours, and the third workshop spanned five hours. Everyone works at their own pace, and there are comments in each group requesting more or less time. Overall, I recommend four and a half hours for this workshop. Based on other artist's book workshops I have conducted, this ideal length of time would also be split over two days to give the participants a break, the opportunity to bring in additional materials from home, and time for reflection before completing and critiquing their books.

Once everyone arrives, I warm up our discussions with introductions that include a 'head-space' statement, that is, what emotions they are experiencing in this moment, what expectations for the day may be, and if there are any outside preoccupations that might prevent them from

being totally present. These statements initiate our time together as a space for sharing and listening.

I begin each workshop with a lecture and slide show on the links between books and bodies. I make this link literal with examples of books bound in human flesh, such as Tagny Duff's artist's books and *Burke's Skin Pocket Book* detailed in Chapter 2. I then summarize the historical intersections between medicine and bookmaking, making note of the collaborative teams that crafted exemplary anatomical tomes.<sup>5</sup> This lecture pays special attention to anatomical flap books, such as physician Johann Remmelin and artist Stephan Michelspracher's *Catoptrum Microcosmicum* (1619), because of their inherently multi-sensory interactions. Viewing these paper layers of the body, I initiate a 'noticing game' to warm up their observational acuity. I ask the audience to describe exactly what they see on the page, which has been projected onto the front of the room. With the bizarre floating organs, volcanic landscape, *memento mori*, and animals surrounding the androgynous nude figure, there is much to be described. I then ask, given the list of denotations we just compiled, what deeper meanings and allegories can be ascribed for this printed body. These connotations may include allusions to biblical figures, gender roles, and mortality. This exercise flexes the participants' description skills and foreshadows the critique procedure we will employ at the end of the workshop.

Next, I show how contemporary artists are expressing themes of illness, disability, injury, mourning, and doctor-patient encounters through their artists' books, like in Joan Lyon's *The Gynecologist*. I then showcase artist Martha Hall and play a portion of her documentary, "Martha Hall: I Make Books."<sup>6</sup> Hall's practice demonstrates how artists' books can initiate and mediate productive communication between patients and physicians. This example makes explicit links to artists' books' potential for a deeper understanding of another's lived experiences by medical professionals and ultimately, more holistic patient care.<sup>7</sup> Finally, I end the lecture by sharing my own artistic collaboration with my sister, Devan Stahl, and the books that we create together.<sup>8</sup> I am able to bring in these books into the workshop so the participants may touch, read, smell, and experience artists' books first hand.

Rather than opening the workshop by reading the "Information and Consent" forms, I choose to introduce them at this juncture between the foregrounding lecture and making process. This form outlines my research goals of the workshop, and explains that the critique and final discussions will be anonymously audio-recorded for later transcription and analysis. This way, the participants have a thoroughly informed idea of what artists' books are and what this workshop entails, rather than a vague understanding at the onset. I also make the creation procedure quite clear at this point, and reiterate the high standards of privacy I uphold in these workshops. That is, that this workshop is an opt-in process, anyone is free to not participate or stop at any point, and no one is obligated to share anything personal about themselves or the work they make. Given the sensitive nature of the "Book as Body" theme, it is crucial everyone has informed consent and that a tone of care and consideration is set in place.

### *Creation Procedure*

Although I do not explicitly frame it as such to the participants, I structure the making

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<sup>5</sup> Examples of this historical perspective are provided in Chapter 2 of this thesis.

<sup>6</sup> Martha Hall, "I Make Books," interview by Jennifer Tuttle, The Maine Women Writers Collection, University of New England, 2004, film, 18:24, <https://www.youtube.com/watch?v=zQCjsutVAtk>

<sup>7</sup> A full account of Martha Hall's books is available in Chapter 4 of this thesis.

<sup>8</sup> A full account of this collaboration is provided in Chapter 3 of this thesis.

process drawing upon the work of phenomenologists Maurice Merleau-Ponty<sup>9</sup> and Donald Idhe.<sup>10</sup> As outlined in Idhe's book, *Experimental Phenomenology*, the phenomenological procedure can be summarized as description, imaginative abstraction, and re-interpretation. The first step begins with identifying and thoroughly describing a sensation or 'symptom' felt within the participants' bodies that "precedes classification and systematization."<sup>11</sup> This symptom could be fairly innocuous, like blurry shortsighted-vision, or more serious bodily preoccupations like severe pain. I also explain that psychological concerns or emotions like mourning, anger, and anxiety are also valid options for this workshop, since they are felt and express themselves in and through the body.

I emphasize the importance of choosing a *symptom*, rather than a diagnosis, for several reasons. First, it retains a sense of privacy for the makers to discuss a sensation rather than diagnostic label. I want to avoid any preconceived notions or judgements of what a diagnosis entails if the maker chooses to disclose the topic of their book. A particular symptom, because it can often derive from numerous different ailments, retains a benefit of the doubt to its origins. Second, it allows us to consider one's particular and subjective phenomena instead of attempting to encapsulate the myriad list of symptoms pertaining to a diagnosis. In a four-hour workshop where we make only a single book, attempting to portray the global change that occurs in one's life during an illness may not be feasible. Finally, an experience of a general symptom is more likely to be shared among the group of participants rather than a specific diagnosis. Although there are vast volumes dedicated to categorizing and naming our ailments, we are far more likely to be familiar with and even share their relatively narrow set of felt manifestations, like knee pain. In this way, the readers of a book may feel more connected with the author's representation of a shared bodily sensation, which increases the potential for intercorporeality.

Once a symptom has been chosen, the next step is to form a privately written sensory description of the phenomena in as much detail as possible. To aid in this auto-ethnographic pursuit, I have developed a list of sensory questions that I ask the participants. Although the questions may seem peculiar and inapplicable at first glance, I encourage them to come up with an answer for each one, nonetheless. This list of questions asks participants to open their imaginations and give new language for a familiar sensation. Since we won't be sharing these lists, I encourage their answers to be as personal, strange, and honest as possible.

- Let's start with how your symptom feels. What is the texture of your symptom? Sandpaper, rough, sharp, prickly, smooth, slippery, or velvet? What is its pressure? Swollen, tight, hard, constricting, stiff, or loose, give under pressure, wobbly, unsteady? What temperature is it? Burning, soothing warm, cold like metal, or icy? What is its weight? Is it heavy, dragging you down, can you carry it in your arms without effort, or does it float above you? How pervasive is its feeling? Is it full of sensation or numbing? Is it always lurking in the background, periodically bursting forth, or constantly known?
- What does it sound like? Loud, crunchy, hollow, thudding, knocking, crackling, or booming; or does it absorb sound, damped it, or is it silent? Does it make a sound that others can hear, or just inside your own body or mind?
- Can you see your symptom? Is it blurry, obscured, hidden, an empty space where

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<sup>9</sup> Maurice Merleau-Ponty, "What is Phenomenology?" in *The Essential Writings of Merleau-Ponty*, ed. Alden L. Fisher (New York: Harcourt, Brace & World, 1969), 28-35.

<sup>10</sup> Don Idhe, *Experimental Phenomenology* (New York: Capricorn Books, 1977), 32.

<sup>11</sup> *Ibid.*, 32.

something should be; or obvious and you can't hide away? What size is it? Can it fit in your hand, carried in a backpack, surround your entire body, or as big as a building? Does it actually fluctuate in size? What color is it? Is it solid color from a crayon box, sliding from one color into another; or iridescent, shimmery, or glittery?

- What does it taste like? Metal, sour, foul, spicy, bile, or spicy heat, or citrus sour, or sweet like a candy, or like menthol, or nothing at all?
- What does it smell like? Citrus, mint, woody pine, cooking spices, floral, sweet like a bakery; or rotting, chemicals, ammonia, astringent alcohol, smoke, or bodily smells?
- How does your symptom move? Does it beat to a rhythm or vibrate? Is its movement unpredictable, chaotic, or regimented? Does it slip through your body like falling like sand or hit you all at once? Where does your symptom reside? If inside your body, where? Does it travel around, stay still, or grow into other parts?

Once the introspective descriptions are compiled, the next step in the phenomenological practice is to describe the ways the symptom impacts daily life, relationships with others, and future plans. It also encompasses what may be a fairly benign symptom in the present, but nevertheless imposes an immense psychological weight of imagining how it may progress. These questions begin to move beyond immediate description and into ascribing meaning to a particular sensation.

- Does your body move through space differently now because of this symptom? How? Are you more cautious in your movements? Are there spaces you no longer have access to? Are there new spaces you frequent?
- Are there tools you can no longer use, or substitutions you have made to accomplish tasks? Have you invented new tools and mobility methods?
- Has your symptom stopped you from doing certain things you used to enjoy? Have you taken up new activities?
- How have your future plans changed because of this symptom?
- How has this symptom effected your relationships with family, friends, and people you just meet? Is this symptom something you generally keep secret from others? Have some relationships fallen away, and have others strengthened?

It is important that this line of questioning does not simply frame illness and the experience of symptoms as a series of losses, but also brings to light the creativity and affirming aspects of living through hardships.

