

Visualizing Non-Visual Phenomena: Making Experiences of Tinnitus Affect Legible

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Abstract

I have been suffering from chronic tinnitus for ten years. While the experiences of people living with disabilities have gained social and critical attention over this time, tinnitus remains invisible in both material and discursive senses, and little understood by the public.

My thesis research asks, *can graphic design be deployed to represent non-visual phenomenon?*

My inquiry focuses on making visible the ways auditory disruptions of tinnitus affect my everyday experiences, with the goal of accomplishing the following three things: 1) creating relational experiences for fellow tinnitus sufferers, 2) making the experience of tinnitus visible for the non-sufferer, and 3) participating in the broader discourse of exploring how to bring a visual legibility to non-visual disabilities. My research draws on disability studies, feminist and sensory visualization theories, and employs autoethnography and an exploratory research-through-design process to inform my research creation.

Dedication

I would like to dedicate this thesis to my dad. For all the support (and patience) you have given me throughout my education... and upbringing. You raised one hell of a kid.

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I would like to thank Jan Hadlaw and Paul Sych, for never telling me what to do. You two have a way of exciting ideas and sparking thought without pointing to a distinct direction. Once I began finding my way, you gave me nothing but the support and guidance I needed to see everything through. I am not only a better designer, but a better person because of the time we spent together.

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To my MDes friends—Lucy, Allan, Richard, and Fredrick—I am grateful for the experiences we shared, and the friendships we now have.

Lastly, thank you to my family. None of you seemed to mind that I had essentially disappeared over the past two years... I will take that as you giving me the space and time I needed to get this work done. I promise to leave my desk and see you all soon.

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Introduction

I have been suffering from tinnitus for approximately ten years, catering to its intrusive hindrances in my day-to-day life.¹ While the experiences of people with disabilities have increasingly gained social and critical attention over this time, this auditory affliction continues to be invisible in both material and discursive senses resulting in a lack of public awareness. The goal of my thesis work is to show how tinnitus hinders and alters everyday experiences for its sufferers. My research question asks, *can graphic design be deployed to represent non-visual phenomenon?* The basis for this inquiry is my interest in making visible the ways in which the auditory disruptions of tinnitus affect my everyday experiences.

Tinnitus is the perception of a phantom sound occurring when no external auditory stimulus is present, often described as a ringing in the ears. It affects 10-25% of adults worldwide² at a range of severities. It can be perceived unilaterally or bilaterally (in a single or both ears), heard at various tones and volumes which vary from person to person. There are two key pairs of identifiers used to describe tinnitus, *chronic* and *acute*, and *subjective* and *objective*. Acute tinnitus is a temporary and will fade over time; an effect of being exposed to acoustic trauma, like a loud concert. Chronic tinnitus is permanent, perpetually heard for life. Subjective tinnitus describes a sound which only the sufferer can perceive, and objective tinnitus can be perceived by a person external to the sufferer by using an enhanced listening device, like a stethoscope.³ This information provides a basis for describing what tinnitus is or could be, but the effect of tinnitus will vary from person to person depending on their lifestyle, coping ability, severity, mental health, and various other factors. This makes tinnitus somewhat of an enigma and undermines any attempt made to generalize experiences as objective.

¹ I recognize that there are debates on the use of the word 'sufferer' to describe those with tinnitus, but I find it best suits the affect. The extent to which tinnitus sufferers are affected can only be understood subjectively, in my case and for my purposes, the term is appropriate.

² Carol A. Bauer, "Tinnitus," *New England Journal of Medicine* 378, no. 13 (2018): 1224, doi: 10.1056/NEJMcp1506631.

³ Berthold Langguth, "A Review of Tinnitus Symptoms Beyond 'Ringing in the Ears' a Call to Action," *Current Medical Research and Opinion* 27, no. 8 (2011): 1635, doi: 10.1185/03007995.2011.595781.

Causes of tinnitus are also enigmatic and difficult to pinpoint.⁴ However, there are consistent correlations between tinnitus and hearing loss, with many tinnitus sufferers experiencing impaired hearing.⁵ In terms of the range of severity, it is recommended that diagnosed tinnitus sufferers be given psychological assessment.⁶ Tinnitus can be debilitating, reducing quality of life and causing social isolation. It correlates with a menu of mental health difficulties including anxiety, insomnia, depression, lack of concentration, and in very severe cases, suicidal behaviour.⁷ Tinnitus onset can cause mental health difficulties to manifest in the sufferer or exacerbate pre-existing difficulties. Either way, treatment for tinnitus often involves learning to manage these comorbidities as a form of coping. At the time of writing this thesis, there is no universal cure for tinnitus and, for most sufferers, the search for a cure is “an unattainable goal.”⁸

Tinnitus can have a significant impact on a person’s quality of life and, in my personal experience, can result in disability. It largely remains, much like other non-visual disabilities, invisible in public discourse. By making tinnitus visible and acknowledging sufferer experiences, my thesis uses personal knowledge to accomplish three things: 1) to create relational experiences for fellow tinnitus sufferers, 2) to make the experience of tinnitus visible for the non-sufferer, and 3) participate in the broader discourse of exploring how to bring a visual legibility to non-visual disabilities. I situate my research in disability studies with a focus on the non-visual, qualitative studies of tinnitus experiences, feminist and sensory visualization theories, and employ autoethnographic and research-through-design (RtD) methods to inform my design work. There is a synchronicity between these theories and methods, all open a space for subjective perspectives to be recognized and

⁴ Bauer, 1227.

⁵ Gerhard Andersson, “Psychological Aspects of Tinnitus and the Application of Cognitive–Behavioral Therapy,” *Clinical Psychology Review* 22, (2002): 986.

⁶ Andersson, 986.

⁷ Andersson, 980; Langguth, 1636; Bauer, 1224-1225.

⁸ Soly Inga-Maj Erlandsson, Linda Lundin and Nicolas Dauman, “The Experience of Tinnitus and Its Interaction with Unique Life Histories–Life Events, Trauma and Inner Resources Narrated by Patients with Tinnitus,” *Frontiers in Psychiatry* 11, no. 136 (2020): 8, doi: 10.3389/fpsy.2020.00136.

valued, validating the contribution of a researcher's experiences and observations. I recognize my subjectivity and use it to communicate personal experience while understanding that my experience is nested within significant cultural and social discourses.

Personal Experience with Tinnitus

I suffer from bilateral chronic subjective tinnitus. There are permanent sounds I perceive within both of my ears which anyone other than myself is unable to hear. The sound cannot be paused, I cannot turn down the volume, I cannot alter the tones. For over ten years, there has been no break and I have no control over this aspect of my body. Significant affect has resulted in my day-to-day life, for instance; I have developed hyperacusis, a sensitivity to high pitch sounds which can cause physical pain; exposure to loud environments causes aggravation, which means the sounds I perceive become temporarily louder resulting in mental unease. Quiet environments are unbearable as all I can hear is the sound. Furthermore, I no longer experience silence, causing irritation and frustration when attempting to focus, read, study, and sleep.

My experience with tinnitus began when I was eighteen, I am now twenty-eight. The cause of its onset could have been head trauma, repeated acoustic trauma, having many ear infections in my childhood, flying with ear infections, any combination of these experiences or none at all. When I was diagnosed the cause was not confirmed. I was initially diagnosed by my family doctor and then again by an Ear Nose and Throat (ENT) specialist. I was also screened by an audiologist to check for hearing loss, my hearing is fine. Following my diagnosis both doctors told me that I was "going to have to get used to it," with no acknowledgement of the possibility that tinnitus could reduce my quality of life and result in experiences of disability. I was never told about tinnitus community support groups, that there were millions of others who also suffered (I still know very few). I thought I was on my own, isolated and left in a state of heightened anxiety and depression.

Over the years, I have learned to live with tinnitus, incorporating it into how I navigate day-to-day experiences. I avoid loud environments, including refusing invitations to social events because I know they will be too loud. I constantly try to control my sound environment. I mask my tinnitus by wearing over-ear headphones playing music at a low volume when I work and travel. I fall asleep to rerun television shows or stand-up comedy every night (anything that does not draw attention, really). I will also leave places if sound becomes an issue. There are instances where sound cannot be controlled, and I must figure out how the experience will interact with my tinnitus. My sensitivity to certain sounds can be unpredictable, anything from a dog's squeak toy to an ambulance's wailing siren can cause inner ear pain.

In this thesis, I do not look to compare my experiences with other tinnitus sufferers. Instead, I document my experience. Tinnitus experiences are subjective, and I am unable to say whether my condition is worse or better than that of another sufferer. I visualize my experiences and do not speak for any sufferers other than myself.

Tinnitus Experiences

The enigmatic nature of tinnitus as a subjective, non-visual affliction is central to my investigation of how graphic design can be employed to visualize non-visual phenomenon. Much of the current literature on tinnitus places a heavy focus on treatment, diagnosis, and neurological issues as recognized by a researcher perspective.⁹ This focus tends to seek more objective findings which can be generalized and hardly acknowledges the experiential specificities which vary from sufferer to sufferer, under-investigating the subjectivity of experience from the sufferer's perspective.¹⁰ A recent break in this literature switches focus

⁹ Erlandsson, Lundin and Dauman, 8.

¹⁰ Emilia M. G. Colagrosso, et al., "A Qualitative Study on Factors Modulating Tinnitus Experience," *Ear and Hearing* 40, no. 3 (2019): 636, doi: 10.1097/AUD.0000000000000642.

to collect qualitative data about lived contextual tinnitus experiences from sufferer perspectives. It recognizes that tinnitus is an individualized phenomenon, and as such comparative analyses does not yield useful data; the only way to learn of its experiential affect is to investigate individual sufferer experiences. Colagrosso, et al. affirm this sentiment saying,

*“it is well recognized that tinnitus experience is subjective in nature, which makes it an ideal topic for qualitative research. [...] Individuals who live with their tinnitus daily can provide valuable information, as their experiences and perceptions can help confirm, inform, or inspire models to better understand and conduct research related to tinnitus.”*¹¹

The research investigating tinnitus from sufferers’ perspectives looks to reveal how tinnitus affect’s a sufferer’s life, with less focus on traits of the sound perceived. Therefore, the experience I embody as a sufferer is key to the tinnitus research agenda.

Tinnitus inserts itself into the sufferer’s identity, becomes inseparable in a way that can have detrimental consequences to the self and participation.¹² Tinnitus affects self-understanding, which can place the body in a perpetual state of internal struggle, and result in a detrimental attitude towards self-image and self-worth.¹³ The invisibility of tinnitus is problematic, potentially leading to a lack of interest and understanding from non-sufferers because there is an absence of visible evidence.¹⁴ Furthermore, within the community of tinnitus sufferers, comparing personal experience can result in self-blame or dismay if others have it worse.¹⁵ Tinnitus becoming part of a sufferer’s identity results in a need for self-evaluation to recognize factors that can contribute to how tinnitus participates in navigating experiences.

¹¹ Colagrosso, et al., 644.

¹² Gerhard Andersson and Emma Edvinsson, “Mixed Feelings about Living with Tinnitus: A Qualitative Study,” *Audiological Medicine* 6, (2008): 50, doi: 10.1080/16513860801899355.

¹³ Andersson and Edvinsson, 52.

¹⁴ Andersson and Edvinsson, 52.

¹⁵ Andersson and Edvinsson, 52.

Colagrosso, et al. have investigated “how individual-specific factors and environmental factors modulate the conscious perception of tinnitus.”¹⁶ Their criterion for analysis begins with *appraisal*, referring to the subjective aural tinnitus sensation. They found a dissociation between sensation and perceptive reaction and employed the term “tinnitus experience ... [as an] all-encompassing term, [to describe] both tinnitus sensation and reaction to it.”¹⁷ The modulation of tinnitus experience can then be evaluated based on *environmental* and *individual specific* factors. Environmental factors include sufferer reaction to soundscape, perception of surrounding noise or lack thereof, and other environmental factors which can include variables like weather and atmospheric pressure. Individual specific factors look at how tinnitus experience is modulated by attentional focus, stress level, physical state, fatigue, and auditory effort. Identifying modulators then leads to evaluating consequences of tinnitus experience. Detriments include distraction, disrupted mental health and mood, headaches, fatigue, sleep disturbances, hearing difficulties, disrupted social life and frustration. There are modulators internal and external to the body which are capable of influencing tinnitus experience, these detriments are capable of inducing disablement in tinnitus sufferers.

Implications of frustration in particular has been used to frame an investigation of variability in tinnitus induced disablement. Dauman et al. define tinnitus frustration as “the subjective experience of being unable to change a situation or to fulfill one’s desire,”¹⁸ as stemming from three identified sources, *losing body ownership*, *lacking perspectives*, and *persevering through difficulties*. Losing body ownership refers to tinnitus affect interfering with sufferer activity and lifestyle. This is further contextualized in subcategories as feelings of *being invaded by an inescapable noise* and acts of *holding onto a fragile body*.¹⁹ Lacking perspectives addresses tinnitus as enigmatic. Sufferers who seek to understand more about their tinnitus’

¹⁶ Colagrosso, et al., 643.

