EMBODIED BOOKS



Experiencing the Health Humanities through Artists' Books

Darian Goldin Stahl

Peter Lang

"We often speak of the body of text, and Darian Goldin Stahl's excellent and timely book deals with sister-inspired texts of the body. Stahl makes the case, beautifully and powerfully, for the value of artists' books to open us up (like a laparotomy) to illness experience."

-Paul Crawford, Professor of Health Humanities, University of Nottingham, UK

This book investigates how handmade artists' books excite the senses to communicate lived experiences of illness and disability. The combination of text, image, materials, and form, along with the gesture of turning pages, make artists' books a powerful source of expressive potential. These works of art not only enable patients to create meaning from their medical experiences, but also invite healthcare learners to an uncensored read of critiques on Western medicine.

Artists' books are increasingly popular among medical institutions in an age of digital screens because of their intimate handheld, multi-sensory expressions of bodily phenomena that may be difficult or impossible to communicate through words alone. By applying a phenomenological practice of sensing and meaning-making, the author provides step-by-step instructions for creating new artists' books as part of health humanities pedagogies. In this way, *Embodied Books* serves as a philosophical and pragmatic example of why and how experiencing artists' books in healthcare contexts is so important.

Darian Goldin Stahl is an interdisciplinary printmaker, bookmaker, and health humanities scholar. After receiving an MFA in Printmaking from the University of Alberta, she was awarded a SSHRC Vanier Scholarship to pursue an interdisciplinary PhD in Humanities from Concordia University in Montreal. Situated at the intersection of fine art, communication studies, and art education, her research–creation investigates how making and reading artists' books communicate lived experiences of illness and disability. Dr. Stahl is now a SSHRC Banting Postdoctoral Fellow at the University of Northern British Columbia's Medical Program, where she facilitates the creation of new artists' books with diverse patient groups. She is also a practicing artist whose work has been exhibited in numerous local and international solo exhibitions. Most notably, all of her artist's books were acquired by the Wellcome Collection Trust in London in 2019, where they continue to evoke health discourses with public audiences.



EMBODIED BOOKS

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EXPERIENCING THE HEALTH HUMANITIES THROUGH ARTISTS' BOOKS

Darian Goldin Stahl



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This publication has been peer reviewed.

This book is dedicated to my sister, Devan Stahl, and to all those who choose to put their bodies into books.

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Introduction: Embodied Books

A book is a body. Even 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 bookmakers employ 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 then 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 leave an impression on the books that we hold dear. Our oily fingerprints yellow the corners of pages, creating a pallor and texture like an aging complexion; and the well-worn creases we impart to our most beloved books evoke the wrinkles inscribed on the surface of skin.

As shareable objects, 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 medium. They mediate the wide spaces between the writer and reader as they entangle the perception and imaginations of both parties. Books then take on a life of their own. They seem to possess a self-determined quality as they pass from hand to hand 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 meaningful and significant if that book was carefully and lovingly crafted by hand.

My first *artist's book*, that is, fine art that takes on the format and concept of a book, was an attempt to understand another person's body better that of my sister, Devan. Six years after her diagnosis of multiple sclerosis in 2009, Devan procured and shared with me several complete sets of her MRI scans that her neurologist copied onto a CD. Devan thought, since I was a printmaker studying the medium's connection to medical history, that I could somehow use these biomedical images in my work. Eagerly scrolling through the black and white digitization of her body, I was first struck by how alien these scans felt. Grotesque slices of Devan's face revealing her nasal cavities, cutting through her eyes, and exposing her brain tissue ensured I could not recognize my own sister's face. Although abstract portraiture can similarly evoke a sense of alienation, the artist's hand imbues emotion, storytelling, and context to their visual choices while also inviting viewers into an open-ended interpretation to the work's personal significance. These images, on the other hand, have a singular purpose: to alert Devan's neurologist to the lesions along her brain and spine. I felt a sense of injustice that these scans could only confirm a diagnosis while communicating absolutely nothing about the life-altering consequences of her prognosis, the impact on Devan's sense of identity, nor what it felt like to live daily with the symptoms of MS. I longed for these medical portraits to communicate more.

I was then struck by the seeming pagination of Devan's body within this digital format. As I scrolled my cursor up or down, layers of her anatomy were stacked or peeled away. I imagined that every minute slice of her MRI scans was a piece of paper that could be compiled, bound, and then pulled across my thumb to form the animated illusion of a flip book. With that thought, I felt compelled to materialize these digital scans into an artist's book (see Figure 0.1). Devan's illness narrative could then be printed along-side the images of the body to rectify the absence of identity and voice in her original MRI scans. We could then share these artist's books with others as a dispersed edition in the hopes of giving support to others who have felt similarly diminished by medical scans, as well as educating physicians on the impact medical scans can have on the patient's sense of self.