Armed with this extensive list of descriptors, the participants can begin to imagine how a symptom can take the form of a book. For example, many of the words they choose to describe their bodies can be likewise communicated through material and touch. If a participant described her dry eyes' texture as 'rough,' she may choose to make her book out of sandpaper to wordlessly express this sensation to the reader. If one focuses on elbow pain, they may reconceive the spine of the book into the hinged movement of an arm. These creative translations may not have been possible without first detailing all the ways a phenomenon is felt and known through the senses.





Figure 5.1: Darian Goldin Stahl, *Crunchy Knees*, Paper, silk, wax, plastic, 6" x 5," 2019.

Since the translation of their chosen symptom into an artist's book may still be ambiguous at this point, I created my own bodily artist's book as a concrete example of this practice (See Figure 5.1). This book communicates my own felt symptom of crunchy, loud knees. I began making this sculptural book by sectioning off half of the book's pages and folding them into a staircase shape, which expresses where I am most acutely aware of the loud crunch of my knees at every step. These steps are colored as a progression from yellow to red, recalling the progression of my symptom and its potentially painful future.

The other half of my book is wrapped in a wrinkled, flesh-like cloth. The pages within this closed section are covered with red corrugated board. This material imparts a reverberation into the hands of a reader who runs their nails down its surface, which likens to the vibration felt along my legs when my knees crunch. Along the median of this section runs a longitudinal, protruding stitch. This scar of this bound skin foreshadows the prospect of future knee surgery. Finally, picking up the book by this section, one may be startled to hear its loud crunch. Between the wrapped pages hides a mass of crinkled plastic, which uncannily crunches in a likewise resonance with my knees.

The elements of this book culminate in a multi-sensorial experience of what is like to live with the symptom of crunchy knees. In it, I represent the present state of my body and how I see this symptom affecting my body in the future. I point out to the participants that I did not have to write about my knee in order to give the reader of my book a sense of it. I also did not need to draw a picture of a knee, but instead I made use of the book's hinge to signify the movements of this joint. The challenge here is not to *illustrate* the body necessarily, but for the book to *become* a bodily referent. I encourage the participants to think abstractly in this way while reiterating that the workshop is completely open to any manner of expression that the participant deems accurate and representative of their own particular experience.

A crucial aspect of the bookmaking workshop is to show the participants how to craft a

handmade book. However, books that make use of multiple folios and signatures are also time intensive, difficult to bind in one's first attempt, use large amounts of potentially expensive paper, and can form what may be an overwhelming number of pages to effectively transform into a single symptom. Therefore, I have found that the simple 'zine' fold is optimal for the structure of this workshop because it makes extremely efficient use of material and time. The participants need only to fold and cut a single large sheet of fine art paper into eight sections in order to form a book with three full spreads and a front and back cover—no binding required. This fold is simple enough for the participants to repeat at home with any size or kind of paper so they may continue a bookmaking practice in their own time. The majority of the workshop, at least two hours, is spent transforming this initial zine book into an external manifestation of their lived experience.

As the participants begin experimenting with the cornucopia of art supplies before them, I reiterate the idea that paper is a skin, and when we fold it, we are creating a dimensional exterior and interior space for the body or thoughts. I ask participants to consider how their symptom would look if a piece of paper were to physically experience it. How can they fold, encase, hide, layer, expand, stuff, glue, expose, tear apart, ball up, color, alter, destroy, build upon, texturize, or emboss this paper to express their symptom? I ask if it is better to transform the book into a static sculpture to show a profound moment, or utilize the turning of a page as a signal for duration.

While making their books, I play classical music and roam the room fielding questions and giving one-on-one feedback on the development of their ideas. I ask each participant if they need technical or conceptual assistance. The music provides a bit of privacy for our discussions and I reiterate that it is not necessary for them to explicitly tell me their chosen symptom in order for me to assist their progress. As an experienced arts instructor, I offer the workshop participants my technical expertise and guidance through the creation process.

The final hour of the workshop is reserved for a roundtable critique of their newly formed artists' books. If the group is larger, like the CHCI workshop in Paris, I split the group and ask a co-instructor to lead the critique for half of the participants in another room. I want to make sure each book has about five minutes of collective reflection within the overall timeframe of the workshop.

The participants sit in a circle holding their books, and I ask them to hand their book to the person on the left. I give a minute for them to explore the new book they are holding before commencing the critique. Instead of the participant explaining their own book to the group, the neighbor who is holding the book is given the first opportunity to describe the book, walk us through its contents, and offer an interpretation of what they think the book may mean. The discussion is then open for others to provide their own interpretation or point out details that may have been missed in the first reading. Finally, the floor is given to the artist if they have a response to the discussion occurring around the meaning of their artist's book. However, the artist is under no obligation to offer any further explanation. This structure of critique ensures each artist retains a sense of privacy surrounding the particularities of their book's inspiration while still inviting the group to collectively reflect on its perceived meaning.

If there is time remaining, I find it useful to receive group feedback on how the workshop went: if they enjoyed this activity, if they found it useful to examine their bodies anew, what it was like to listen to others discuss their books, what it meant to transform their bodies into a book, and finally, what was surprising or insightful about the workshop. After this group analysis, I ask them to fill out individual anonymous feedback forms with similar questions but

with more emphasis on how this workshop can be improved in the future.

### **Examples of Books and ‘Bookness’**

The artists’ books the participants created exhibit a full range bookness. The artists chose to either exemplify or subvert bookness in ways that enabled them to communicate their lived experiences of symptoms. To accomplish these expressive feats, the participants capitalized on and created tensions between form, material, sensory interaction, text, narrative, temporality, and performativity. These aspects of bookness also contributed to the practice of phenomenology by materializing the inward and outward facing effects of symptoms, and then the intercorporeal relations between subjects as we experienced them together. This next section examines their creative solutions to the workshop prompt.

#### *Form*

The forms of the books ranged from traditional codex to completely sculptural, with little-to-no reference to the original zine book. Of course, the more traditional books proved to be more straight-forward for the reader to navigate and understand as a progression of time or narrative. The sculptural books, however, often confounded the reader as the typical gesture of turning pages became obstructed or impossible. We often asked, “How does one read a book without pages?”





Figure 5.2: Anonymous Workshop Participant, *Blurry Vision*, Paper, pins wax, 6" x 5" x 3," Paris, June 17, 2019.

One such sculptural book engaged the symptom of blurry vision. The artist formed a large, white, cloud-like mass atop red paper in the center spread of her book, which prevented the reader from fully viewing the other page spreads (See Figure 5.2). This mass could also be described as a pin cushion, since numerous colorful sewing pins are sticking into the form. We, as readers, are given more insight into the meaning of this book by looking at its front and back covers, which are populated with iridescent discs and a floral motif. When describing her book, the artist explains:

I have some eye problems.... After several examinations, [the optometrist] figured out, actually, there are some wastes my eyes, which naturally I was born with. And it kind of reflects the light that goes into my eyes... like this Oriental motif [on the front and back covers]. I like those, and they are kind of part of my identity. But also, I think those little plastic circles, like the wastes in my eyes, kind of reflect light.

And this [sculpture] is the fear of going through a cataract operation. Those [colors underneath] are blood. This fear also prompts me to study Early Modern description and surgical experience for my dissertation. I probably read too many 16th century descriptions of sharp objects going into the eye. So it's very literal to my body.

Basically, a cataract is kind of a white jelly in the eye and opaque like this.<sup>12</sup>

The artist exemplifies how purposefully obstructing an aspect of bookness, like the function of pages, brings all of the reader's awareness to the page at hand. As the concern of impending blindness becomes a preoccupation, or *dys-appears*, as Leder would say,<sup>13</sup> so too is the reader's attention focused on this concern. Although a traditional book uses the turning of pages to progress a narrative, this book's single spread nevertheless depicts the progression of a symptom into the future. As a single momentous sculptural form, this book points to the artist's research on historical eye operations, present fear of going blind, and future prospects of surgical interventions all at once.

### *Materiality*

Another aspect of bookness the participants used to form meaning was their materiality, that is, how the materials incorporated into the pages and covers formed literal and conceptual links between human and non-human actants. Some artists did this by thoughtfully incorporating atypical media into their books as material signifiers for how a symptom feels. For example, one participant formed a multi-layered enveloping of books, whose center is slowly revealed to contain a small pebble. He explained that a small growth sits at the base of his coccyx, "and it always feels like [he is] sitting on a pebble and it's hidden inside many little layers" of his body.<sup>14</sup>



<sup>12</sup> Anonymous workshop participant, group critique by Darian Goldin Stahl, Paris, June 17, 2019.

<sup>13</sup> Drew Leder, *The Absent Body* (Chicago: The University of Chicago Press, 1990), 88.

<sup>14</sup> Anonymous workshop participant, group critique by Darian Goldin Stahl, Canterbury, April 10, 2019.