¹⁷ Colagrosso, et al., 639.

¹⁸ Nicolas Dauman, et al., “Exploring Tinnitus-Induced Disablement by Persistent Frustration in Aging Individuals: A Grounded Theory Study,” *Frontiers in Aging Neuroscience* 9, no. 272 (2017): 6, doi: 10.3389/fnagi.2017.00272.

¹⁹ Dauman, et al., 7-10.

cause or connotations are left unsatisfied. With no cure available and little medical assistance beyond a diagnosis they are often left to self-manage.²⁰ Persevering through difficulties then affects social and personal relations and ability to participate in corresponding activities. The three categories are informed by frustration as a modulator of tinnitus induced disablement which can reduce a sufferer's quality of life.

Tinnitus-affect invades a sufferer's self-identity and experiences to the extent of disability. The sufferer needs to know factors that modulate their tinnitus-affect to inform personal management, a crucial aspect of maintaining quality of life. The subjectivity of tinnitus affect can be difficult to decipher, but research suggests that an effective means of self-management is to learn about the experiences of other sufferers. Erlandsson, Lundin and Dauman investigate sufferer experiences of living with tinnitus articulated through self-narratives to evaluate quality of life. The self-narratives could be identified as being *progressive, regressive, or stable*.²¹ Narrative *tones* arise which indicate the "overall valence of the narratives, described as how agency is posited toward events that are narrated and challenging to the participants."²² The tones could be described as *pessimistic, optimistic, or objective*. Furthermore, narratives are thematically contextualized using descriptors of being a struggle, competent, empathetic, sad, or proud. This narrative approach helps to situate how tinnitus participates in subjective experiences to reveal enigmatic complexities of tinnitus. For Erlandsson, Lundin and Dauman "a narrative perspective on tinnitus enlightens its potential impact on the sense of self, life orientation and experienced time, that are seldom addressed in the literature."²³ This argues for the value of more narratives of tinnitus experience, a visible manifestation of tinnitus sufferer experience in narratives can reveal subjective knowledge of tinnitus, which can be useful for other sufferers and those researching tinnitus.

²⁰ Dauman, et al., 10-11.

²¹ Erlandsson, Lundin and Dauman, 5.

²² Erlandsson, Lundin and Dauman, 5.

²³ Erlandsson, Lundin and Dauman, 10.

Making visible subjective knowledge about tinnitus experiences is a necessary component in qualitative studies of tinnitus. Sharing knowledge builds community, informs other sufferer experience, and contributes to tinnitus research. Informing sufferers of causes, effects, management options, community, and service/treatment options can work therapeutically to improve a sufferer's quality of life, inspiring confidence in being able to manage their tinnitus. Adams et al. investigate how sharing tinnitus knowledge is beneficial for sufferers, using two main themes to contextualize the learning experiences: *if you can't cure me, I'll cope* and *empowerment through information and education*. If you can't cure me, I'll cope "highlights the predicament of current audiological/medical management for those with tinnitus: the absence of a cure."²⁴ Empowerment through information and education "highlights the benefits gained from ensuring people understand more about their condition and the clinically proven management options available."²⁵ Information about tinnitus and the experiences of tinnitus sufferers therein can work therapeutically to alleviate concerns about living with tinnitus and inform personal management. In the study of tinnitus, it is of utmost importance that experiences are shared to inform sufferer community, tinnitus-related experiences, and tinnitus related information.

Sharing knowledge with, and educating tinnitus sufferers about experiential affect participates in how "the way people think about their tinnitus impacts on their perception of it."²⁶ Pryce and Chilvers thematically explore tinnitus perception articulated as *losing silence, gaining acceptance*. Their definition of *sense-making* is a core evaluation category which refers to a rationalization process that helps the sufferer gain an understanding of tinnitus affect. If sense-making is directed toward acceptance then negative responses can be alleviated, if sense-making is directed toward ridding the self of tinnitus then the result is distress.²⁷

²⁴ Jennie Adams, et al., "Adults' Perception of their Tinnitus and a Tinnitus Information Service," *The Australian and New Zealand Journal of Audiology* 32, no. 2 (2010): 91.

²⁵ Adams, et al., 91.

²⁶ Helen Pryce and Katie Chilvers, "Losing Silence, Gaining Acceptance: A Qualitative Exploration of the Role of Thoughts in Adult Patients with Subjective Tinnitus," *International Journal of Audiology* 57, no. 11, (2018): 806, doi: 10.1080/14992027.2018.1500041.

²⁷ Pryce and Chilvers, 806.

Acceptance of tinnitus as a chronic condition is an ongoing process continuously rationalized by the sufferer through sense-making, with the beneficial outcome of alleviating instances of negative tinnitus affect which can reduce the sufferer's quality of life. Acquiring knowledge of tinnitus experiences, and using this knowledge to manage subjective cognitive responses to it, can inform perception and rationalization with beneficial outcomes of acceptance to better quality of life. This process is informed by internal and external knowledge, being able to identify, compare, and learn from experiences to make sense of enigmatic tinnitus affect. There is no cure, experiential knowledge of affect and management can promote acceptance and improve the sufferer's quality of life.

The aforementioned qualitative investigations into tinnitus experiences stem from audiology²⁸ and psychology,²⁹ a correlation is found where all designate the tinnitus sufferer as the only valid and reliable source of experiential tinnitus knowledge. There is no universality in tinnitus experiential data; every sufferer perspective is unique and of value for study. Unique sufferer perspectives are acknowledged and integrated in the research methods, which consist of semi-structured interviews and journaling.³⁰ The recollection, personal documentation, and expression of tinnitus experience from the sufferer perspective is proven in these studies as successful toward collecting rich data. The emphasis on investigating individualized experiences articulated from the sufferer perspective, and this being acknowledged as a valid and reliable source of data, situates autoethnography as the precise data collection method suitable for my thesis research. To my knowledge, none of researchers in the aforementioned studies self-identify as tinnitus sufferers. In my research, the researcher and tinnitus sufferer are one.

²⁸ Andersson and Edvinsson; Colagrosso, et al.; Adams, et al.; Pryce and Chilvers.

²⁹ Dauman, et al.; Erlandsson, Lundin and Dauman.

³⁰ Andersson and Edvinsson; Colagrosso, et al.; Adams, et al.; Pryce and Chilvers; Dauman, et al.; Erlandsson, Lundin and Dauman.

Investigating the Self

Experiences of tinnitus affect have been, and continue to be, under investigated. Studies using qualitative data collection methods to investigate sufferer experiences of tinnitus-affect identify the tinnitus sufferer as the only reliable and valid repertoire of knowledge for this research. Given this, my hybrid researcher-sufferer status offers an ideal vantage point for my inquiry, and validates the use of an autoethnographic method.

Autoethnography is a qualitative data collection method which integrates “the *self* (auto), *culture* (ethno), and *writing* (graphy)”³¹ to investigate subjective experiences from within cultures. The researcher is central to the data collection and the production of new knowledge that is the outcome of cultural activity, documentation of experience, and analysis.³² Through this process, insider experiences are made accessible to be interpreted, compared, and contrasted with other insider and outsider experiences.³³ Ellis et al. continue in this thought, stating

*“the autoethnographer not only tries to make personal experience meaningful and cultural experience engaging, but also, by producing accessible texts, she or he may be able to reach wider and more diverse mass audiences that traditional research usually disregards, a move that can make personal and social change possible for more people.”*³⁴

Autoethnographic research facilitates accessibility to insider knowledge of cultural experience, knowledge that can then be made visible and understandable to outsiders, and provide an accessible alternative viewpoint for other insiders.

³¹ Tony E. Adams, Stacy Holman Jones and Carolyn Ellis, “Doing Autoethnography,” in *Autoethnography* (New York, NY: Oxford University Press, 2015), 46.

³² Adams, Jones and Ellis, 46; Carolyn Ellis, Tony E. Adams and Arthur P. Bochner, “Autoethnography: An Overview,” *Historical Social Research / Historische Sozialforschung* 36, no. 4 (2011): 273-274.

³³ Adams, Jones and Ellis, 49; Ellis, Adams and Bochner, 276.

³⁴ Ellis, Adams and Bochner, 276.

The validity of autoethnography as a reputable research method correlates with the 1980's emergence of postmodernism, ideas of objectivity and universality of knowledge fell under critique and research practices such as ethnography were reevaluated as a means that allowed other, marginalized voices to be heard.³⁵ Autoethnography as a response "acknowledges and accommodates subjectivity, emotionality, and the researcher's influence on research, rather than hiding from these matters or assuming they don't exist."³⁶ Neutrality and objectivity in the research process were recognized as hardly achievable, the self cannot be considered separate from the research.

Duncan describes autoethnography as an introspective research methodology, the basis for which is summed up very succinctly as a need to "externalize inner dialogue."³⁷ Duncan distinguishes between ethnography and autoethnography, by identifying ethnographers as *outsiders* looking to seek knowledge of *insiders*, and autoethnographers as *insiders* who seek *insider* knowledge. She explains further:

*"the essential difference between ethnography and autoethnography is that in an autoethnography, the researcher is not trying to become an insider in the research setting. He or she, in fact, is the insider. The context is his or her own. Through autoethnography, those marginalized individuals who might typically have been the exotic subject of more traditional ethnographies have the chance to tell their own stories."*³⁸

The insider is able to narrate idiosyncratic personal experiences which may have been excluded from outsider or other insider perspectives. Discernment between the two methods is continued in the context of reality, how realities are not objectively fixed, that perceptions and meanings are in a state of responsive fluctuation according to subjective experience

³⁵ Ellis, Adams and Bochner, 273-274.

³⁶ Ellis, Adams and Bochner, 274.

³⁷ Margot Duncan, "Autoethnography: Critical Appreciation of an Emerging Art," *International Journal of Qualitative Methods* 3, no. 4 (2004): 29.

³⁸ Duncan, 30.

and external variable factors.³⁹ Personal voice is able to provide a subjective viewpoint that recognizes this variability and annotate how experience influences the individual. Personal experience is then able to be contextualized, supported and confirmed by external resources, opening data and outcomes to a process of compare and contrast with existing knowledge.

To contextualize autoethnography as a process-oriented methodology appropriate for design research, Munro interprets the suffix 'graphy' to include, "any process that commits idea to form."⁴⁰ Munro contextualizes this definition in the design process, where the designer (auto) is central to creative projects and, through a messy and non-linear process, is a vessel for research creation and output. She draws on Sawyer's proposition that decision-making involved in creation engages three dynamic processes.⁴¹ The first, *cultural idiosyncrasy* describes designer agency (a combination of professional practice, personal experience, and education) as inseparably influencing their process. This process is also influenced by, but not limited, *gatekeepers* (experts in the field), who establish paradigms of what and how projects are accepted into cultural discourses. The designer uses their cultural idiosyncrasy to participate in and shape culture while culture simultaneously shapes the designer, in this interactive and reflexive process the documentation of experience informs knowledge formulation.⁴² This knowledge can then be *triangulated*, compared with and contextualized against existing knowledge to reveal potential innovation. Munro identifies journaling as an ideal documentation method because it produces a narrative that establishes experiences emerge over time, an accumulation of raw data.⁴³ Journaled data can reveal new knowledge that

³⁹ Duncan, 30.

⁴⁰ Allan J. Munro, "Autoethnography as a Research Method in Design Research at Universities," in *Sixth International DEFSA Conference Proceedings*, (Design Education Forum of South Africa, 2011), 157.

⁴¹ Munro, 157-158.

⁴² Munro, 158-159.

⁴³ Munro, 162.

*“might fall into any one (or more) of the three cultures enumerated. It might be, for example, that the designer discovers something about himself or herself (a style flaw or strength, a clinging to a dominant approach and so on, for example); it may be that the new knowledge delivers new insights into design strategies, methods, processes or technologies, or it might be that the new knowledge engages critically with the established parameters of critique, questioning validity or certainties, for example.”*⁴⁴

A researcher using the autoethnographic method acknowledges their centrality by showing rigor in personal documentation, and through a rich collection of experience, analysis, and comparison the autoethnographic method validates new knowledge.

Bochner and Ellis propose the opportunity for artistic process and outcomes to function as a transgressive form of narrative inquiry, citing autoethnography as the appropriate informative method. Artist subjectivity works as a ground for research and, by utilizing the first-person voice, lived cultural experiences can be revealed in the form of narratives. Bochner and Ellis state,

*“our goal has been to produce stories that create the effect of reality, showing characters embedded in the complexities of lived moments of struggle, resisting the intrusions of chaos, disconnection, fragmentation, marginalization, and incoherence, trying to preserve or restore the continuity and coherence of life’s unity in the face of unexpected blows of fate that call one’s meanings and values into question.”*⁴⁵

Autoethnography is capable of bringing a visibility to the lived experiences of marginalized groups through narratives that communicate idiosyncratic insider knowledge. Here, subjective knowledge is recognized, represented in process and production, and

⁴⁴ Munro, 162.