Our collaboration bloomed into a rich, reciprocal practice of making and reflection. We began to interweave our respective interdisciplinary backgrounds in medical ethics, religion, printmaking, art education, and communication studies into the meaning of these creations, and how each of these disciplines affords us lenses through which to view the artist's books. It is also a collaboration that enables us to speak more directly to each other about difficult topics like illness when there is an artist's book between us. Ultimately, I understand the labor required to transform Devan's body into

Embodied Books



Figure 0.1: Darian Goldin Stahl, *The Importance of Dualism*, Photo-intaglio on waxed silk tissue Gampi paper, 6" × 5.5", 2014.

a book to be a gesture of my care: to let her know I am deeply considering the impacts of a diagnosis on her life and, in a small way, bending the world she moves through toward more empathetic understandings of what it is like to live with illness—one artist's book at a time.

Embodied Books emerges from this initial collaborative bookmaking practice and expands to include how others employ artists' books to express their lived experiences, communicate with their physicians, critique harmful Western medical paradigms, and point toward a more collaborative and creative future in health research and education. I use a combination of artistic, philosophical, and field research to investigate the potential of this medium as a primary resource in health and illness research. The core argument of this monograph is that artists' books are uniquely suited to educate readers about bodies by engaging their sensing bodies.

Methodology and Methods

In my experience as a fine art health humanities researcher and educator, I have found a dearth of research and pedagogies that mobilize *research-creation*, that is, the methodology of learning through the process and outcomes of creating art, within healthcare contexts. Research-creation takes up the call of other health humanities scholars to form critical, theoretically grounded approaches to the intersections of art and health. Rather than simply promoting the sense of wellbeing that arises through exercising creativity, I am investigating if and how critical artists' books might foster critique, dialogue, and learning to enact meaningful change. Therefore, I aim for this book to provide substantial philosophical justifications and pragmatic considerations for integrating research-creation within health research.

Throughout my fieldwork, I created artist's books to organize and analyze the qualitative data I collected. I found creating books that layer textual, image-based, and sensory research to be an effective method of entangling interdisciplinary concepts. Centering bookmaking researchcreation throughout my investigation led to new insights into how, for example, scent can enact caretaking for readers, or how nonhuman beings become implicated in the study of human bodies. Once research takes on the form of a tangible object, the initial proposition that an embodied engagement with artwork fosters meaning-making that could not be ascertained through more traditional means of knowledge dissemination alone (like this written book) becomes demonstrably evident. Ultimately, reading and making artists' books became the primary evidence for the effectiveness of research-creation in the critical health humanities.

The initial question driving this research is, "How can artists' books effectively communicate the wide range of lived illness experiences?" Illness is a vast topic and universal condition, yet effects each person uniquely. Given the variabilities of illness, I argue that the multimodal openness of artists' books, such as the intermingling of text with collage, photography, painting, drawing, printmaking, sewing, materiality, and more, is suited to accommodate the variability of sensory methods a person may require to express themselves with fidelity, meaning, and impact. I am also interested to discover if the *process* of translating one's ill body into an artist's book informs or even transforms one's sense of identity and agency.

From a relational standpoint, does reading and experiencing artists' books foster empathy with those who live with illness? If so, how can philosophy help us to contextualize meaning-making and the sense of connectedness while engaging with artists' books? This book, as well as the research-creation produced alongside it, examines if relationality can be fostered with those who experience illness through the embodied processes of making and sharing artists' books.

My goal is not only to investigate what artists' books can offer makers but also how these artworks may go on to impact and sensitize health practitioners. To this end, I examine how teaching bookmaking within a health humanities context can promote criticality and empathy with those who live with illness. Artists' books are a means to create 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. As medicine becomes more and more technologically mediated, a return to embodied forms of learning through touch, temporality, and gesture within the intimate sensory engagement of artists' books helps to mend the epistemic gap between treating and living with illness.

The methodology I use to situate the allure and power of artists' books to form embodied connections between makers and readers is phenomenology. A phenomenological practice is apt for this investigation because it examines lived experiences, and in particular, re-examines habituated phenomena. This reexamination is especially significant when the matter at hand concerns how the body changes in times of illness. Likewise, phenomenology is useful to examine how artists alter the typical reading and format of books to indicate the ill body. Contemporary critical¹ and

I Lisa Guenther, "Critical Phenomenology," in 50 Concepts for a Critical Phenomenology, eds. Gail Weiss, Ann L. Murphy, and Gayle Salamon (Evanston: Northwestern University Press, 2020), 11–16. feminist² phenomenology provide further frameworks for reexamining lived experiences that are cognizant of how identity subjectively influences perception in order to promote productive change and more inclusive practices within fields like healthcare.³ Explicit acceptance of subjectivity in the topics of health and illness is crucial to our discussion of artists' books because, as the ill body is translated and abstracted into the structure of a book, it is then up to every subsequent reader to interpret meaning from these hermeneutical objects. The ability to evoke a multiplicity of personalized significances forms the basis of the connective power of artists' books that keeps the medium lively and impactful. Artists' books that take on the form of the (ill) body, as well as books that are literally composed of body parts, will be examined as evidence for generative research-creation and phenomenological practices.