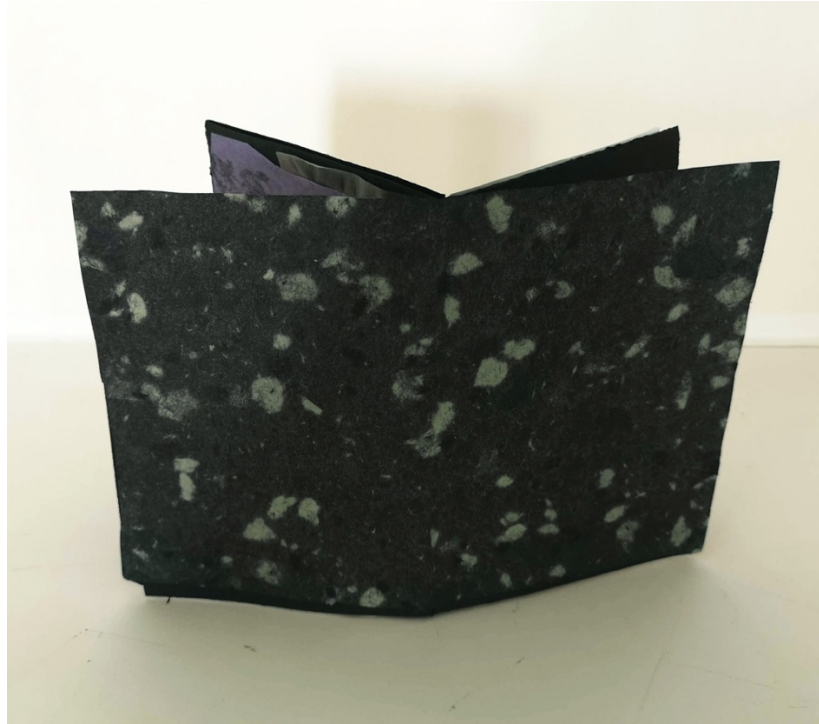


Figure 5.3: Anonymous Workshop Participant, “If I Die,” Paper, cloth, beads, 6” x 4,” Paris, June 17, 2019.

Another artist formed her book out of dark paper with light flecks that looks similar to soil, and incorporated a sculpture of a mushroom to recall the dissolution of self she experiences during a seizure (See Figure 5.3). The first interpreter of this book intuited the reference to fertile soil by stating, “So when I opened up, the first page says, ‘If I Die,’ and to me, I’m always reading it as a landscape.”<sup>15</sup> In response to this interpretation, the artist explains:

I love the reading with it as a landscape. This is about a seizure, which I’ve had a few of in my life.... [Referring to the mushroom sculpture] This thing in the middle, just so everyone’s aware, it’s based on a mushroom that bleeds.... This was like the feeling of being drawn into the earth. But I’ve had this experience. It’s like, I’ve kind of been sucked into my surroundings. I can’t distinguish my body from the earth.<sup>16</sup>

The author effectively uses the combination of earth, mushroom, and the short text, “If I Die,” to express the feeling of losing her sense of bodily agency. This book also foreshadows a time when she may not recover from an experience of another seizure and becomes a part of the earth. Her use of materials communicates the sense of mortality and joins all of us as readers into the knowledge that our material bodies will one day transform and absorb into another form of life.

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<sup>15</sup> Anonymous workshop participant, Paris.

<sup>16</sup> Ibid.

### *Senses*

Although artists' books are inherently multi-sensory, some of the artists in the workshops focused heavily on a sensory reading of their books to construct their meaning. One artist relied on color to contrast the emotions of exhaustion and exuberance, as well as to signal his own identity (See Figure 5.4). The first interpreter of this book detailed its contents:

Here is the first page, and these are very irritated and watery looking eyes with reflective pupils. So, my reading, I guess, is that whatever is happening in the world has kind of produced this state of inflammation and sadness. ... And then the final images are these eyes that, while they do seem to resonate with the first one and that there's been sort of bags that are under them, they are very brightly colored--they are rainbow. And they have stars as pupils, which are still reflective but seem to be less about maybe throwing back whatever is coming in, but also about taking it in and seeing something divine in them.<sup>17</sup>



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<sup>17</sup> Anonymous workshop participant, Paris.



Figure 5.4: Anonymous Workshop Participant, *Queer Eyes for a Dark Heart*, Paper, watercolor, 6” x 4,” Paris, June 17, 2019.

Another artist used the contrast of color to speak towards issues of identity, discrimination, and her symptom of frustration (See Figure 5.5). The cover of her book shows white lace fixed over black paper. The internal contents show two photographs of classrooms, one vintage and one contemporary, both portraying People of Color grouped and sequestered to the edge of the classroom. The final back cover of the book portrays a zebra pattern, which the artists explains is meant to represent Black and White persons living and learning side by side rather than in segregation. In the artist’s words:

We’ve got White kids in the long table like this one, taking classes. And you can see the tiny Black two kids by the side kept all alone. So I bring them social justice in here. You know, bringing them equality in art. Everybody should be included in whatever is going on in the classroom.<sup>18</sup>

<sup>18</sup> Anonymous workshop participant, Canterbury.





Figure 5.5: Anonymous Workshop Participant, *Untitled*, Paper and lace, 6" x 4," Canterbury, April 10, 2019.

The colors used in both of these books heavily influence our reading. In the beginning of each, the focus on the red, dark, baggy eyes or the layering of white on black connote the emotional toll of discrimination. The use of rainbow and zebra patterns by the end of the books are not only used to point towards the authors' identities, but also towards a more optimistic future of inclusion and equity.

Creating texture was another way that the artists imparted meaning for their readers. Several participants pierced their pages with pins and needles, which forced a delicate handling. Most often, the pins were used to indicate the symptom of pain—psychological or physical—felt by the author, and also had the potential to impart a very real pain for the readers if they were not careful. For example, one participant relays that she was forced to retire from her career as a physician due to a spinal surgery that left the right side of her body compromised. She could no longer effectively examine patients, and lost her independence with ordinary, everyday tasks like carrying heavy grocery bags or driving. She represented this bodily and emotional pain as pins piercing through the word “Doctor” written in her book.<sup>19</sup>

Other books used sound to engage the readers' senses. One participant expressed her recent symptom of fever, and wished to portray her frustration at not being able to sleep. She did this by layering multitudes of thin, crinkled paper over her pages that the reader is forced to turn over. The artist states, “So we have multiple layers to go through and they make this rustling sound because I couldn't rest at all. And I wanted to express this by rustling.”<sup>20</sup> In all of these examples, the authors are attempting to form a connection with the readers through an embodied ‘reading’ of their books. They are using their books to touch the reader, in a very real sense, in order to elicit an empathetic response.

### *Text*

Although text as an aspect of bookness is not the focus of this workshop, the tension between words and images was utilized by many of the participants. Text is built into the structure of the workshop in the form of the participants' lists of sensory descriptors. One nurse chose to use her list as a kind of poetry to caption her images for the symptom of a hot, burning face (See Figure 5.6). Having just undergone skin cancer treatments, this participant drew the red, inflamed skin on her nose and cheeks over and over in her book. Alongside these drawings, she included text like:

hot, sensitive, fire, throbs, prickly, burning, on-fire, sunburn, always there, heat, ever-present, painful, face burns, cream, don't get to close, avoid me, warning sign, danger, on-fire, look scary, nowhere to hide, the cream soothes the pain, 3 layers deep, peeling, sun burn, sun-burn, sun-burn.<sup>21</sup>

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<sup>19</sup> Anonymous workshop participant, Canterbury.

<sup>20</sup> Anonymous workshop participant, Paris.

<sup>21</sup> Anonymous workshop participant, Canterbury.