⁴⁵ Arthur P. Bochner and Carolyn Ellis, “An Introduction to the Arts and Narrative Research: Art as Inquiry,” *Qualitative Inquiry* 9, no. 4 (2003): 509, doi: 10.1177/1077800403254394.

verified through readers' ability "to understand, feel, and grapple with the experiences being expressed."⁴⁶

The individualized and introspective method of autoethnography acknowledges my subjectivity as a hybrid researcher-tinnitus sufferer, functioning as the precise approach to informing my research of tinnitus experiences. Studies of tinnitus experience have generally employed grounded theoretical models to categorize findings and seek correlations of experience. My autoethnographic process employs journaling to document experiences of tinnitus affect. I then translate this data into knowledge through making, and design. I use my data to inform design processes and outcomes which visualize experiences of tinnitus.

Knowledge in Processes & Outcomes

In the context of design research, Meyer and Dykes define knowledge as "something a design study researcher comes to know through an inquiry."⁴⁷ To accomplish the goal of my thesis project—visualizing experiences of tinnitus—I employ research-through-design (RtD) to interpret my autoethnographic data and inform the processes and outcomes which shape the articulation of visual experience.

Meyer and Dykes identify criteria for rigor in visualization required to construct knowledge through design. An interpretivist perspective is proposed to frame how the researcher views the acquisition of knowledge. Recognizing that knowledge is "socially constructed—rather than objectively determined—[an interpretivist approach uses] methods such as dialogical approaches that are spoken, written, and interpreted. Subjectivity is embraced and considered shorthand for the construction of knowledge through

⁴⁶ Bochner and Ellis, 509.

⁴⁷ Miriah Meyer and Jason Dykes, "Criteria for Rigor in Visualization Design Study," *IEEE Transactions on Visualization and Computer Graphics* 26, no. 1 (2020): 90.

interpretation.”⁴⁸ The researcher is active in their process, participating in contextual environments of study as opposed to seeking neutrality. This is referred to as action research: the researcher needs to create and make, recognizing that learning occurs in these processes, active participation informs approaches in design in design research such as RtD.⁴⁹ In the processes of creation, it is important to continuously work in conjunction with domain expertise and existing knowledge to inform processes and outcomes, which in turn manifest as meaningful, insightful documents and artefacts encoded with created knowledge.⁵⁰ In these processes the researcher embraces reflexivity to identify how their subjectivity influences their work. Reflexivity is achieved through “observation, reflection, note-taking, discussions with colleagues and participants, and open, authentic accounts in reporting. Autoethnography is a specific approach that applies reflexive investigation to self-observation.”⁵¹ In the context of my research, my subjectivity and accounts of tinnitus experience illuminate the processes of making and creation which are also informed by domain expertise in the development of visual knowledge.

The discussion of visual knowledge production is expanded by Chapman and Sawchuk who outline creation-as-research (CaR) as a non-linear productive and academic form of *action research* which validates knowledge as revealed through making processes and critical reflection. This is often a cross disciplinary act: research is thus something you do and something that is. The term “critical making is used to reference the reflexive, critical potential of scholarly work that results in self-consciously ‘made’ outcomes.”⁵² Making here is a term which describes how knowledge is generated and collected in active processes of creation and through creation unexpected and unknowable outcomes can emerge.⁵³

⁴⁸ Meyer and Dykes, 88.

⁴⁹ Meyer and Dykes, 88.

⁵⁰ Meyer and Dykes, 89 & 91.

⁵¹ Meyer and Dykes, 91.

⁵² Owen Chapman and Kim Sawchuk, “Creation-as-Research: Critical Making in Complex Environments,” *RCAR Revue d’Art Canadienne Canadian Art Review* 40, no. 1 (2015): 50, doi: 10.7202/1032753ar.

⁵³ Chapman and Sawchuk, 50.

Making becomes crucial to revealing potential in how the non-visual can manifest as visual, exploratory creation is the only way to find opportunity.

To further locate active research methods in the discourse of design, CaR can be considered as a form of RtD. RtD recognizes the role of the maker and researcher as the designer. This role is contextualized by Frayling as research through art and design, which signifies a practice where materials research, developmental work, and action research unify in a paradoxical process where “the brain controls the hand which informs the brain,”⁵⁴ practice and research are one in the same process. This is further contextualized by Frayling as, “how can I tell what I think till I see what I make and do”⁵⁵ implying that thought occurs in the process of creation and in turn influences the original thought which dawned the initial process of creation. Process and thought inform one another, as articulated somewhat ambiguously by Frayling.

Frankel and Racine continue in the same vein as Frayling, replacing the term “art,” to describe research-through-design as an *applied* method of design research. Applied in this context refers to investigating design problems within nested discourses that can be appropriated for various instances of the broader parent discourse.⁵⁶ Employing these strategies of research-through-making, my thesis uses visualization to bring tinnitus into view, making an invisible disability visible and therefore comprehensible. RtD supports an idiosyncratic focus as long as it is understood as participating in knowledge creation in broader contexts, to emphasize the formulation of design knowledge found in processes which could be appropriated for other uses, and not placing all value on a final design artefact. Frankel and Racine also reference Snyder in saying, “research through design may combine the practice-based research approach of practitioners with reflection and a research

⁵⁴ Christopher Frayling, “Research in Art and Design,” *Royal College of Art Research Papers* 1, no. 1 (1993): 4-5.

⁵⁵ Frayling, 5.

⁵⁶ Lois Frankel and Martin Racine, “The Complex Field of Research: For Design, Through Design and About Design,” (*International Conference of the Design Research Society*, 2010), 4.

question that ‘is not restricted to the product on which research is being conducted.’”⁵⁷ It is the process, knowledge developed through doing, and knowledge that is produced in outcomes that is of value in this research methodology, not any single outcome.

I employ an interpretivist RtD approach in my processes of making and reflection, I am able to reveal subjective knowledge about visualizing tinnitus experiences. When conducting research on visualizations of tinnitus and tinnitus experiences I found very little. I see opportunity in this absence of representation; an open space to employ RtD, exploring how tinnitus experience could be visualized.

My autoethnographic documentation of non-visual tinnitus experiences provides the data for visualization. Visualization is a form of storytelling⁵⁸ I employ to develop visual narratives. An exploratory RtD process of reflexive material exploration initiates my visualization process. RtD allows me to explore how my experiences can be made visible and legible via materiality. The autoethnographic data and materials are then integrated to formulate a narrative which is communicated through a book. This design artefact becomes a legible representation of a personal tinnitus experience. I reflect on the processes and outcomes to evaluate how they participate in cultural and material contexts. The reflection informs how I replicate the process in order to visualize another tinnitus experience. My thesis design outcomes consist of RtD processes and three books as design artefacts which are representative of my tinnitus experiences.

⁵⁷ Frankel and Racine, 6.

⁵⁸ Rosemary Lucy Hill, “What is at Stake in Data Visualization? A Feminist Critique of the Rhetorical Power of Data Visualizations in the Media,” in *Data Visualization in Society*, eds. Martin Engeström and Helen Kennedy (Amsterdam: Amsterdam University Press, 2020), 391, doi: 10.5117/9789463722902_ch23.

Making the Invisible Legible

The invisibility of tinnitus and its debilitating effects prompted my research in disability studies, specifically into how visibility acts to make disabilities legible. Tinnitus as a non-visible disability suffers from a lack of legibility which leads to misunderstanding and/or lack of recognition. Visuality also problematizes disability due to its participation in shaping public understanding. Although the field of disability studies has greatly expanded in recent years to better account for experiences of disability, the issue of how representation informs understanding remains.

Mack Hagood uses tinnitus as a case study of *biomediation* which he describes as the interplay between disability and media technologies, articulating how they so often constitute one another and have the opportunity to afford legibility, visibility, and audibility.⁵⁹ Hagood problematizes the representation of disability as having an expected or implied pre-existing visibility or legibility, which shapes cultural and public discourses, leaving non-visible disabilities, like tinnitus, absent. He states,

*“people who suffer from tinnitus frequently report that doctors tell them to go home and ‘learn to live with it,’ while providing no advice on how to do so. In such moments, people suffer from the illegibility of impairment—the fact that the bodily phenomena they contend with have not been mediated into a clearly recognizable ‘object’ of understanding and treatment.”*⁶⁰

Illegibility in this context refers to the fact that medical professionals cannot identify a physiological cure for tinnitus, as well to the correlation between the invisibility of tinnitus and the lack of recognition by those not afflicted. Illegibility of impairment is a concept which encapsulates how non-visual disabilities lack legibility due to lack of tangible or

⁵⁹ Mack Hagood, “Disability and Biomediation: Tinnitus as a Phantom Disability,” in *Disability Media Studies*, eds. Elizabeth Ellcessor and Bill Kirkpatrick (New York, NY: NYU Press, 2017), 326.

⁶⁰ Hagood, 316.

visual evidence, and that cultural and public understandings of disability are continuously shaped by how visibility correlates with legibility. With visibility playing a crucial role in understandings of disability, representation of non-visual disabilities permits their recognition and acknowledgment in public and cultural discourses.

Davis and Smith support the notion that understanding of disability is shaped by the visual, stating “‘disability’ and ‘visuality’ so often constitute one another [...] visuality is both determined by and determining of our understanding of disability.”⁶¹ In the context of non-visual disabilities, this builds on Hagood’s problematization of how the power of the visual in discourses of disability can shape understanding and representation (or lack thereof). It is embedded in public and cultural discourses that the visual can constitute understanding, absence of visual representation is problematic as it leads to illegibility.

When disability reaches representation, other problems can arise. Fraser conducts a semiotic analysis of (primarily cognitive) disability as represented in prose literature and visual narratives to “investigate the seam between the material and immaterial forces that impact disability representations,”⁶² arguing that the mind and body unify as biologically material, they are not separate and should be treated equally in the study of disability. The ‘seam’ is a metaphor employed by Fraser, adopted from Mark Jeffrey’s writing *The Visible Cripple*, to refer to where the body joins culture.⁶³ Fraser’s analysis is further framed using Mitchell and Snyder’s notion of disability as a product of an ableist society determined by the constructed binary of able/disabled, which relies heavily on visible bodily characteristics.⁶⁴ Representation of disability in prose typically relies on its contrast with a ‘normal’ and able-body, a culturally agreed upon understanding of the able/disabled binary. Stereotypical visual characteristics associated with disability can then be employed by writers to

⁶¹ Lennard J. Davis and Marquard Smith, “Disability–Visuality,” *Journal of Visual Culture* 5, no. 2 (2006): 132, doi: 10.1177/1470412906068869.

⁶² Benjamin Fraser, “Disability Scholarship at the Seam: The Materiality of Visual Narrative,” in *Cognitive Disability Aesthetics: Visual Culture, Disability Representations, and the (In)Visibility of Cognitive Difference* (Toronto, ON: University of Toronto Press, 2018), 74.

⁶³ Fraser, 75.

⁶⁴ Fraser, 76.

represent bodies in opposition which will be understood by a reader. In the reader-text interaction, the writer and reader both rely on cultural and societal understandings of disabled representations to make meaning. When this representation is presented in visual narratives there is imagery to support text. This somewhat relieves the reader of conjuring meaning based on descriptive stereotypes, the visual cues work to establish the able/disabled separation. The term *icon redundancy* is used to describe this phenomenon as the repeated use of text and image to continuously reactivate and contextualize meaning as the narrative progresses.⁶⁵ In turn, representation raises questions: *how* disability is represented, *how* representations of disability shape understandings of disability, *who* is representing disability, and are representations verifiable?

The representation of disability has an extensive history and has prompted many debates about what disability represents, how disability is represented, what it means to represent disability, ethics of who can represent disability, and who/what is represented/absent; many of which are beyond the scope of my thesis. I will therefore focus on a few key points which I find directly relevant to the context of my research, specifically self-representation. I agree with Bérubé's notion that self-representation of disability in the arts: "arises partly from the conviction that traditional forms of artistic representation of disability, and people with disabilities, have led to severe misunderstandings of disability as well as literally and allegorically demeaning depictions of people with disabilities."⁶⁶ The misrepresentation of disability can result in stigmatization and communication of inaccurate realities which then contribute to shaping public perceptions. Self-representation validates the experience of the disabled self as an expert of their disability, capable of communicating a true and accurate representation, thus limiting stigmatization.⁶⁷

⁶⁵ Fraser, 87.

⁶⁶ Michael Bérubé, "Representation," in *Keywords for Disability Studies* eds. Rachel Adams, Benjamin Reiss, and David Serlin (New York, NY: New York University Press, 2015), 153.

⁶⁷ Bérubé, 153-154.