Audience and Contributions to Knowledge

The interdisciplinary nature of *Embodied Books* means that anyone who has experiences or interest in art, bookmaking, illness, and/or healthcare will find value in this work. I envision readers to include ill persons, care-takers, healthcare workers, health researchers, healthcare students, librarians, artists, curators, instructors, and all of the overlaps between these categories. For those interested in creation, I go into detail on how to make and interpret artists' books. I aim for the full range of makers, from those with little-to-no artistic background to extensive artistic practices to be well equipped to create a meaningful artist's book by the end of this

- 2 Linda Fisher, "The Illness Experience: A Feminist Phenomenological Perspective," in *Feminist Phenomenology and Medicine*, eds. Lisa Folkmarson Käll and Kirstin Zeiler (Albany: SUNY Press, 2014), 33–52.
- Further reading on the topics of feminist phenomenology include Gail Weiss, *Intertwinings* (Albany: State University Press of New York, 2004); and Elizabeth Grosz, The Volatile Bodies: Toward Corporeal Feminism (Bloomington: Indiana University Press, 1994).

read. Considerations for collection and display of artists' books will prove useful for art and library workers who wish to proliferate the medium for general or targeted audiences. For scholars, I provide philosophy and theory on the relational power of artists' books. Healthcare practitioners may utilize *Embodied Books* to become more attuned to the nonlinguistic, creative ways patients may express themselves. For instructors, I provide a step-by-step case study for conducting bookmaking within medical humanities classrooms. In all of these topics, I detail the pitfalls one may encounter and methods to overcome these challenges so readers will feel empowered to take up this medium and experience it for themselves.

Embodied Books primarily engages the disciplines of artists' books, the phenomenology of illness, and the critical health humanities. As artist's book scholars like Stefan Klima,⁴ Charles Alexander,⁵ Joan Lyons,⁶ and Johanna Drucker⁷ point out, the medium has had fluctuating appeal since its conception in the 1970s, which has resulted in a scarcity of literature on the topic from philosophical and sensory perspectives. However, the diversification of the artist's book genre, recent appeal to university library holdings, and uptake by women in particular have led to a resurgence of the medium for the twenty-first century. Most of the publications concerning artists' books focus on the art history and categorization of the medium, but what is far less analyzed is their philosophical precedent for empathy creation. As artists' books become more well known, it is vital to set a methodological foundation on which to contextualize their potential within other fields of research, such as healthcare.

With regard to artists' books on topics of illness, a foremost scholar is Stella Bolaki, who is the principal investigator for the Prescriptions Collection held at the University of Kent.⁸ This project collected over

- 4 Stefan Klima, *Artists Books: A Critical Survey of the Literature* (New York City: Granary Books, 1998).
- 5 Charles Alexander, *Talking the Boundless Book: Art, Language and the Book Arts* (Minneapolis: Minnesota Center for Book Arts, 1995).
- 6 Joan Lyons, *Artists' Books: A Critical Anthology and Sourcebook* (New York: Visual Studies Workshop Press, 1985).
- 7 Johanna Drucker, *The Century of Artists' Books* (New York: Granary Books, 1995).
- 8 Stella Bolaki, "Artists' Books and Medical Humanities," *Journal of Medical Humanities* 41 (2020).

seventy artists' books on the broad topics of health, illness, and mortality.⁹ I conducted fieldwork in this collection, and many of these artists' books are cited in the following chapters as primary resources.

For the discipline of artists' books, research-creation contributes valuable methodologies for their formation and interpretation. Specifically, I outline the aspects of *bookness*, that is, our engrained and preconceived notions of structures and formats for various books, and how artists manipulate these aspects to engrain meaning. The written word in conjunction with images and an activation of the senses enables multimodal strategies for expression that can hardly be matched by any other medium. When the topic of these works concerns illness, disability, and medical encounters, their potentiality for countering bias and stigma by fostering empathy positions artists' books as a medium of vital significance.

The applied research-creation proposed in *Embodied Books* is a wholly original approach to the phenomenology of illness. Although Merleau-Ponty (and many other phenomenologists since) employs a study of paintings like Cezanne's to conceptualize perception and the (in)visible,¹⁰ I take this practice a step further and ask what the multi-sensory aspects of engaging with artists' books may reveal about the body's perceptual abilities. Additionally, phenomenology aids in conceptualizing how *making* art with and for others initiates an empathetic response between authors and makers. Finally, there has never been an explicit connection made between the caretaking aspect of artists' books with and for others, as my collaboration with my sister exemplifies, is a method of showing care and intertwining phenomenological "flesh," which is a novel contribution to this philosophical space.

The third discipline this research-creation engages is the critical health humanities, which is a broad and inclusive field for critical health research that may fall outside of clinical boundaries. Rather than a set of pedagogies for mobilizing the humanities within medical school, generally known as

⁹ Stella Bolaki and Egidija Ciricaite, *Prescriptions: Artists' Books on Wellbeing and Medicine* (London: Natrix Press, 2017).

¹⁰ Merleau-Ponty, "Eye and Mind," in *The Essential Writings of Merleau-Ponty*, ed. Alden L. Fisher (New York: Brace & World, Inc., 1969), 259.