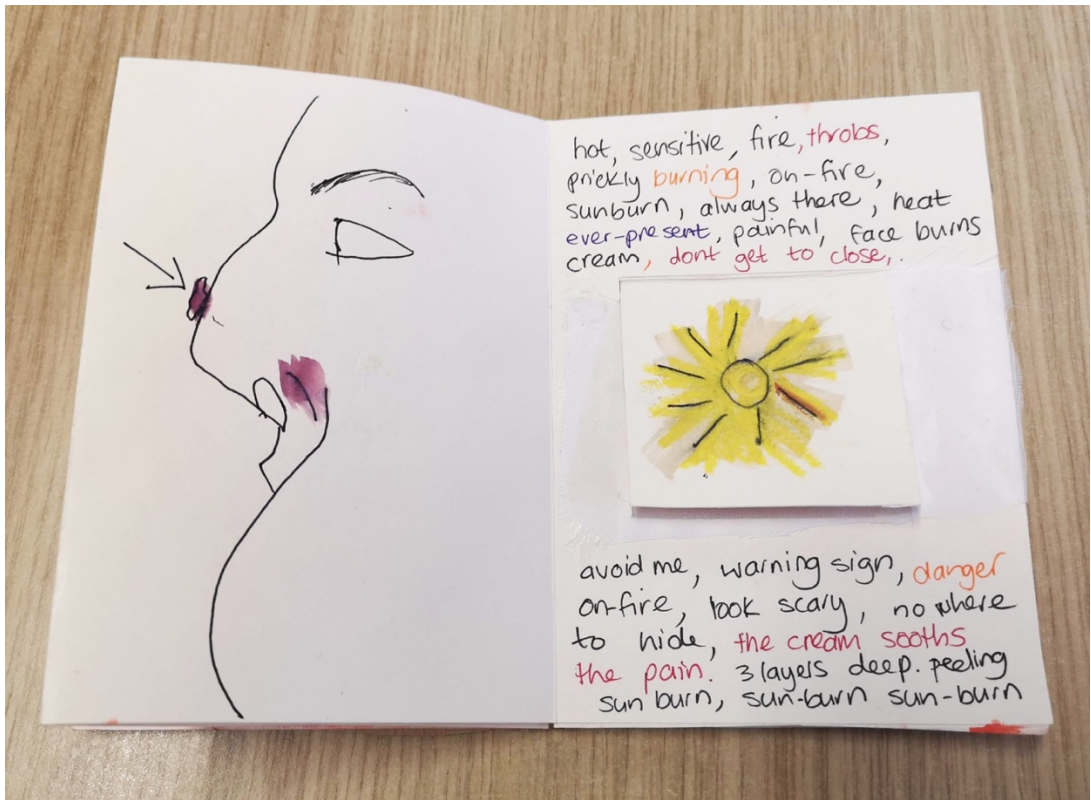
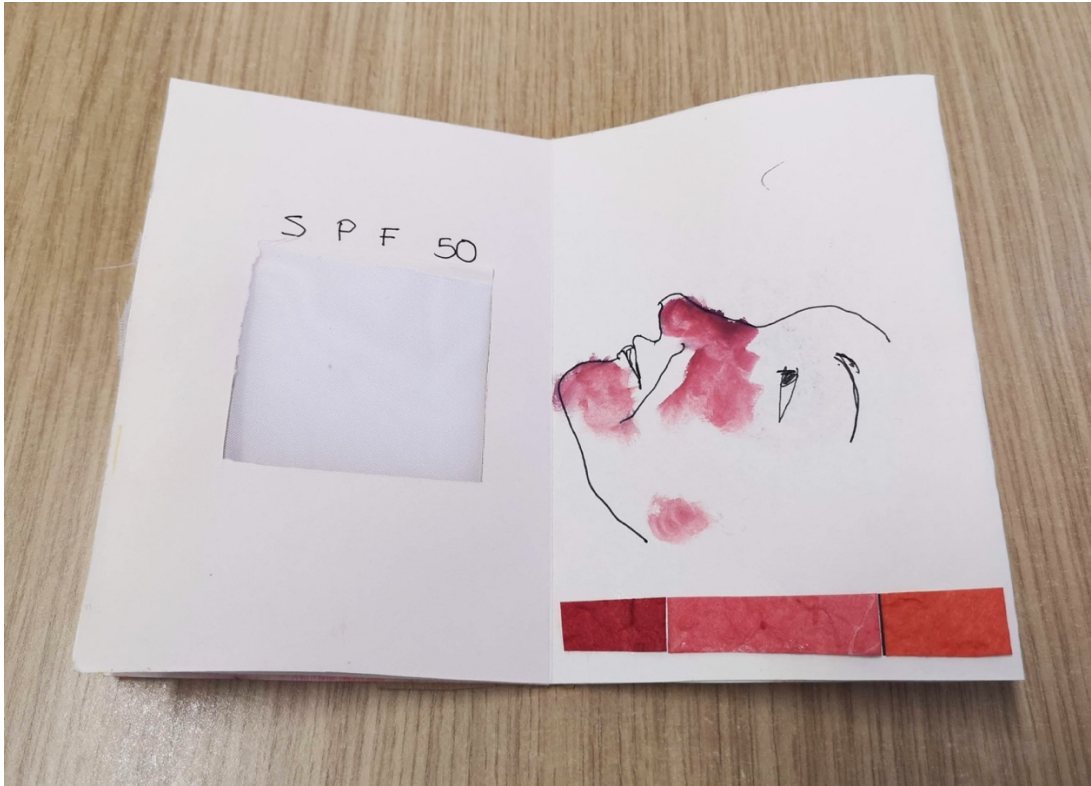


Figure 5.6: Anonymous Workshop Participant, "Burning Skin," Paper and lace, 6" x 4," Canterbury, April 10, 2019.

The incorporation of her sensory text gives the reader a glimpse into both the internal sensations of burning flesh and how the external manifestations of the treatment, an inflamed face, may result in a sense of shame and isolation. The interrelation of personal and interpersonal impacts of these symptoms are made visible through the artist's poetic combination of text and image.

### *Narrative*

Through the progressive turning of pages, workshop participants exemplified narrative even in the near-complete absence of text. For example, the image-based narrative presented by a participant depicts a loved one's progression through mental distress over the course of its pages (See Figure 5.7).





Figure 5.7: Anonymous Workshop Participant, *What's On My Mind?* Paper and yarn, 6" x 4," Paris, June 17, 2019.

Titled, *What's On My Mind?* the artist collages several cutouts of shirt shapes over the span of her book, which are meant to depict how her loved one changes outfits over and over at the beginning of a manic episode. The initial interpreter tacitly understood that a transformation was occurring over the span of this book: "We're shown three versions of the body in different images. What I appreciate about this is the sense of the body as always changing."<sup>22</sup> The artist then expanded on this initial meaning in our group discussion:

"What's on my mind?" So for someone who has a mental illness and who's seeking help, that's a question that they feel that everyday everyone's asking them. "So what's going on? What's going through your mind today? How are you feeling today?" Especially anyone who knows the condition can ask them that. So, "What's on *my* mind?" This person is asking back. This [book] is basically what I would think when they are at the peak of mania and so much activity going on. The person shows the mania stages when they keep changing the clothes.<sup>23</sup>

Although this is a generally wordless artist's book, there is a clear beginning, middle, and end to signal a narrative. The first outfit shown is bold and surrounded by colorful letters and

<sup>22</sup> Anonymous workshop participant, Paris.

<sup>23</sup> Ibid.

symbols of lightning bolts to signify hyperactivity. The final shirt is shown against a black background, which the artist explains signals the entrance into the depressive state at the end of her loved one's manic episodes. This exceedingly short narrative nevertheless has much to say: it informs the reader how an inward, psychological symptom goes on to influence one's outward behavior; and finally, how this manifestation of a symptom then signals an outpouring of inter-relational concern and care from others.

### *Temporality*

The next aspect of bookness I found within the participants' books is the purposeful use of temporality to propel or stymie a coherent narrative. In one participant's diaristic book, the line, "Take one tablet every day," is repetitively scrawled across the center spread underneath of four actual prescription medications that he incorporated (See Appendix 5.8). As the first interpreter explains:

And then we open it, and we get this date, "July 26, 2016," which obviously must be significant because it's just there on its own. Maybe it's like, reminiscent of a diary entry. Following that we get a recommendation with an asterisk, that this person takes a tablet every day, and "every day" is written repeatedly.<sup>24</sup>

The artist then offered an explanation of a daily ritual:

It was pretty much about my mental health issues. I've struggled with depression, anxiety, and everything else for a few years now. But I started my therapy on July 26, of 2016. ... It was a weird experience at first because, having come from an immigrant family, mental health isn't an issue that is talked about. Once I started taking medication, it almost became this weird routine of how medication became this daily performance, routine, that made me really question how useful it really was.<sup>25</sup>

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<sup>24</sup> Anonymous workshop participant, Paris.

<sup>25</sup> Ibid.

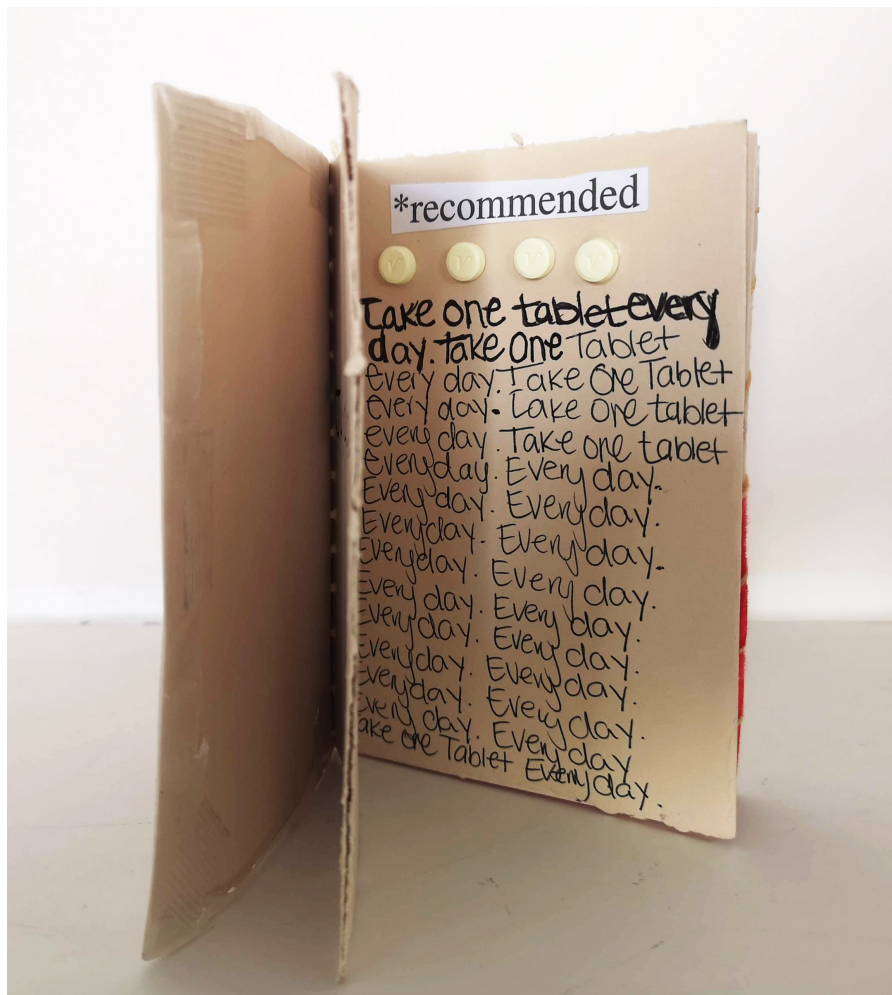


Figure 5.8: Anonymous Workshop Participant, “Take One Tablet Every Day,” Paper, ink, and medication, 6” x 4,” Paris, June 17, 2019.