Costanza-Chock discusses the self-representation of disability in the broader context of *design justice*, as “a framework [and community] for analysis of how design distributes benefits and burdens between various groups of people.”⁶⁸ They also employ a conceptual model called the *matrix of domination* which “helps us think about how [interlocking systems of] power, oppression, resistance, privilege, penalties, benefits, and harms are systematically distributed.”⁶⁹ An argument for those who inhabit disabled bodies as experts on their disabilities is prefaced with a critique of *user personas* employed in design processes. User personas are fictional identities developed during a design process used as a tool to speculate potential use cases of a design. User personas are useful to characterize potential users and initiate design decisions but can be detrimental when they fail to account for the creator’s location in the matrix of domination.⁷⁰ Costanza-Chock problematizes one body representing another, personal agency can inform biases and assumptions concerning how experiences are navigated. One’s understanding of another can also be based on objective and stereotypical factors that do not acknowledge the complexity of the body being represented, this is especially of concern when representing marginalized or oppressed communities.⁷¹ In the context of user personas, developing a fictional user where there is truly no body represented at all, can lead to discriminatory design decisions affecting real world users.

Costanza-Chock problematizes representation as a form of *disability simulation*. In disability simulation, an able-body pretends to have a disability in order to understand how a disabled person might use a particular design. This, they point out, is an ableist approach which does not credit experiential knowledge that can only be gained by living with a disability. The result is an able-bodied interpretation of what a disabled body needs/desires from the design.⁷² Costanza-Chock quotes Wittkower to reject disability simulation

⁶⁸ Sasha Costanza-Chock, *Design Justice: Community-led Practices to Build the Worlds We Need*, (Cambridge, MA: The MIT Press, 2020), 23.

⁶⁹ Costanza-Chock, 20.

⁷⁰ Costanza-Chock, 83.

⁷¹ Costanza-Chock, 83.

⁷² Costanza-Chock, 83.

as a solution: “ultimately, attempting to imagine other people’s experience is ‘no substitute for robust engagement with marginalized users and user communities. ... [systematic variation techniques], although worth pursuing, are strongly limited by the difficulty of anticipating and understanding the lived experiences of others.’”⁷³ Beyond engaging with those marginalized, Costanza-Chock supports self-representation in design processes so that valid experiences from various locations in the matrix of domination can contribute to more inclusionary and accountable design. The notion that there is no substitute for lived experiences validates my use of self-representation. My tinnitus is not reproducible, to play another person an audio sample of the sounds I hear in my head would simply be a problematic simulation. Through my years of living with tinnitus I have developed expert knowledge of my disability and in turn I am able to self-represent my experiences, and as Costanza Chock puts it, “experiential knowledge of community members is sure to produce ideas, approaches, and innovations that a non-member of the community would be extremely unlikely to come up with.”⁷⁴

Disability is embedded in human experience, and as Hendren writes, “disability is a common part of human life—an ordinary experience, infinite in variety, replete with creativity and heartbreak, from sources internal and external, and carrying social stakes everywhere.”⁷⁵ Representations of disability in narrative, art, and popular culture contribute to knowledge about these human variations and representations can work against, or for disabled realities. Garland-Thomson discusses several examples of disability including, Claude Monet’s vision loss and Chuck Close’s impaired manual dexterity as experiences of disability being self-integrated into their work. She goes on to critique modernity’s embrace of standardization as contributing to normalizing the able-body. Modernity’s technological and medical advancements led to the body being rationalized in terms of materiality.⁷⁶

⁷³ Costanza-Chock, 84.

⁷⁴ Costanza-Chock, 94.

⁷⁵ Sara Hendren, *What can a Body Do? How We Meet the Built World* (New York, NY: Riverhead Books, 2020), 14.

⁷⁶ Rosemarie Garland-Thomson, “Disability and Representation,” *Modern Language Association* 120, no. 2 (2005): 524.

Williamson and Guffey similarly discuss how medical innovations frame the mentality of understanding disability in terms of the *medical model*.⁷⁷ The medical model of disability describes disabled bodies as ‘curable,’ able to be ‘fixed’ through medical intervention to become a standard and ideal (normal) able-body. Looking at the disabled body as in need of medical intervention leads to marginalization, social exclusion, and unjust representations of disability. Garland-Thomson adopts the word “resymbolization” from Nancy Eiesland to argue that the meanings which have been socially and culturally associated with disability must be altered to bring about social change and progress equality.⁷⁸ Disability representations in narrative, art and popular culture can participate in resymbolization to encourage this process. Garland-Thomson provides further examples to support the argument, I have selected one to discuss which correlates with graphic design. The image of Harriet McBryde Johnson in her wheelchair on the cover of the *New York Times Magazine* overlaid with the text “Should I have been Killed at Birth? The case for my life.” (Fig. 1).⁷⁹ McBryde Johnson’s disability is depicted legibly without exploitation or references to a body need of medical interference. Paired with the text, the cover wants the viewer to question misconceptions of disabled bodies. This visual rhetoric is one of power and validity, working against medical solutions for disabled bodies being unable to meet modern ideals.

⁷⁷ Elizabeth Guffey and Beth Williamson, *Making Disability Modern: Design Histories* (1st ed.) (Bloomsbury Visual Arts, 2020), Introduction: Rethinking Design History Through Disability, Rethinking Disability Through Design, Apple Books Ebook.

⁷⁸ Garland-Thomson, “Disability and Representation,” 525.

⁷⁹ Garland-Thomson, “Disability and Representation,” 527.

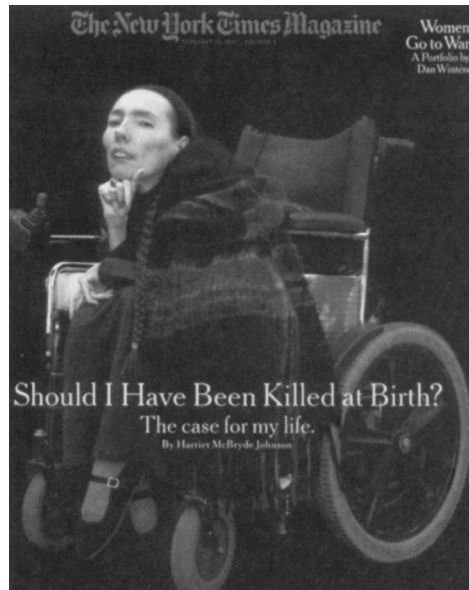


Fig. 1. The New York Times Company, 2003 Cover with Harriet McBryde Johnson.

Rosemary Garland-Thomson, "Disability and Representation," *Modern Language Association* 120, no. 2 (2005): 527, fig. 4, "Copyright © The New York Times Company."

To problematize an instance of disability representation, I consider the International Symbol of Access (ISA) (Fig. 2). To the best of my knowledge, the ISA is the most widely recognizable visual representation of disability, “marking accommodations on a global scale.”⁸⁰ This symbol’s global recognition shapes an understanding of disability as visible, physical, and in need of an assistive device. The ISA presents a hierarchy of accommodation which places the idea of its visually recognizable disability at the forefront and all others (including invisible disabilities) somewhere behind, being considered “less disabled.”⁸¹ This issue of representation has been recognized by disability theorists and taken up as a design activism case study for redesign in the Accessible Icon Project (AIP) (Fig. 3). The AIP is a development which redraws the figure in motion to communicate self-reliance, independence, and progression.⁸² This update alters the view of people with disability as static and inactive, but does it alter the perception of disability as visible and physical? A narrow representation of disability is still present in the graphic and does not participate in

⁸⁰ Elizabeth Guffey, *Designing Disability: Symbols, Space, and Society*, (Bloomsbury Academic, 2017), A Critical Design? (1990-Today), Apple Books Ebook.

⁸¹ Georgina Kleege, “Visuality,” in *Keywords for Disability Studies* eds. Rachel Adams, Benjamin Reiss, and David Serlin (New York, NY: New York University Press, 2015), 153.

⁸² Sara Hendren, “Accessible Icon Project,” accessed August 29, 2020. <https://accessibleicon.org>.

the broader spectrum of what disability can be. Although these representations of disability have achieved widespread recognition and helped with instances of accommodation and access, I believe their limitations still contribute to a lack of representation for those who do not meet the depicted criteria.



Fig. 2. The International Symbol of Access.

Susanne Koefoed, *International Symbol of Access*, 1960, <https://accessibleicon.org>



Fig. 3. The Accessible Icon Project.

Accessible Icon Project, *The Accessible Icon Project*, 2009-2011, <https://accessibleicon.org>

Self-narrated representations of disability comprise Alice Wong's book, *Disability Visibility*. Narratives are expressed from disabled perspectives, bringing a legibility to subjective experiences. For example, June Eric-Udorie's writing, *When You are Waiting to be Healed*, narrates a personal story about acceptance. Eric-Udorie begins by describing how family members encouraged her to pray for a 'fix' to resolve an invisible sight disability onset at birth. She describes their inability to accept her condition as leaving her feeling broken. Medical intervention did nothing beyond a diagnosis and she was advised to register as partially sighted; "[...] I learned that there was something permanently wrong with me. I was not a piece of clockwork waiting to be fixed. I had lost too many pieces and would never be fixed."⁸³ The notion of registering as partially sighted brought about questions of

⁸³ June Eric-Udorie, "When You are Waiting to be Healed," in *Disability Visibility: First-Person Stories from the Twenty-First Century* ed. Alice Wong (New York, NY: Vintage Books, 2020), 55.

authenticity, if she was ‘disabled enough’ or deserved to be disabled, and how registration made her disability permanent. The remainder of the story follows her personal journey to acceptance, looking inward and not relying on others to inform her disabled identity. As she accepts her disability, a fix is no longer sought, and acceptance leads her to understanding her disability as a unique component of her whole being. Acceptance is also a component of coping with tinnitus, and can contribute to improving the sufferer’s quality of life. In acceptance, the sufferer achieves a state of mind which is not dominated by negative implications,⁸⁴ just like Eric-Udorie.

Another narrative of interest is written by Liz Moore, titled, *I’m Tired of Chasing a Cure*.⁸⁵ Moore describes her journey of spiritual/religious healing, crystal healing, and medical/prescription drug intervention, all pursued in effort to cure non-visible debilitating chronic pain. Moore’s narrative provides a view of how a ‘cure-finding’ mentality led to medication abuse, which worsened her health and quality of living. Chasing a cure put her life in danger and forced her to manage comorbidities which arose from drug intervention. Over time she was able to recover and revert to managing only her chronic pain, accepting her chronic pain, but maintaining that if a proper cure were to emerge, she would take it. Moore concludes by discussing how neither doctors, family, or friends could understand her disability, she is the only one who can fully understand her experiences. Moore’s outlook on chronic pain coincides with my own towards tinnitus: if successful cures became available, we would use them. Both Moore and I focus on acceptance while remaining open towards a cure. This conflicts with the popular *social model* of disability. In the social model, “it’s the interaction between the conditions of the body and the shapes of the world that makes disability into a lived experience, and therefore a matter not only for individuals but also for societies.”⁸⁶ This model is a response to the medical model which sees the disabled body as

⁸⁴ Pryce and Chilvers, 805-806.

⁸⁵ Liz Moore, “I’m Tired of Chasing a Cure,” in *Disability Visibility: First-Person Stories from the Twenty-First Century* ed. Alice Wong (New York, NY: Vintage Books, 2020), 75.

⁸⁶ Hendren, *What can a Body Do? How We Meet the Built World*, 15.

needing a ‘cure’ to meet normative ideals of the able-body. The social model problematizes experiences of disability as instances of inaccessibility and lack of accommodation in society, liberating the body from being a cause of disability. In response to the social model, Moore states, “some disabled people may want a cure. Particularly with matters like chronic pain/chronic illness, a cure is seen as something that can itself be liberating: a way to simply be in one’s body without feeling pain, for example.”⁸⁷ Moore and I both manage the internal discomfort of our bodies as experiences where societal change is not as desired as a cure.

The first-person narratives collected in Wong’s *Disability Visibility* value the authors’ experiences of disability. Reading the narratives, I found that the authors spend very little time describing their disability and heavily focus instead on how disability correlates with lived experiences. Although I do not share the same disabilities as the authors, the events, feelings, and emotions associated with their disabilities speak to my own. A sense of belonging and knowing that I am part of a larger community brings comfort, helps me to accept my tinnitus for what it is, and to experience empathy. *Disability Visibility* restricts itself to written narratives, but visualizations of disability have also been successful in communicating experiences of disability.

Narratives of personal experiences of disability, inaccessibility, and marginalization are also visualized in Graphic Medicine and comics about deafness to evoke empathy in readers. Some of these visual methods include obstructed speech bubbles to visualize difficulty interpreting spoken language, asemic writing communicating incomprehensible speech, and rendering speech outside of speech bubbles to make it difficult to distinguish where it is coming from.⁸⁸ An example of this is Cece Bell’s comic, *El Deafo* (Fig. 4). This comic stems from Bell’s personal experience, depicting a deaf character wearing hearing

⁸⁷ Moore, 75.