Even though he didn’t quite finish his artist’s book, he plans on filling the final blank pages with imagery that “should have to deal with some gay culture, gay issues, but at the same time is very celebratory. ...Even though you’re in this particular moment, you know, you still have some empty pages to fill in, which is... a literal materialization of where I’ve been, but also where I might go.”<sup>26</sup> The temporality shown in this artist’s book portrays many different kinds of passing time. By referencing a diary, we can interpret that each page is meant signify a day in his life. However, this pace is significantly disrupted when the repeating words, “every day,” fill the space of a single spread. This page effectively portrays the condensing of a much longer period of time, punctuated by the routine of taking another dose of his medication. Finally, the blank pages at the end of this book project a future space for his identity and health to flourish.

### *Performativity*

The final aspect of bookness that the artist’s use to express themselves and create bodily connections with their readers is performativity. Rather than a typical turning of pages, some

<sup>26</sup> Anonymous workshop participant, Paris.

artists constructed their books with more complex methods of navigation that force the reader to slow down and more closely investigate the meaning behind such a structure. For example, one medical student's book appeared quite plain at first: a blank, white paper substrate with a subtle white fringe on its covers. However, once the reader moves into the center spread, she comes across an enveloping mass of bright red, orange, and yellow tissue paper and the single instruction, "...unfold" (See Figure 5.9). Performing this queue, the reader discovers the bright papers unfurl into a structure that can no longer be contained by the book covers, and appears to create a fiery eruption from the center of the book. Speaking with its maker, this book is meant to portray his hidden feelings of anxiety and their potential to explode from within. By performing this book, the reader detonates an anxiety that the medical student struggles to keep under wraps.



Figure 5.9: Anonymous Workshop Participant, *Unfold*, Paper, 6" x 4," Paris, June 17, 2019.

Another book that must be performed to be understood is a psychiatrist's portrayal of her patients' minds. Recalling the idea that the mind is a mysterious 'black box,' she has constructed her book into a black box configuration, with a top flap that the reader must peel back to 'read' the contents within (See Figure 5.10). The first interpreter gave this description of the unconventional book:



It's really fragile. We can feel the vulnerability of it as a body or a mind. So I need to be very careful the holding it, and to try to find how to read it and to comprehend it. But if you try to open it like a book you see it is going to collapse. So you need to find another way to read it and look at it. ...I just did try to look from above. I don't know, it's kind of a metacognition thing or psychoanalysis thing, since I know the author.<sup>27</sup>



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<sup>27</sup> Anonymous workshop participant, Paris.



Figure 5.10: Anonymous Workshop Participant, “Black Box,” Paper, string, and pins, 6” x 12,” Paris, June 17, 2019.

The artist then gave a further explanation for her sculptural book:

So my first thoughts going into the project were about the ‘black box’ of the mind, and the psyche that I encounter with my patients in psychiatric hospital. So I was thinking in particular about the relationship with the patient, this sort of anxiety being closed up in their mind, and then the difficulties to relate to me, and also to relate to their environment.<sup>28</sup>

As the reader performs this book by pulling back the top and investigating the contents of the ‘black box,’ the artist places the reader into her position as a psychiatrist. This confounding book thus effectively portrays the dual struggles of being ill and caring for those who have a mental illness.

Although the prompt for this workshop is to thoroughly investigate a single symptom, what is clear in the description of these books is that they are never solely about one thing. In their reading, the artist shows us how one symptom can form a network of personal and interpersonal impacts on one’s life. For instance, a book may appear to address the repetitiveness of taking a medication every day, but it also concerns the toll on one’s mental health when he is unable to openly communicate his sexuality with his conservative immigrant family. Further, although I have categorized these books within particular aspects of bookness, each one could be seen to purposefully subvert more than one element of a traditional book in order to propel its meaning, focus the readers’ attention, and form a bodily connection.

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<sup>28</sup> Anonymous workshop participant, Paris.

## Feedback

There were several opportunities for me to receive feedback about the workshop from the participants. First, through the one-on-one consultations with each participant during the creation of their books. Next, at the end of the workshops, we held a group discussion on the qualities of the workshop. After this, I gave the participants anonymous feedback forms that use a mix of qualitative and quantitative feedback. A complete summary of these feedback forms can be viewed in Appendix 1.

Overall, the participants rated their experiences high on a scale from 0- 5. For instance, the participants rated the background lecture an average of 4.8/ 5 for exemplifying the creative and communicative potential of artists' books. When asked to rate if this workshop helped them to develop their creative thinking and communication skills, the average score is a 4.5/ 5. The lowest score was for the question, "This workshop will help me communicate more fully with a clinician as a patient," which received an average score of 3.5. One potential reason for this lowest evaluation could be that the participants would not anticipate taking their books into clinical appointments like Martha Hall did. On the other hand, it took several years of a sustained bookmaking practice for Hall to feel confident enough to show anyone other than her immediate family her artist's books. Perhaps with more integration of research-creation in the health humanities, these participants could also feel more comfortable speaking with and through their creations.

Aside from the numerical feedback, I also received written responses to qualitative questions. Some highlights from the 'strengths of this workshop' section include:

- Opportunity to explore without expectation.
- Exploring the meaning of words, symptoms from a personal point of view v. doctor's point of view (pain v. sore; raw and blistered v. redness).
- Really appreciated the talks before the workshop to help me understand better the links between books & body in the history of art. I like that it is getting us out of our comfort zone. I like that it doesn't apprehend art in an expressive, not necessarily healing way.
- No binding guidelines, freedom with the form of book.
- The teaching was an eye opener to my ability to create my piece of work. Articulating and putting down ideas were conveyed to me in the process.

The questions concerning the weaknesses of the workshop generally involved its length of time, which some deemed too long and others too short. Finally, in the "additional comments" section, participants wrote:

- I loved the teaching process and organization. It helped me start thinking about how powerful colors can be in passing a message.
- I loved this workshop, a powerful and emotive workshop that allowed insightful experiences to be explored in a supportive environment.

While evaluation forms are helpful in some respects, I find the most productive feedback occurs when participants are in the midst of the creative process or communicating the significance of the artist's books during the final critique. These recordings and transcriptions are valuable not only to gauge the buy-in and effectiveness of the methods I employ, but contain the main source

of analytical evidence to assess if the goals of the workshop are met.

### **Analysis of the Workshop Outcomes**

These goals of this workshops are, once again, to demonstrate how the practice of phenomenology enables one to elucidate lived experience, exemplify the potential of research-creation for materializing the experience, and finally, to use these artists' books as a catalyst for forming generative reflections on particular and collective meanings of symptoms. The workshop's essential provocation, that books can express the body, is a research-creation prompt that "situates what often seem like disparate practices, giving them a conduit for collective expression" to evoke "new forms of knowledge."<sup>29</sup> Overall, the aim of this workshop (and this thesis more generally) is to investigate if and how artists' books foster intercorporeality between makers and readers.

#### *Phenomenological Practice*

As noted by Idhe, the first step in a phenomenological practice is to perceive a sensation anew and describe it thoroughly before any kind of cognitive interpretation.<sup>30</sup> It was clear in the group discussion that the description prompts from the beginning of the workshop enabled the participants to reconsider a sensation from a novel multi-sensory perspective. One participant noted, "I thought the prompts were really good. You know, what I was working on was something I thought about a lot from a sensory perspective. And still, it's like, giving me new, new things to work with that I wouldn't have thought of otherwise."<sup>31</sup>

After feeling and description, the next step in this phenomenological practice is to imaginatively abstract the symptom through the creation of their artists' books so that the artists and readers may comprehend another's a lived experience in a new and embodied way. The sensory description lists aided participants in making connections between a sensation and aspects of bookness. One participant noted, "It was great, because I think the book is really kind of the bridge between the feeling and the knowledge."<sup>32</sup> The intertextual translations from sensation, to language, to book form is where the heavy conceptual work of this practice takes place. Although I take measures for the participants to feel confident in their ability to translate their symptoms into artists' books, I also do not want participants to feel entirely sure how the artists' books would turn out. Leaving room for spontaneity enables the makers to learn *through* the process of making, otherwise known as research-creation.

As Idhe points out, there is an "essential obscurity"<sup>33</sup> that must occur while one shifts between expressive modalities. Obscurity can open the imagination towards a sense of wonder, experimentation, and learning by circumventing conventional modes of expression. The abstraction and translation inherent in the workshop's prompt, to create an artist's book that materializes a symptom, challenges the participants to form original creative solutions through (auto-)ethnographic, sensory, and material research. It is the abstraction that enables both maker and reader to perceive something new. Idhe explains, "for a new thought to be expressed, it must either introduce a radially new language—at risk of not being understood at all—or stretch the

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<sup>29</sup> Erin Manning, "Ten Propositions for Research-Creation," in *Collaboration in Performance Practice*, eds. Noyale Colin and Stefanie Sachsenmaier (London: Palgrave Macmillan, 2016), 133-141.