⁸⁸ A. David Lewis, “How do Techniques from Comics Narratives of Deafness Create a Sense of Disorientation and Potential Alienation that Reveal the Role of Sound in Graphic Medicine?” accessed August 23, 2020. <https://themiddlespaces.com/2019/04/09/seeing-sounds-part-one>.

assistive devices for the first time.⁸⁹ It visualizes a non-visual experience from the perspective of the person with disability. The devices are uncalibrated and result in the character hearing all sound as an overwhelming background noise, external to a clear and legible thought bubble stemming from their head. This representation is spatial, the z-index of the overwhelming sounds/speech fill the entirety of the comic cell background, bleeding off the edges over which the character and their thought bubble are imposed. The assistive devices work to provide auditory stimulus, but it is overwhelming and incoherent. The comic is an accurate and legible representation of a problematic interaction with hearing assistive devices, allowing readers to empathize with an experience of mechanically assisted hearing.



Fig. 4. Cece Bell's, *El Deafo*, 2014, depicting a character's interaction with an uncalibrated hearing device.

A. David Lewis, "How do Techniques from Comics Narratives of Deafness Create a Sense of Disorientation and Potential Alienation that Reveal the Role of Sound in Graphic Medicine?" <https://themiddlespaces.com/2019/04/09/seeing-sounds-part-one>.

Sclerosis Script (Fig. 5) is a typeface designed by Jason Bailey for *Fuse Magazine* 18: Secrets. Bailey's mother was diagnosed with Multiple Sclerosis (MS) before his birth, making her disability-affect a familiar part of his life.⁹⁰ Bailey translates the experience of his mother's ability to write into this typeface. Bailey writes that for his mother, "one

⁸⁹ Lewis, "How do Techniques from Comics Narratives of Deafness Create a Sense of Disorientation and Potential Alienation that Reveal the Role of Sound in Graphic Medicine?"

⁹⁰ Neville Brody and Jon Wozencroft, *FUSE 1-20 From Invention to Antimatter: Twenty Years of FUSE* (Taschen, 2012), 324.

of the most frustrating aspects of MS is the way in which one's ability to communicate is impaired."⁹¹ The typeface replicates his mother's handwriting, representing typographically the uncontrollable symptoms of MS. This typeface is an example of graphic design which visualizes and communicates a frustrating experience of his mother's MS. Although Bailey is not the person with disability in this instance, I would argue that this is a particular experience of disability that affected Bailey as well. It may be an able-bodied interpretation of a disabled experience, but there is an intimate familiarity among the two actors at play in the representation.

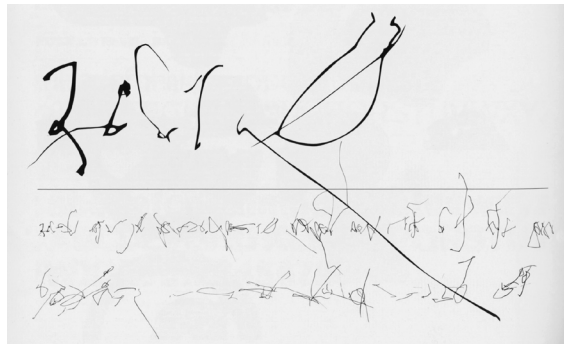


Fig. 5. Jason Bailey's, *Sclerosis Script*, 2000, depicting digital letterforms inspired by his mothers handwriting.

Neville Brody and Jon Wozencroft, *FUSE 1-20 From Invention to Antimatter: Twenty Years of FUSE* (Taschen, 2012), 324.

To enrich an honest and valid discussion about disabled experiences I think it is important that they are represented and expressed from the perspective of those who live with the disability. There is no substitute for the insider knowledge of disability which can only be gained through experience. I employ self-representation in this thesis, speaking for myself while recognizing that my experiences may engage readers empathetically. Is an able-body person's representation of experiences of disability problematic? I think interpreting experiences of disability can easily be informed by stereotypical, objective, and generalized

⁹¹ Brody and Wozencroft, 324.

information. This can lead to unjust representations which inaccurately shape perceptions of disability, harming disability culture. Visualization, be it text or image, plays a central role in bringing a legitimacy to these experiences and there is a need for more of the disabled population to make their experiences accessible to the world. The expert knowledge from experience will communicate disabled realities and contrast misrepresentation.

Visualization

Feminist theory provides a framework for understanding the problems of bodily representation. Historically, the female and disabled body have similarly been socially, culturally, and politically marginalized and bound in unjust representation “in opposition to a norm that is assumed to possess natural physical superiority.”⁹² Garland-Thomson suggests that feminist theory offers disability studies an insightful framework. Both disabled and female bodies

*“challenge existing social relations; both resist interpretations of certain bodily configurations and functioning as deviant; both question the ways that differences are invested with meaning; both examine the enforcement of universalizing norms; both interrogate the politics of appearance; both explore the politics of naming; both forge positive identities.”*⁹³

Disabled and female bodies are culturally sorted as anomalies, universally and objectively categorized with disregard of subjective identity.⁹⁴ Feminist theory’s rejection of universality and essentialism creates a space where experiences of ‘the other’ can be heard and valued.

⁹² Rosemarie Garland-Thomson, “Theorizing Disability,” in *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York, NY: Columbia University Press, 1997), 19.

⁹³ Garland-Thomson, “Theorizing Disability,” 22.

⁹⁴ Garland-Thomson, “Theorizing Disability,” 24.

Garland-Thompson discusses how established feminist theories can be employed as models to theorize the emerging field of disability studies. She explains how dominant groups establish socially constructed norms of acceptable bodies and employ their power to stigmatize those who deviate, reaffirming normativity and inequality.⁹⁵ Representation of disability plays a central role in this construct; it contributes to shaping how disability is understood by the dominant group. Making experiences of disability accessible, visible, and legible can inform dominant group ideals, disassembling the normative construct while recognizing the widespread experiences of disability as a common occurrence. It can disrupt stereotypes and acknowledge the subjectivity of women and people with disabilities.⁹⁶

Garland-Thompson suggests employing feminist standpoint theory to position disabled experiences as subjective in nature. Standpoint theory “recognizes the immediacy and complexity of physical existence. Emphasizing the multiplicity of all women’s identities, histories, and bodies, this theory asserts that individual situations structure the subjectivity from which particular women speak and perceive.”⁹⁷ Standpoint theory translates seamlessly from the female body to the disabled body. Trying to generalize or seek a universal understanding of what it means to have a particular disability can lead to stereotypes and disregard the complexity of individual disabled experiences, separating the disability from the body. Instead, disability should be considered as a subjective experience from a particular body who is a part of a complex matrix of experience. Multiple bodies may share similar disabilities, but this does not mean their embodied experience of the disability are the same. Representations of disability which communicate universality are then problematic for their focus on the disability and disregard for the individual experience. The individual experience is what needs representation to make legible the complexity of disability.

⁹⁵ Garland-Thomson, “Theorizing Disability,” 31.

⁹⁶ Garland-Thomson, “Theorizing Disability,” 24-25.

⁹⁷ Garland-Thomson, “Theorizing Disability,” 24.

Understanding that “representation structures reality,”⁹⁸ my thesis employs a RtD method to visualize representations of my subjective experiences as a tinnitus sufferer. Using an autoethnographic method, I play an active role in data collection, data interpretation, and visualization. My visualizations work as a form of storytelling, and I understand visualizations “work within the narrative frames of their designers and disseminators.”⁹⁹

D’Ignazio argues that the processes and outcomes of visualizations are inevitably tied to the bodies who produce them, and problematizes visualizations which seem to stem from neutral and objective perspectives. This false sense of looking inward from the outside can corrupt data through underlying personal biases of the visualizers and data collectors. Making visible the bodies who participate in visualization processes and outcomes provides context on how they are connected to the world and their data.¹⁰⁰

D’Ignazio and Klein describe how feminism has evolved beyond the initial dialogue of women’s rights and suffrage, “becoming a range of ideas about how identity is constructed, how power is assigned, and how knowledge is generated, as well as how a range of intersectional forces such as race, class, and ability, combine to influence the experience of being in the world.”¹⁰¹ They identify the principles of feminist theory which inform feminist visualization, including those applicable to my research: *embracing pluralism*, *considering context*, and *legitimize embodiment and affect*. Embracing pluralism shares a direct postmodern connection with autoethnography, in that it challenges “objectivity, neutrality and universalism, emphasizing instead how knowledge is always constructed within the context of a specific subject position.”¹⁰² Visualization processes which embrace subjectivity can help express more intimate narratives which are more contextually rich. Considering context emphasizes how situated contexts can play a part in production and reception of a visualization,

⁹⁸ Garland-Thomson, “Theorizing Disability,” 28.

⁹⁹ Hill, 391.

¹⁰⁰ Catherine D’Ignazio, “What Would Feminist Data Visualization Look Like?” accessed August 31, 2020. <https://visionscarto.net/feminist-data-visualization>.

¹⁰¹ Catherine D’Ignazio and Lauren F. Klein, “Feminist Data Visualization,” *MIT Center for Civic Media* 20 (2015): 1.

¹⁰² D’Ignazio and Klein, 2.

the agency of the visualizer influences their processes, and the contextual framing of interpretation for the reader.¹⁰³ This embraces the use of my insider knowledge as a person who suffers from tinnitus as a disability to inform the process and outcomes I employ and produce. Lastly, legitimizing embodiment and affect acknowledges personal experience as a means of knowing and employs subjective knowledge in the processes and outcomes of visualization. My history of, and continued living as, a tinnitus sufferer makes my knowledge of tinnitus affect a legitimate and reliable form of knowing through personal experience which can be employed in visualization.

An idea that D'Ignazio continuously uses when contextualizing a feminist critique of visualization is adopted from Donna Haraway, identified as the *god trick*. A god trick refers to a supposed neutral perspective, an objectivity, or lack of personal agency in visualization processes and outcomes. This implies that the visualizer is not present in their work, and visualizations are absent of any referents to a contextual author out of a desire “to see from the perspective of no person, no body.”¹⁰⁴ This false premise of neutrality limits how visuals are interpreted by readers, there can be a bias stemming from research processes, visualization techniques, data collection methods, and other processes that inform visualization. Visualizers have a responsibility to acknowledge their subjectivity and biases in order to provide contextual information which may have informed the visualization processes and outcomes.

Hill agrees with D'Ignazio and Klein in the arguments where researchers and visualizers are inevitably tied socially and culturally to the processes and outcomes that they participate in creating,¹⁰⁵ supports the absurdity of the god trick,¹⁰⁶ and how the bodies that participate in visualization need to make their stances visible in order to reveal possible biases that could manifest, to “re-embody disembodied data.”¹⁰⁷ Furthermore, Hill discusses

¹⁰³ D'Ignazio and Klein, 3.

¹⁰⁴ D'Ignazio, “What Would Feminist Data Visualization Look Like?”

¹⁰⁵ Hill, 392.

¹⁰⁶ Hill, 392.

¹⁰⁷ Hill, 393.

how visualizations cannot prescribe a specific way of reading, although they can influence how reading takes place, in that visualizations can be read different ways by different people depending on certain contextual information. These variables of interpretation need to be considered from the visualizer standpoint to acknowledge how reading can be “influenced by gender, nationality, language ability, education, age, and by the discourses around data, society, and culture.”¹⁰⁸

Feminist theories inform contextual information around visualization in terms of evaluating, employing, and developing outcomes, who is the visualizer, who is the reader, and what information in these practices is contributing to the representation of visual information. This theoretical knowledge can be applied to a broad spectrum of visualization practices and does not necessarily affiliate itself with any particular content for visualization. To seek further information on specific fields of visualization I consider sensory design, specifically combining auditory and visual stimulus in sound visualization.

Sensory design and sound visualization provides an understanding of how auditory experiences can be translated into, or influence, visual experiences. Lupton and Lipps have written extensively about sensory design in their book titled, *The Senses: Design Beyond Vision* to discuss how design is not for any single sense and the body interprets the world through various forms of cognitive intake simultaneously. Bodies develop presumptions about actions and environments that become embedded based on past experiences. Design that evokes a multisensory experience is inclusive, “each person’s sensory abilities change over the course of a lifetime. By addressing multiple senses, designers support the diversity of the human condition.”¹⁰⁹ Disability in particular is acknowledged as justification for the need to design beyond single sense design interactions, or rather the avoidance of making design that relies too heavily on a single sense.

¹⁰⁸ Hill, 402.

¹⁰⁹ Ellen Lupton and Andrea Lipps, *The Senses: Design Beyond Vision* (Princeton Architectural Press, 2018), chap. Why Sensory Design? Apple Books Ebook.

Representing the auditory phenomenon of tinnitus, a non-visual disability, correlates with existing processes which have investigated translating sound experiences into visualizations. Lupton and Lipps write about crossing the visual and auditory in sensory design, “graphic interpretations of sound illuminate patterns and structure and generate new memories and associations. Communication that bridges our different senses helps connect us to each other and to the physical world.”¹¹⁰ In sensory design, auditory information can be translated through visualization to reveal knowledge about sound experiences.

Sound visualization heavily relies on visualizer agency, in that materials and methods stem from the individual, it is their knowledge and practice which informs systems of translation. For instance, Lupton and Lipps designate “typography [as] multisensory - it is audio and visual, sound and symbol.”¹¹¹ Letterforms are able to communicate a multisensory experience in terms of symbolic cultural understandings of pronunciation and phonetic expression/interpretation and also through the rhythmic qualities that curate the reader experience in the order and arrangement of letterforms. Sound visualization manifests a quality of sound, and not the sound itself through representation. Representation is a form of mediation, even type has to be made visible through a medium.

Musical notation is another form of sound visualization. Like writing, it uses abstract notation which the reader/musician translates into sound—either spoken word or notes to be played on an instrument. Musical notation is normally confined to the five-bar staff, although some composers deviated from this tradition and sought new methods of communicating the correlation between notation and musician/instrumental response. John Cage is considered a father of graphic notation, a visualization interpreted by musicians to inform sounds played with instruments they choose which creates contingent audible outcomes that break convention (Fig. 6 & 7). This form of visualizing music employs line, repetition, rhythm, and layering to represent sound to be interpreted by a musician reader.

¹¹⁰ Ellen Lupton and Andrea Lipps, *The Senses: Design Beyond Vision* (Princeton Architectural Press, 2018), chap. Visualizing Sound, Apple Books Ebook.

¹¹¹ Lupton and Lipps, chap. Visualizing Sound.

I understand this as relating to the disabled body; there may be the norm of staff-based notation, but visible here is a method which offers its own contribution to the discourse of composition. Graphic Notation reveals abstract methods can communicate sound information to a reader, as long as it is understood in the proper context.

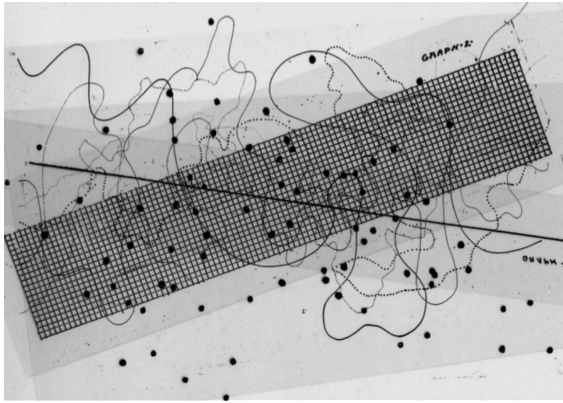


Fig. 6. John Cage, *Fontana Mix*, 1958, <https://medium.com/@nghinghiem04/fontana-mix-1958-john-cage-3145720-b66c2ab3ceca>

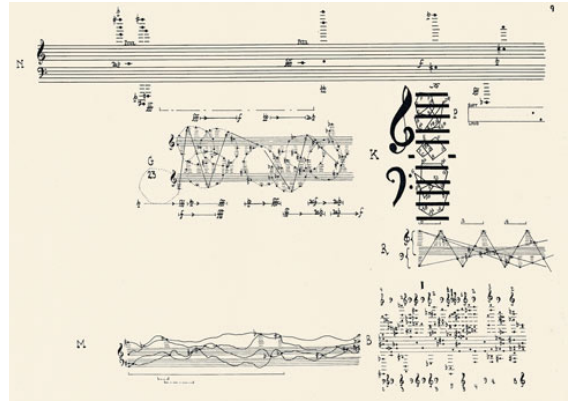
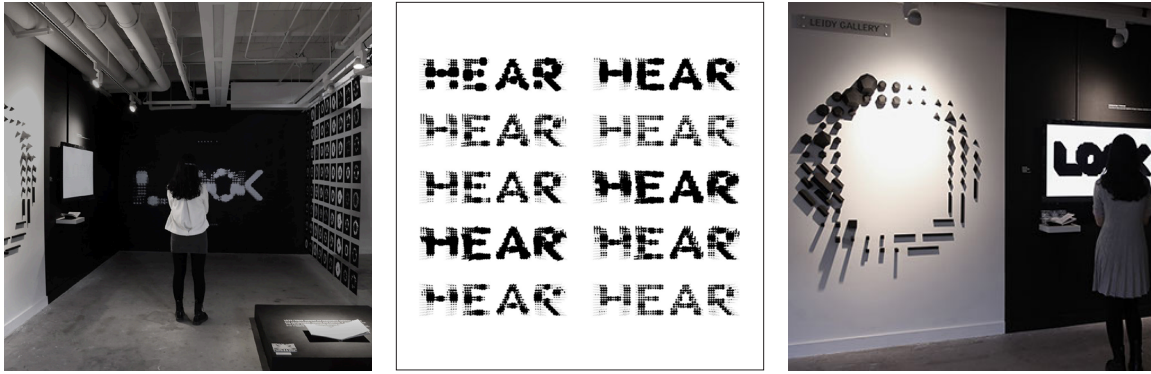


Fig. 7. John Cage and Ray Johnson, *Concert for Piano and Orchestra*, 1957-58, <https://www.e-flux.com/announcements/37569/john-cage-and-ray-johnson/>

Systematic approaches to sound visualization have also been explored in graphic design, for example, *LOOK/HEAR* is a thesis project from designer Ran Zheng, (Fig. 8) who developed an interpretative process of turning recorded sound from various environments into visual typographic expressions.¹¹² Zheng's process is informed by analyzing external sounds and using computational procedures to translate them into typographic form. In contrast, my project visualizes internal sound only I can hear. Zheng's use of texture, scale, form, and rhythm offered opportunities to influence experimentation as I pursued my materials exploration processes.

¹¹² Ren Zheng, "LOOK/HEAR: Essay," accessed September 1, 2020. <http://thesis2016.micadesign.org/ran/essay.html>.



Figs. 8.1, 8.2 and 8.3. Ran Zheng, "LOOK/HEAR: Essay," 2016, <http://thesis2016.micadesign.org/ran/essay.html>

Feminist visualization theories and sensory design with a focus on sound made visual inform the prospect for tinnitus experiences to be visualized. I understand that I am not neutral in the visualization of tinnitus experiences and that I have a personal bias based on by subjectivity. This subjectivity is beneficial in the participation of visualizing idiosyncratic experiences as positioned within broader cultural and societal discourses. My visualizations do not seek to represent the tinnitus sounds I perceive, but rather how my perception of tinnitus affects experiences. I am interested in how experiences of sound affect translate into visual information through processes and outcomes.

Autoethnographic Data

Journaling served as my autoethnographic data collection method. This action research tool allowed me to track experiences of tinnitus affect as a non-visual disability in my day-to-day life. Journaling has been used successfully as a tool to collect data about subjective experiences, including in qualitative studies of tinnitus experience,¹¹³ and is considered a reliable method by autoethnographic theorists.¹¹⁴ Employing autoethnography makes my

¹¹³ Colagrosso, et al., 643.

¹¹⁴ Munro, 162.

subject position explicit and provides the raw data to inform the processes and outcomes which comprise my visualizations of tinnitus experiences.

I recorded 38 journal entries from September 13, 2020 to October 11, 2020. One additional entry was added October 21, 2020 for a total of 39 journal entries. I designed my journals as small booklets, which fit into my pocket, so they could be carried on my person throughout the day (see Appx. A for a sample spread of my journal). Each page of the journal allowed for the following criteria to be recorded: *date, time, activity, situation, and notes*. The date and time document the occurrence of tinnitus affect. Activity recorded what I was doing at the time. Situation recorded additional contextual information about the activity. Any further information that I felt was contributing to the tinnitus affect was documented under notes. This could include my mood, thoughts, and feelings. An example of a journal entry is:

Date & Time: *14/09/20 @ 23:42*

Activity: *Reading*

Situation: *Sitting in bed, quiet house, loud head.*

Notes: *Reading (long reading) is always difficult. I can't read with music playing or with any sounds that distract my attention. I try to read in the quiet, but my head is never quiet. While I read, I get distracted listening to my tinnitus. I constantly have to back track and re-read what I've already gone through. My eyes keep moving through the lines while my tinnitus pulls my attention away from the writing.*

(Pryor, Tinnitus Journal Entry No. 06)

Data collection by journaling was the first step in making my tinnitus experiences visible and accessible. After completing the four weeks of data collection I transcribed my handwritten journal entries into digital text files. I then re-read all entries multiple times and categorized them based on similarity of experience. Four categories emerged from this process, *socialization & other daily activity* (6 journal entries), *design/school/student work* (13 journal entries—I will just refer to this as the 'design work' category moving forward), *waking up*

Going to sleep (11 journal entries), and *reading & writing* (9 journal entries). Each category of tinnitus affect emerging from my journaling affords an opportunity for visualizing an experience. The additional findings, which I call *correlations of experience*, are used to further inform each visualized experience. I combine categories and correlations of experience to develop narratives of tinnitus affect which take the form of books. Exploration of visual media is pursued as a RtD process informed by visualization. All categories show evidence of tinnitus affect as a non-visual hindrance.

Socialization & other daily activity records my activities in environments with other people. These activities ranged from social engagement with others to silently being in the same space. To help contextualize my living situation, at the time of journaling I was living in a house with four other adults, a young child, and an infant during the COVID-19 lock-down orders. Socialization would primarily occur in the mornings and evenings, with intermittent interactions throughout the day.

The *design work* category is devoted to my participation in activities as a student, graphic designer, and teaching assistant. I would work at a desk alone in my bedroom, most often listening to sound played through over-ear headphones, masking my tinnitus. Tinnitus is detrimental to my concentration and ability to work when masking is not present. Time spent working commonly took place from late morning through to late night.

Waking up & going to sleep recorded how tinnitus affected my experience of trying to fall asleep and immediately after waking up. I have difficulty falling asleep in quiet environments. I have to listen to sounds every night to mask my tinnitus in order to fall asleep comfortably. When waking up, tinnitus is often the first thing I hear. If I wake up too early, it can be difficult to get back to sleep because I have to begin listening to masking sounds again and they tend to cause awakening in the morning. I usually go to sleep late at night or in the very early hours of the morning and wake up mid-morning.

Lastly, *reading & writing* is a category which has overlaps with *design work*, but the two categories are treated as separate because, in contrast to *design work*, I commonly read and write without masking. Tinnitus dramatically hinders my concentration in environments

where there is very little to no external auditory stimulus, making reading and writing slow paced and frustrating activities. Sounds I use for masking tend to hinder concentration while reading and writing. For me, pushing through while only hearing tinnitus sounds tends to be slightly more manageable. I often read late in the afternoon or at night.

In addition to the categories of activities I also found correlations of experience in my journal entries. A category of activity describes tinnitus affecting my body in a particular context, and correlations of experience describe attributes of tinnitus affect. These correlations were applicable to multiple categories and influenced how tinnitus affect contributed to experience. Many instances of affect were familiar before initiating this study, but the journaling process helped to verify and contextualize my understanding of these instances.

My experiences of tinnitus affect can often be predictable and repetitive. Having lived with tinnitus for around ten years I can predict when and how it will affect experiences. This leads me to constantly evaluate how sound, or lack thereof, will influence my participation in environments and activities. For instance, I know that tinnitus will hinder my ability to sleep every night so I have to take measures to manage the affect so I can comfortably fall asleep. Predictability and repetition inform my management options, but do not make experiences easier. I have to cater to my tinnitus.

I am sensitive to high pitch sounds, which cause me physical and mental discomfort. Journalled examples of these sounds include, dog squeak toys, dental tools, babies crying, and objects hitting metal. Being sensitive to sounds makes me feel anxious when thinking of my future: will I be exposed to sounds that I cannot control or get away from? The high-pitched sound of babies crying causes me inner ear pain, this makes me worry about starting a family in the future.

Tinnitus affect also makes quiet environments very uncomfortable. When external auditory stimulus is low in volume, my tinnitus feels louder, it is all I can hear. I exist in a state of constant hearing, my attention can quickly be drawn to minute sounds, such as a creak in the floorboards. I struggle with concentration while working on activities that require quiet,

resulting in frustration as my concentration becomes monopolized by tinnitus. Additionally, if I am doing something where there are fluctuations in the volume of sounds, like watching a movie, as soon as there is a silent or low volume moment my tinnitus makes itself known. I cannot take breaks from hearing, there is no silence.

Tinnitus also affects my mental health. I believe stress aggravates my tinnitus, bothering me more. Tinnitus affects my body and mind as a sufferer and is not confined to aural perceptions. When my body and mind are tired my tinnitus feels louder, causing feelings of irritation and defeat—this can contribute to making sleep more difficult. Anxiety about the future, and frustration building while participating in quiet activities also commonly occurs. These instances are hard to manage, I cannot avoid succumbing to feelings of tiredness, stress is not avoidable, I believe my sound sensitivity will never resolve, and there is no cure to get rid of the tinnitus sounds I perceive. I do not know how to manage this beyond trying to listen to my body and cater to its physical and mental needs, which in turn could help manage my tinnitus.