<sup>30</sup> Merleau-Ponty, "What is Phenomenology?" 28.

<sup>31</sup> Anonymous workshop participant, Paris.

<sup>32</sup> Ibid.

<sup>33</sup> Idhe, *Experimental Phenomenology*, 18.

meanings of previous terms to cover new uses.”<sup>34</sup> This generation of new ideas by abstracting the familiar through alternative modalities is at this heart of research-creation practices.

The process of translating a symptom into an artist’s book often occurred through an intuitive exploration of the materials rather than conscious linguistic articulations. Taking into account that these is a group generally had no prior experience in fine art, much less in the medium of artists’ books, the variety of materials promoted experimentation. As one participant recounts, “I wasn’t sure how it was going to come out. But just looking at the materials actually gives you the idea.”<sup>35</sup> Another participant adds, “I think for me, it was also generative. And to your point about the materials inspiring the thing, I found a new material that made me think of what the next step was.”<sup>36</sup> For both of these makers, the *materials themselves* generated the links between ideas. This embodied way of approaching research furthers the notion that “subjective, tacit knowledges are ... where ideas or strategies emerge according to demands that present themselves in the midst of creative processes.”<sup>37</sup> Creating a book thus invited the makers to explore the material aspects of bookness and how those elements coalesce to convey the meaning of symptoms in excess of its text.

### *Intercorporeality*

The final step in this phenomenological practice is to hand the artist’s book to another participant to reinterpret the symptom represented and return it with new, intersubjective sensibilities. I found the obscurity of the artist’s book medium to be in a benefit in this regard. Without preconceived notions of what a ‘good’ or ‘bad’ artist’s book looks like, the participants are less likely to hold their final book to a standard which they may or may not meet. For mixed groups of participants that range from healthcare professionals, to students, to laypersons, breaking down hierarchies of knowledge is crucial for open peer-to-peer communication that fosters the feeling that ‘we are in this together.’ My observation is that the novelty of the medium results in more willingness share the final artist’s book with less fear of judgment.

All participants were invited into this generative practice in the form of our roundtable critique. During the critique, the readers offered multiple and layered interpretations of each other’s artists’ books due to their abstracted nature. The interpreters formulated meaning through the books’ form, content, and perhaps some limited knowledge of the author, while keeping in mind that all of these interpretations were influenced and framed their our own life experiences. This step is meant to initiate the intercorporeal connections between makers and readers by physically handing the book to another person, and focusing our collective attention on its potential meanings. With these many interpretations in hand, we were able to comprehend the wider implications of a particular symptoms, and even relate them to our own experiences. What’s more, the interpretations offered the artist the opportunity to reconsider their own experiences from new perspectives.

What first became evident in the critique was the significance of receiving these precious handmade objects from their creator. One participant remarked:

The first thought that came to my mind when I got this is like I'm being given a gift,

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<sup>34</sup> Idhe, *Experimental Phenomenology*, 22.

<sup>35</sup> Anonymous workshop participant, Paris.

<sup>36</sup> Ibid.

<sup>37</sup> Kim Sawchuk and Owen Chapman, “Research-Creation: Intervention, Analysis and ‘Family Resemblances,’ ” *Canadian Journal of Communication* 37, no. 1 (2012): 12.

something I have to unwrap. I sort of have to open it. So that was a feeling of curiosity, also sort of attention that, you know, that it is was given to me.<sup>38</sup>

Another participant notes:

The thing that struck me first is just how small it is. And because of that there's a kind of intimacy in here. I feel like I'm being led into somebody's inner world. And we really are in such a simple and beautiful way.<sup>39</sup>

The gesture of handing one's book to their neighbor formed an instant relation between maker and reader. During the critique, these connections deepened by taking the time and care to consider the book as a materialization of experience. The author is not simply giving another person an impression of their body, but also receives feedback on the significance of their creation to others. One participant noted, "I enjoyed the experience of creating a narrative or reading a symptom, commenting on someone else's symptom, and watching the comments on mine. It kind of made me rethink my interpretation of the symptom I was talking about."<sup>40</sup> The exchange of ideas facilitated by the artist's book forms a reciprocity of care and attention for the impacts of symptoms.

After such a focused investigation of their own bodies, it was surprising for many participants to hear how their artists' books stimulated entirely different meanings for its readers. For example, the 'black box' artist's book noted above inspired many possibilities to its meaning. The initial interpreter of this book saw it not as a book at all, but rather "when [he] was looking at it globally, it seemed to [him] like maybe a kind of a ship or something."<sup>41</sup> This interpretation provided an opportunity for the artist to consider how another's perception of a ship could be equally true to her own intention of portraying a black box, and how these interpretations can coexist. The artist responded,

Is this a black box that I'm trying to open in the therapy, through the development of a relationship to the patient so far, too? There's also a moment of a journey, I thought, a journey and you named it like a ship. And I also kind of like that idea, because in a certain way, you engage on a trip, the missions, and we walk along with the person and sort of do this together.<sup>42</sup>

A phenomenological practice upholds the perception of both the maker and reader to be valid, meaning that, as Idhe states, "all phenomena must be considered 'equally real' within the limits of their givenness."<sup>43</sup> The blending of interpretations for this abstract book demonstrates how widening the possibilities of meaning to include not only the maker's intention, but the subjectivity of each person who reads it, forms an entanglement of intercorporealities that grows to encompass all those who take the time to engage with artists' books. Because of the layering of meaning evidenced in the group critique and reflexive dialogue these artists' books sparked on

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<sup>38</sup> Anonymous workshop participant, Paris.

<sup>39</sup> Ibid.

<sup>40</sup> Ibid.

<sup>41</sup> Ibid.

<sup>42</sup> Ibid.

<sup>43</sup> Idhe, *Experimental Phenomenology*, 37.

the particular and shared experiences of symptoms, I find the “Book as Body” workshops to successfully meet the preliminary goals.

### *Pitfalls*

My analysis of the artist’s book workshops includes some drawbacks as well. First, my analysis from the feedback forms and group discussions draws from a small pool of thirty five participants. Although this intimate setting allows me to conduct one-on-one feedback with each participant, the overall impact on these workshops on the field of health humanities is, at the moment, also small. The ideal future for these workshops would be to form a replicable model for other collaborative teams of instructors to take up and conduct with their own institutions, positioned within their own expertise and media choices, and thus help research-creation health humanities proliferate.

The biggest pitfall to demonstrating the transformative, intrinsic value of research-creation is that the participants are self-selected, and therefore already have the time and at least a cursory interest in health humanities. In my discussion with one physician-participant, she found the workshop helped her to reconsider the impact of symptoms for patients, but that other healthcare workers would not generally have the time, or perhaps the will, to conduct such reflexive considerations on their own. She stated,

[The workshop] really helps you identify and define the aspects of yourself that's been affected, which is not just conventional things. More so it's like exploring taste, smell, the sound, the sensory, and how each condition has that. But we [as physicians] don't consider it because we don't have the time.<sup>44</sup>

Another participant expressed similar sentiments in the anonymous feedback form: “I am not sure the doctor's cabinet would allow for such non-conventional expansion, but if the doctor's cabinet would allow for such non-conventional communication in some shape or form, I think it could be valuable.”<sup>45</sup>

To overcome the hurdles of time, and even permission, to engage in phenomenological investigations within the health humanities, Vaccarella argues that “if we want to really strengthen the collaboration with medicine, it has to be really well integrated so it’s not just something like ‘a little hobby.’”<sup>46</sup> For the most thorough assessment of impact for this kind of workshop, an ideal setting would be as part of a sustained, integrated, and mandatory health humanities curriculum or ongoing education program, where the biases for self-selection are accounted for and everyone has permission to spend their valuable time in creative, reflexive pursuits.

The final pitfall I have identified in the analysis of this workshop concerns an artist’s access to perform such health humanities inquiry as a non-medical professional. I have found that it is essential to identify a health humanities scholar or medical professional who *already* champions the value of arts-based inquiry and is willing to put in additional time and effort to integrate art into their outreach and curricula. In this regard, I am grateful for my collaboration with Stella Bolaki and the immense amount of time, professional networks, and experience she brought to these workshops.

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<sup>44</sup> Anonymous workshop participant, Canterbury.

<sup>45</sup> Anonymous workshop participant, feedback form by Darian Goldin Stahl, Canterbury, April 10, 2019.

<sup>46</sup> Maria Vaccarella, interview by Darian Goldin Stahl, February 12, 2019.