An interesting finding of the journaling was an experience which I have called *masking fatigue*. This occurs when I have been masking my tinnitus for long durations and my ears are exhausted from constantly listening. I can choose to stop masking and listen to my tinnitus, or continue masking and further stress my ears. I have both a mental and physical reaction to my inability to stop hearing in this situation. My inner ears can become sore from hours of masking, headaches can occur, my mind can feel exhausted, overwhelmed, frustrated, irritated, and I get a general feeling of being tired and defeated; knowing I am in a perpetual state of hearing. It is not just a few hours in a day that does this, I mask my tinnitus every day. Over the days, weeks, and months this takes a toll and I just want to be able to stop listening and hearing sounds and experience silence.

The four identified categories are experiences of tinnitus affect and each affords an opportunity for visualization. The correlations of experience describe attributes of affect which are employed to communicate aspects of tinnitus affect which take place in the context of the category. In my thesis I explore the experience of masking as well as two identified

categories: reading & writing and waking up & going to sleep. These categories are combined with correlations of experience to inform the design and development of books which act as visualizations of tinnitus affect.

Design Processes & Outcomes

The design outcomes of my thesis consist of three books. I have chosen books because they are intimate design objects which address the reader as an audience of one. They afford a subjective and personal experience, which readers can navigate at their own pace (much like tinnitus). The narrative form of books is also well suited to describe experiences that unfold over time. The books are expressive of my own experiences, and the symbolism in my design choices is something that I create. I assign meaning to visually and materially communicate thinking and ideas which derive from my autoethnographic data.

The first book I designed is somewhat of an outlier to my method as it is not informed directly by the autoethnographic data. The first book was produced while I was journaling and explored the experience of tinnitus masking. This is an experience I participate in every day and consider crucial to my tinnitus management. Masking helps me sleep, helps me work, helps me rest; masking drastically improves my quality of life as a tinnitus sufferer. Because tinnitus masking is so important to my daily management, this seemed like a logical entry point to examine and explore my tinnitus affect visually and materially.

BOOK 1—KEEPING THE GHOST AT BAY

I live in a body that is always hearing, but not always listening. I constantly try to manage my exposure to auditory stimulus, often using sounds to cover my perception of tinnitus in a process called *masking*. When masking, I choose what I hear. I prefer to listen to music,

rainfall sounds, comedy tracks, and television show reruns (reruns do not require the same attention as new shows). In addition to the masking sounds I can control, environmental sounds which I cannot control also mask my tinnitus. Bustling city street noise and the sea of conversations in busy cafés are examples of sounds that act as environmental masks.

The relationship between how I perceive internal and external sounds is difficult to articulate, but I will try to explain. I hear my tinnitus underneath and/or in addition to external sound. When an external sound is louder than my tinnitus, it overwhelms and ‘masks’ the tinnitus sounds. My tinnitus is temporarily inaudible (but still present) when masked. If the external sound is not louder, then I perceive both external and internal sounds. My tinnitus does not interfere, cannot overwhelm, and does not distort my perception of external sounds. My ability to hear external sounds is fine, I just also hear sounds within my head. The reason I do not try to replicate my tinnitus sounds as an auditory experience in my design work is because a tinnitus sound that is external to the listener’s head would not provide the same hearing experience as mine. Nor would it reproduce the permanence of my experience. For instance, a listener would know that they could lower the volume or turn off the sound, making the listening experience escapable. These options are not available to me.

My first book, *Keeping the Ghost at Bay*, visualizes my experience of tinnitus masking. A metaphorical narrative describes how masking is a crucial form of tinnitus management. The visual language describes the dissonance and discomfort of my tinnitus. I explore how typography and collage as formal devices can communicate experiences associated with my perception of tinnitus sounds, and as an interference and rhythmic disruption.

1—MATERIAL EXPLORATION & MAKING PROCESS

To begin visual exploration of tinnitus masking I interpreted the term ‘masking’ as a trope. I used plaster bandage to cast masks of my own face, casting eleven masks in total. My masks draw their form from my body’s most identifying physical characteristic. They make my

subject position explicit and only fit me properly. My masks could be worn by others, fitting improperly, just as my masking process is most suitable to my personal experience of tinnitus and would not guarantee relief for other sufferers. I then decided to cut my masks into unique shapes. I listen to a variety of masking sounds; this is reflected in a variety of physical mask forms. I photographed a full-face mask and brought the image into Photoshop to digitally explore potential mask shape variants. The digital exploration was quick, and I did not need to damage any masks. I developed 20 digital variants. I selected several shapes to cut into masks, leaving one uncut. Unfortunately, some masks broke in the process. By the end I had five masks, four cut variants and one full-face. I was still unsure how I was going to use the masks, so I settled for five and did not choose to cast more.

During the digital mask exploration, I found that one of the variants looked like an uppercase “F.” Acknowledging this finding, I decided to investigate if a full alphabet could be created based on this cell character. I printed an image of my full-face mask, overlaid tracing paper and sketched letterforms over top of the image. I drew letterforms by following the facial contours in the mask. The hand rendered sketches were then used as references to digitally cut letters out of a full-face mask image, resulting in a digital mask alphabet I titled *Casted* (Fig. 9.1) (see Appx. B for more visuals of *Casted*). No physical masks were cut into letters. To try and push this process further, I took the contours of the digital mask letters and filled them with a flat black, removing all texture and tone. This change resulted in a macabre alphabet of bitmap silhouettes, unrecognizable as a mask and void of facial resemblance (Fig. 9.2). I no longer considered this alphabet as corresponding with the experience of tinnitus masking. Erasing the textural detail from the letterforms took with it their meaning as an object formulated from my identity—a step too far in exploration. From here, I returned to exploring the physical masks.

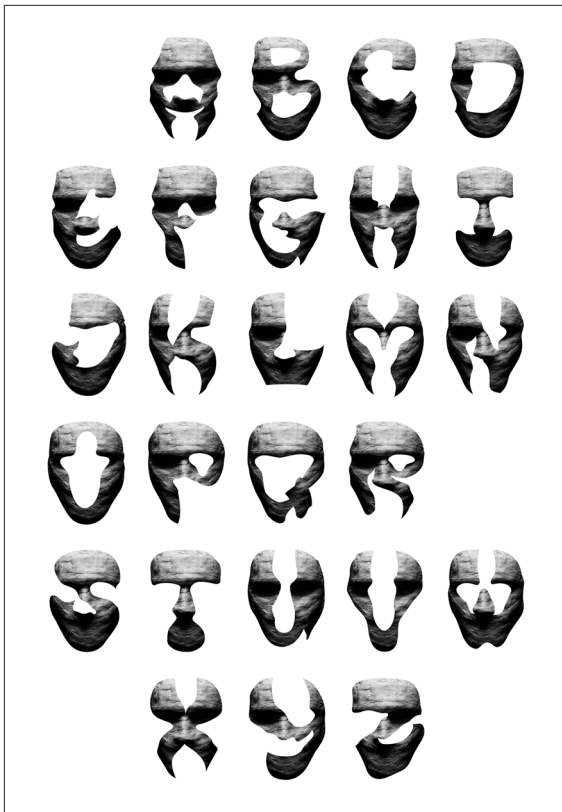


Fig. 9.1. Carter Pryor, *Casted*, 2020, alphabet.

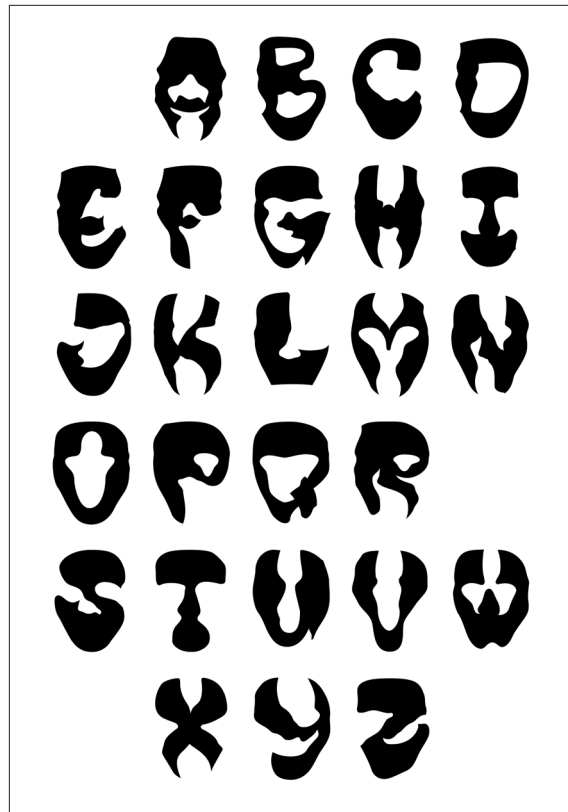


Fig. 9.2. Carter Pryor, *Casted (Bitmap Silhouettes)*, 2020, alphabet.

I use aural masks to cover my tinnitus sounds and I explored this idea of coverage by shooting self-portraits while wearing my masks. I photographed each mask being worn as well as individually isolated on white and black backgrounds. Ideas of coverage and layering began to emerge visually. I explored this further by shooting a second series of self-portraits through fogged glass while wearing the masks. The fogged glass creates an effect which obstructs the clarity of the self-portrait, a distortion of identity and presence.

Working with the mask visuals brought me to think about the qualities shared by physical and aural masks. I am often able to select the aural masks I use to cover my tinnitus, just as I am able to select and wear the masks I have cast. For me, I understand that when a mask is worn it adds positive space to cover a physical characteristic of my body, just as an aural mask uses sound to cover an auditory characteristic. In both the physical and aural cases, when there is no mask, I experience an uninterrupted vulnerability. I considered aural

masks as positive space and silence as negative space. The spatial relationship I found in masking could translate into visuals, tinnitus can be an interruption of negative space.

With some design ideas developed, I began writing about masking as an experience. I researched expressions of tinnitus in prose and poetry to investigate how tinnitus has been described in text. I found that authors primarily use metaphor, simile, or analogy to articulate tinnitus based on familiar or easily imagined sounds. I decided to write a metaphorical narrative to express my experience of tinnitus masking. In this story, I represent tinnitus as an omnipresent ghost (tinnitus) to which I am bound for life. I wear masks to temporarily escape the ghost's haunting embrace. Throughout the story I use language drawn from literature on disability studies. The text refers to my ghost as *non-visible*, my mask working as "a key to *access* sleep and focus," and how I am never alone, "in an *isolated margin* my ghost is maddening company" (see Appx. C for the full manuscript).

With the narrative established, I pursued more material explorations in the context of a book, looking at spread composition and typography. I used typography to visualize dissonant rhythms as well as interruptions of compositional negative space, while imagery was responsible for achieving the idea of layering. Keywords are cacophonic, set using multiple weights, scale variations, and forms of one type family. Body text generously uses negative space to influence reading tempo, creating pauses to emphasize certain words and phrases. For me, all the elements contribute to the interruption of rhythm, and in this process, simultaneously set a particular off-beat and disruptive rhythm of my own making.

A collage approach employs layers of imagery and typography to develop a visual language of interruption, coverage, and obstruction. The book uses an achromatic colour scheme, my understanding of tinnitus does not correlate with any colour. Abstract imagery uses the bitmap silhouette mask alphabet developed earlier on. These forms are cropped and sometimes appear with a coarse grey noisy texture to correlate with the atonal texture of my tinnitus. The addition of brush strokes brings a directionally predictable, yet sporadic texture to the spreads. Finally, self-portraits and mask images support sections of the narrative throughout.

1 — BOOK ARTEFACT

Keeping the Ghost at Bay (Fig. 10) visualizes an experience of tinnitus management, bringing visibility and legibility to my personal experience of tinnitus affect. The book is designed at a large scale, 16"×11" for a 22" spread, making it slightly uncomfortable to hold, occupying quite a bit of space. The soft cover does little to protect the book, making it susceptible to damage if mishandled. While a reader flips through pages, they will find large keywords clustered with collages of images to create loud eye-catching disruptions located in a generous amount of negative space. Body text creates smaller disruptions and an oddly paced reading rhythm by using inconsistent spacing and unconventional line breaks. Abstract imagery helps to lead the reader's eye through compositions and frame content. The reading experience is paced to have instances of loud and unbalanced spreads followed, or preceded, by minimal spreads. There are very few similarly composed spreads to keep the reader away from ideas of familiarity or consistency, while maintaining unity through repeating design elements. An intermission of the narrative is located close to the centre of the book, where keywords set in *Casted* and large images of my masks on black and grey backgrounds take over for a few spreads. The book concludes with a tightly cropped image of myself wearing one of my masks with one eye looking directly at the reader. This is paired with text reading "They [masks] are all I have to keep the ghost at bay." A statement of vulnerability and necessity, what would I do without my masks?