## Conclusion

Although it is difficult to know the long-term impact of a creative inquiry such as this, it was clear through the qualitative feedback and critique that the participants found value in translating their bodies into books. The combination of the introductory lecture, the use of real-world examples, guided art making, and final critique from an artist invested in the subject matter provided the necessary conditions for the high percentage of buy-in and engagement. Even though I did not frame it as such for the participants, aligning the process of this workshop with a phenomenological research-creation practice enabled each person to deeply perceive a bodily sensation. Participants were then able to identify a single symptom's links within a network of personal and interpersonal impacts on their current lived experiences and future plans. Finally, these books acted as a catalyst for understanding the multiple and shared perceptions of health and illness in a collective setting. Because every artist's book is a layering of intention and interpretation, its capacity to simultaneously inhabit multiple meanings between its covers make this medium an unparalleled generative medium.<sup>47</sup> For these reasons, the "Book as Body" workshop has met the overarching goal of exemplifying how artists' books can foster productive communication and intercorporeality between makers and readers.

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<sup>47</sup> This portion of text was first published: Darian Goldin Stahl, "Field Notes: How To Be Generative," *Synopsis: A Health Humanities Journal*, July 7, 2019, <https://medicalhealthhumanities.com/2019/07/07/synopsis-in-paris-field-notes-how-to-be-generative/>.



## Conclusion

Ultimately, this thesis concerns the many ways art gives form and meaning to bodily phenomena. First, creating an artist's book about one's experience of illness is a method of closely investigating one's own body. Such research-creation involves giving renewed attention to sensations that have become habituated, or feelings that are obstinately difficult to fully comprehend, in order to imaginatively give form to the formless. For the participants in the "Book as Body" workshops and artists like Amanda Couch and her artist's book, *Entrail Troyen*, transforming ephemeral sensations into a tangible object had the effect of familiarizing oneself with the mysterious internal. Once externalized, the ways these phenomena impact not only their own bodies, but how they move through the world and plan for the future become more apparent. Creating the book became a method of situating a symptom within the much wider network of impacts to one's life, which ultimately gives meaning to what may feel like random biological occurrences.

For artists and potential makers, I aim for this thesis to demonstrate the power of translating bodily experiences through archival artists' books. Artists' books present a hybrid of expressive modalities: sensory, textual, image-based, performative, and material. The sheer versatility of creative choices enables more multi-sensory engagement than almost any other form of art. As well, the accessible nature of folding paper and stacking folios means that most anyone, especially in collaboration with a trusted partner, can create their own artist's book and populate its pages with any manner of media. When the topics of these books concern the experiences with illness and disability, accessibility is a central consideration. The flexibility of the medium enables each maker to create a book that best expresses their own particular experiences, using the media that best suits their ability and comfort.

Apart from a solely personal meaning-making investigation, artists' books are also a method for makers to reach out and communicate to others about their experiences with illness, disability, and encounters with medicine. This method of teaching is especially important for circumstances that seem to elude language. For artists like Erin K. Schmidt and her *Unfinished Blanket*, the book serves as an attempt to communicate the incomprehensibility of loss. As the termination of unviable pregnancies remains a taboo topic, as well as death more generally in our society, makers are able to circumvent the need for linguistic communication and instead utilize books' more sensory modes of meaning-making.

For the medical student, these objects provide an opportunity to engage with honest portrayals of illness and how it impacts the lives of their patients who may otherwise feel unable to communicate such sensitive or private concerns with their doctors. Likewise, healthcare workers will not always be able or willing to invest themselves emotionally with each and every patient. Making time to engage with patient artist's books, physicians are then able to hold the stories of others from a distanced position, when there are no high stakes for 'solving the problem' or 'curing the patient.' They can simply listen, learn, and be with.

Research-creation has been further exemplified in this thesis as a way to focus distinct disciplines around their interconnectedness. Aesthetics become a nexus between scientific, medical, and artistic research when producing images is used to evidence bodily phenomena across these disciplines. The layering of their imagery, including medical scans, printed matter, and microscopy, into an artist's book like *Field Notes* visualizes how interdisciplinary research-creation can be when it comes to the topics of health and illness. Therefore, this medium can be

employed as vital learning resources across these fields as the images speak to and inform one another.

Mobilizing artists' books as primary pedagogical material exemplifies the intrinsic value of research-creation within medical paradigms. Artist bookmakers challenge the barriers between medical professionals, stakeholders, and the general public by democratizing what health research looks like. Once bound, the artist's book structure offers a sense of peer-reviewed, publishable authority to story within because of The Book's status in our culture for encapsulating truths and knowledge. The elevated status of the maker's own voice, propelled by the book form, is vital for communicating lived experiences not only to those charged in their care, but also to broad public audiences who are not privy to specialized medical knowledge or academic journals. Such "resistive potential of art is now being harnessed by social researchers increasingly committed to dismantling stereotypes, accessing the voices of marginalized groups, and engaging in research that propels social change."<sup>1</sup> Given the vast power differentials between doctors and patients within the clinical setting, where one may be requested to recite a narrative of their private ailments in a harsh sensory environment for near-strangers who may use alienating specialized knowledge, all while barely clothed in a hospital gown no less, it is essential to provide an opportunity for patients to reclaim a sense of authorship to their lived experiences and bodily phenomena at their own pace, in a comfortable space. Bookmakers are then better able to express the disease they carry and how that feels, as well as the effects of illness that fall outside of strict clinical boundaries: their daily lives, independence, relationships with others, impacts on their career, socioeconomic status, or future prospects; in short, how illness also impacts intersubjectivity and one's way of being in the world.

For the artist's bookmakers profiled in this thesis, the process of making, including all of the artistic choices, framing, and subject matter, enabled them to gain a sense of authority and control over the meaning of their experiences. For those who choose to share their works directly with healthcare workers, like Martha Hall, these artists' books are found to be capable of sensitizing physicians to the needs of their patients. It is also found that the mediation of abstract books opens the possibility, perhaps counter intuitively, for more direct and honest communication by acting as a stepping-stone between two people. Such feelings of relational understanding are not restricted to a close proximity to or even within the lifetime of their maker, as one's archival book-body will live on and speak volumes as a legacy of lived experience.

Teaching how to create an artist's book is the final way this thesis demonstrates how research-creation is vital for learning. First, through the hands-on process of translating a sensation into a book form. From this experience, makers are subsequently better at picking up on the subtle ways other artists' books merge text, image, and the senses to communicate. In the health humanities, such pedagogies alert us to how rigid our linguistic-centered communication has become. There are other ways, perhaps even more constructive ways, to communicate one's lived experiences than being prompted to efficiently verbalize the arc of illness. Those who hold power in our healthcare systems ought to be well attuned to the myriad methods patients may employ in their attempts to make themselves understood. Bending towards abstract or metaphorical methods of describing bodily phenomena employed by patients, who do not have the benefit of specialized medical knowledge and scientific terminology, will ultimately foster more aligned understandings of what it is like to live with illness and goals for living well.

The abstract and subjective nature of artists' books promotes a sense of intercorporeality between makers and readers as both parties become implicated in the meaning of this book.

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<sup>1</sup> Patricia Leavy, *Method Meets Art: Arts-Based Research Practice* (New York City: Guilford Press, 2015), 291.

Bookmakers evoke an infinite number of relations within a finite object, which sustains their dynamic significance over many different readers. There is the sense that artists' books are in a state of becoming, dependent upon the next interpretation. Although I have made suggestions on how to translate one's body into book form, there is nevertheless no single prescription for making an artist's book nor for determining some kind of 'ultimate meaning'—and this is their strength. Just as phenomenology asks us to consider a sensation anew, each artist's book begins a new practice of examination and interpretation. As Merleau-Ponty states, "The unfinished nature of phenomenology and the inchoative atmosphere which has surrounded it are not to be taken as a sign of failure, they were inevitable because phenomenology's task was to reveal the mystery of the world and of reason."<sup>2</sup> Instead of providing concrete answers, artists' books are best utilized to ask more questions: What is surprising about the perspective and experiences portrayed within this book-body? What emotions rise to the surface as you engage with this work? What does this artist's book *do* for the production of health knowledge? What is the worth of spending this time? I aim for this thesis to initiate further dialogues about the worth of research-creation in health humanities contexts as a philosophical and pragmatic method of examining illness and disability experiences.

Making and acquiring artists' books is gaining momentum. After dipping in popularity around the 1990's, artists' books are now in the midst of a Renaissance with new programs, collections, and courses established in universities across North America. I assert that the medium's resurgence is not occurring in spite of digital technologies encroaching on the printed page, but because of it. The prediction of digital readers replacing printed text and relegating the book object into obsolescence has sounded for decades, and yet, has not come to pass. The desire to hold a book, smell ink, flip pages, and display a treasured work on the shelf endures. Our attraction to books is linked to our long cultural history with them to, as Drucker states, "serve as a vehicle to communicate far beyond the limits of an individual life or contacts"<sup>3</sup> due to their archival form. When technology advances production into automation and then digitization, the material, hand-made practice achieves an enticing aura of legacy and artistry. These objects become all the more precious when they are lovingly crafted by the hands of the author.

However, this is not to say that artists' books are antithetical with technology. Speaking with the artist Veronique Chance about her artist's book, *In the Absence of Running*, she relays that this work is presented in exhibitions alongside a tablet that enabled the reader to digitally scroll through 'pages' of her arthroscopic knee surgery rather than experiencing them all at once in the massive, unbound-sheet presentation of her artist's book. As well, the documentation of *Field Notes: How to Be With* also includes a digital reformulation and recitation so that it can be shared beyond its five physical editions. Although we may think of the digital versions of these artists' books as more accessible and at-hand, this may not be true in perpetuity. As technology continues to change styles, formats, and hardware, these digital files will inevitable become incompatible or incommensurable. For instance, when I visited the Prescriptions Collection at the University of Kent to view Chance's book, the digital tablet version was not included. Chance explained that incorporating a tablet that has to be charged and managed with updates was ultimately incongruous with the archive. The legacy of this work is in its paper form.

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<sup>2</sup> Maurice Merleau-Ponty, "What is Phenomenology?" in *The Essential Writings of Merleau-Ponty*, ed. Alden L. Fisher (New York: Harcourt, Brace & World, 1969), 43.

<sup>3</sup> Johanna Drucker, *The Century of Artists' Books* (New York City: Granary Books, 1995), 8.

This thesis is building towards the integration of research-creation practices in the health humanities. These health contexts may include patient advocacy groups, art therapies, as well as medical classrooms. While creative methods like Narrative Medicine are readily employed in this burgeoning field, arts-based methods are much less often represented. A goal of this thesis is to demonstrate the value of learning with and through creative arts practices, especially for those who hold positions of power. I also advocate in this thesis for collaborative partnerships in these interdisciplinary pursuits to ground the inquiry within a clear and effectual rationale. For a field that is only beginning to include research-creation, we are in the position to shape its future. As we continue to build and configure the health humanities, this thesis argues for making space to conduct the thinking and feeling that can only occur during the process of making.

From the time artists were dismissed from the anatomical theatre in favor of photographic documentation methods, their role in medicine has generally shifted to critical outsider. Many of the artists profiled in this thesis take on this important perspective to reveal the miscommunications, biases, and injustices that continue to pervade Western medical institutions. With the broadening acknowledgement that the greatest medical concerns we face are not entirely biological, but also humanistic in how we understand each other in a polarizing world and, primarily, how best to take care, arts and humanities perspectives will continue to become ever more vital within in health discourses. From this position *within*, artists and humanities researchers have the potential to transform understandings of illness from inside the institution. This shift occurred most notably in the work of Hall, whose artist's books began as a critique of the communication styles of her physicians, and evolved to become pedagogical primary resource material for new generations of medical practitioners.

If we aim to achieve health equity, then the narratives we use to evidence what it is like to move through our healthcare systems must come from diverse perspectives. Those who are empowered with the knowledge and skills to create auratic artists' books then become the arbiters of truth for the stories printed between their covers. The future of this project is to seek out those whose voices are missing from the medical and health humanities collections and curricula and enable others to represent their own authoritative stories in the sharable, archival, and sensitive medium of the artist's book. As we grapple with when and how to come together in a post-pandemic society, such artists' books exemplify how research-creation can mediate and generate discourses between health professionals and those who live daily with illness. The multitude of perspectives bound together around a shareable artist's book embodies ways of being with, even at a distance.

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## Appendix 1:

### Anonymous Survey Results of the “Book as Body” Workshops

Location: University of Kent, April 10, 2019

Participants: A mixed group of community members, retired medical professionals, medical humanities students, and professors.

Answer on a scale from Totally Disagree (1) to Totally Agree (5)

1. The lecture was informative and helped me understand the benefits of creating medical art.

Responses: 4, 5, 5, 4.5, 5, 5, 5

Average score: 4.8

2. I felt prepared and equipped to carry out the hands-on workshop.

Responses: 5, 5, 5, 5, 5, 5, 5

Average score: 5

3. The learning environment was safe and comfortable

Responses: 5, 5, 5, 5, 5, 5, 5

Average score: 5

4. This workshop expanded my comfort zone.

Responses: 4, 5, 5, 5, 5, 5, 4

Average score: 4.7

5. Creative outlets like this workshop help me better express uneasy memories and experiences

Responses: 4, 5, 5, 5, 4, 5, 5

Average score: 4.7

6. This workshop helped me develop my creative thinking and communication skills

Responses: 4, 5, 5, 5, 4, 5, 5

Average score: 4.7

7. This workshop will help me communicate more fully with a clinician as a future patient.

Responses: 3, N/A, 4, Not sure, 3, N/A, 4

Average score: 3.5

8. What were the strengths of this workshop?

- It's fun and gets you to think about health in a way you wouldn't have otherwise
- To consolidate previous thoughts and processes of an ongoing project
- Very comfortable and safe space for sharing/creating discussion
- Step by step. One on one moments. Asking advice. Warm environment.

- Opportunity to explore without expectation.
- The teaching was an eye opener to my ability to create my piece of work. Articulating and putting down ideas were conveyed to me in the process.
- Exploring the meaning of words, symptoms from a personal point of view v. doctor's point of view (pain v. sore; raw and blistered v. redness)

#### 9. What were the weaknesses or things you would change?

- Perhaps some priming when other people interpret the books to guide the interpretation
- Handout or references from the first part would be helpful as context
- Perhaps more time for creating?
- Maybe a little more on Darian's books and how they were produced!
- N/A
- N/A
- I needed more time :-)

#### 10. Additional comments

- It could [help me communicate more fully as a future patient], but I am not sure the doctor's cabinet would allow for such non-conventional expansion, but if the doctor's cabinet would allow for such non-conventional communication in some shape or form, I think it could be valuable.
- Some tap water on hand.
- Really enjoyed the talking part. Thanks! :-)
- Amazing workshop. Really enjoyable.
- Very interesting experience.
- I loved the teaching process and organization. It helped me start thinking about how powerful colors can be in passing a message.
- I loved this workshop, a powerful and emotive workshop that allowed insightful experiences to be explored in a supportive environment.

Location: Columbia University Global Centers, June 17<sup>th</sup>, 2019

Participants: Eighteen health humanities graduate researchers

Answer on a scale from Totally Disagree (1) to Totally Agree (5)

1. This workshop was worthwhile and I would recommend it to others

Responses: 5, 5, 5, 5, 5, 5, 4, 5, 5, 4

Average score: 4.8

2. The lecture was informative and helped me understand the potential of artists' books

Responses: 5, 4, 5, 5, 5, 5, 4, 5, 5, 4

Average score: 4.7

3. I felt prepared and equipped to carry out the hands-on workshop

Responses: 5, 4, 2, 5, 4, 5, 2, 5, 5, 4

Average score: 4.1

4. The creative environment felt safe and comfortable.

Responses: 5, 4, 4, 5, 5, 5, 4, 5, 4, 5

Average score: 4.6

5. This workshop expanded my comfort zone.

Responses: 5, 4, 5, 5, 5, 5, 3, 4, 4, 3

Average score: 4.3

6. Creative outlets like this workshop help me better express uneasy memories and experiences.

Responses: 5, 3, 5, 5, 5, 5, 4, 5, 5, 4

Average score: 4.6

7. This workshop helped to develop my creative thinking and communication skills.

Responses: 5, 3, 5, 5, 4, 5, 4, 5, 5, 3

Average score: 4.3

8. I feel more equipped to communicate using the senses in my future endeavors in the health humanities

Responses: 5, 4, 5, 5, 4, 5, 4, 5, 4, 3

Average score: 4.4

9. What were the strengths of this workshop?

- Supportive atmosphere, creative playfulness
- The group discussion, the lecture, some of the work
- I loved the prompt questions--they got me thinking about aspects of my sensory experience that I might not have on my own. Great materials, too.
- The preparation of the instructors. Very well thought out lectures.

- Darian is an awesome communicator. Really appreciated the talks before the workshop to help understand better the links between books & body in the history of art. I like that it is getting us out of our comfort zone. I like that it doesn't apprehend art in an expressive, not necessarily healing way.
- Individual attention, a great introduction, samples to help
- The interactive aspect of it, the lecture, being 'guided' but not imposed on
- Lecture, opening us to adjectives to describe our chosen symptom, the show + tell at the end
- No binding guidelines, freedom with the form of book

10. What were the weaknesses or things you would change?

- A bit long
- More glue and scissors
- Time. Perhaps having some pre-prepared materials to start.
- Great experience overall. Challenging.
- More time? Narrower parameters
- A longer lecture might be better. More pairs of scissors and materials for the next one.
- Not knowing how much time was allotted to create, having to talk about personal things without prefacing the activity/convo with some sort of disclaimer/ safe-space statement

11. Additional comments

- Great experience overall.
- Great job. Keep going :-)
- I really enjoyed this workshop. Would love to attend a similar one again sometime.
- The lecture was VERY interesting

**Appendix 2:**  
**Ethics Certificate**



CERTIFICATION OF ETHICAL ACCEPTABILITY  
FOR RESEARCH INVOLVING HUMAN SUBJECTS

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Name of Applicant: Darian Goldin Stahl  
Department: Faculty of Arts and Science\Communication Studies  
Agency: N/A  
Title of Project: The Artist's Book as the Patient's Body: How the  
medical humanities facilitate expression and empathy  
for doctors and patients  
Certification Number: 30010017

Valid From: October 01, 2018 To: September 30, 2019

The members of the University Human Research Ethics Committee have examined the application for a grant to support the above-named project, and consider the experimental procedures, as outlined by the applicant, to be acceptable on ethical grounds for research involving human subjects.

A handwritten signature in black ink, appearing to be "J. Pfaus".

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Dr. James Pfaus, Chair, University Human Research Ethics Committee