Fig. 10.1. Carter Pryor, *Keeping the Ghost at Bay*, 2020, book, 11"×16".



Fig. 10.2. Carter Pryor, *Keeping the Ghost at Bay*, 2020, book, 11"×16".

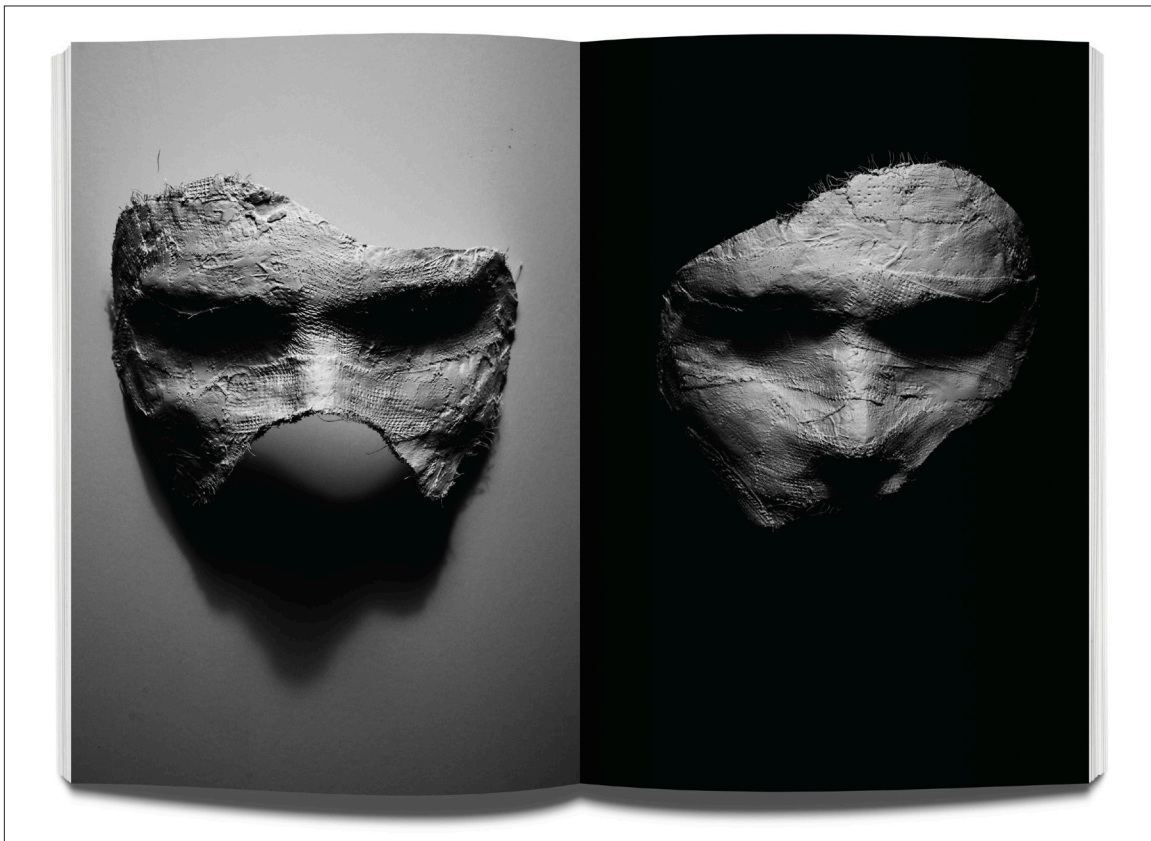


Fig. 10.3. Carter Pryor, *Keeping the Ghost at Bay*, 2020, book, 11"×16".

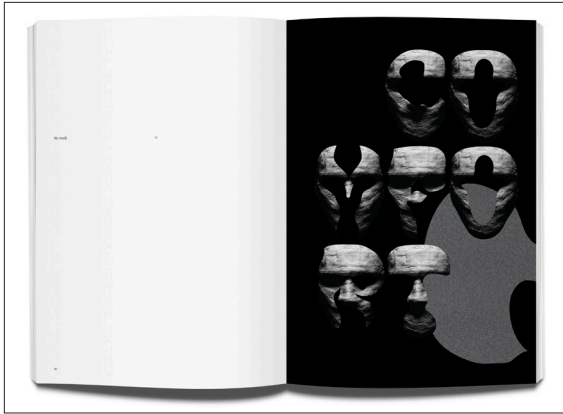


Fig. 10.4. Carter Pryor, *Keeping the Ghost at Bay*, 2020, book, 11"×16".



Fig. 10.5. Carter Pryor, *Keeping the Ghost at Bay*, 2020, book, 11"×16".



Fig. 10.6. Carter Pryor, *Keeping the Ghost at Bay*, 2020, book, 11"×16".

BOOK 2 — I CAN'T SLEEP

Waking up and going to sleep are events identified in my autoethnographic research as disrupted by tinnitus affect. Although falling asleep is an experience that commonly requires a quiet environment so a person can rest, and be calm and comfortable, this is not the case for me. My tinnitus is impossible to ignore when my environment is quiet, I listen for nothing but cannot stop hearing. Sleep difficulties are common amongst tinnitus sufferers, and insomnia is often described as a side effect.¹¹⁵ I do not consider myself an insomniac, most nights I can sleep comfortably because I take measures to manage sound exposure and avoid silence. To sleep, I have to use masking with sounds that do not draw my attention and that maintain a consistent volume. I have difficulty falling asleep if the masking sound is too loud. If it is too quiet, I pay attention to my tinnitus. Further difficulty comes when my tinnitus is aggravated. When aggravated, my tinnitus has a louder sensation and I have to use louder masking sounds. Unfortunately, there are times where sleeping feels impossible because the sounds in my head and those I use to mask are competing at a loud volume.

My second book, *I Can't Sleep*, visualizes my experience of sleeping with tinnitus. I have to manage auditory stimulus in my sleep environment every night, if I am unable to do so my tinnitus compromises my ability to relax, causes unescapable irritation, and I have difficulty sleeping. I express my repetitive and irritated thoughts, the need to use external sounds to shift my attention away from listening to my tinnitus, and the fact that this an inescapable daily experience. My tinnitus affect has to be managed daily and it has permanently changed the way I sleep.

2 — MATERIAL EXPLORATION & MAKING PROCESS

To begin material exploration, I worked with the idea of a continuous experience that reproduced the unpredictability of my tinnitus. I explored analog image making using

¹¹⁵ Andersson, 978.

wet-on-wet ink and water, paper folding, paper scoring, sewing string through paper, gluing string to paper and combinations of these explorations. I found that I continuously manifested visuals as a horizontal line which bled off the left and right sides of a page. For me, bleeding the image off both sides of the page make it appear to not have a beginning or ending, connoting perpetuality.

I selected paper scoring and the wet-on-wet ink and water explorations as ideas to pursue further. The wet media was difficult to control, this characteristic resonated with my experience of tinnitus. I scored a horizontal line through paper, folded along the score line to damage and create a bump along the line, applied a layer of water then brushed a line of black ink along the score line. The ink sporadically bled through the water away from the line. I combined this process with ground salt to add directional and textural complexity to the bleeding ink. I created a series using this process. The series ranged from applying a low volume of ink to have slight bleeding and minimal surface coverage, to applying a high volume of ink which bled to achieve full surface coverage.

I also designed a book made up of full bleed horizontal score lines on blank pages and identical photographic image inserts of my ears which split every spread (Fig. 11). The score line does not add or take anything away from the pages, it is a subtle distortion to what is already there and cannot be undone. The lines run centred across spreads, feeding through the ear imagery as the reader flips through the pages. All spreads are identical to make the experience repetitive and make it easy for the reader to lose their place in the book.

I conducted digital explorations simultaneously with the analog. The digital explorations began with using a grey noise texture in Photoshop and applying distortions to achieve movement and disruption. The idea for using this texture came from the atonal noise imagery used in *Keeping the Ghost at Bay*. The texture variants showed aspects of vibration, directional pressure, waves, and sporadic movement. The digital explorations also bled off all sides of the working canvas, no beginning or end. The wave distortions were selected to investigate further. I made large scale images which began as a grey noise texture with two white horizontal lines bleeding through the centre and then applied wave distortions to the

entire image. In this process the lines harmonized and flowed with the noise-wave distortion rhythms. I then digitally painted black into the deep areas of the waves to emphasize their movement and depth. The result was a cacophonous landscape of noise flowing across the digital canvas (see Appx. D for exploratory and selected noise-wave imagery). An idea emerging from this was to integrate noise-waves with the abstract wet-on-wet ink and water series. I developed a wave generating Photoshop action (a recorded series of manipulations) that I could apply repeatedly to an image. One use of the action generates a low volume of waves, as more actions are applied the volume increases. I then scanned the wet-on-wet ink and water images so they could be combined with the noise-wave images.

After scanning the wet-on-wet ink and water images I altered their tonal value so the line running along the centre was white, the background was white, and ink coverage was black. I overlaid the images atop noise-wave imagery created with the Photoshop action, black areas became transparent to reveal waves. The small coverage overlays one application of the noise-wave action, the next overlays two actions, and so on. I produced a series of eight abstract images that increased in volume, complexity, and coverage (Fig. 12).

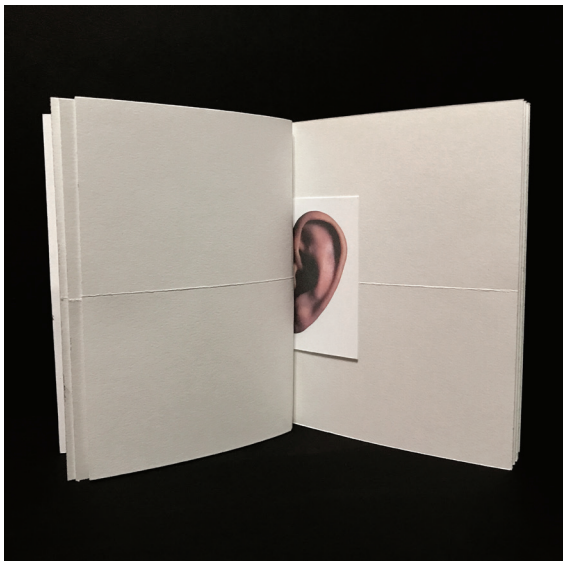


Fig. 11. Carter Pryor, *Scoring Book Version 1*, 2020, book, 5.75"×6".

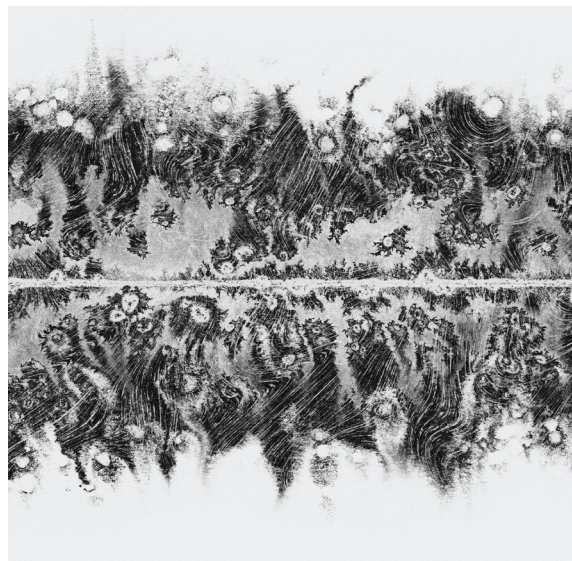


Fig. 12. Carter Pryor, *Cropped Sample of Abstract Image*, 2021, digital image.

My continued use of a bleeding horizontal line brought me to consider how I could design a typeface around this idea, distort the ideas of beginning and ending and incorporate elements of disruption. How can a typeface communicate a perpetual experience? How can letterforms disrupt the consistency of a horizontal line? My answer to these questions is a typeface I named *Spectre* (Fig. 13), drawn with upper and lowercase and basic punctuation.



Fig. 13. Carter Pryor, *Spectre*, 2020, typeface.

Spectre's letterforms are module swells that align to a grid of horizontal lines. Textual communication manifests as vibrational interruptions of consistency, creating rhythmic textures. The swells of the letterforms are fluid and can be rendered at various sizes. The swell size correlates with the legibility of the typeface, larger swells are more legible and easier to read while smaller swells are difficult to read. Individual swells can also be varied within letters to create a complex vibrational quality. If the swells are made too large, they obstruct meaning. Balance must be found to achieve clarity in the typographic communication (see Appx. E for more visuals of *Spectre*).

I thought there was more there to be explored with the analog making because most of my exploration involved a bleeding horizontal line and I wanted to see if there were other visuals which could connote perpetuality. I came across the form of a mobius strip. The mobius strip is a three-dimensional object with an infinite plane. I made variations of my own mobius strip using paper, exploring width, length, and texture. I selected one where I wet the paper and rubbed off a layer to create a subtle and coarse texture (Fig.14). I scanned my mobius strip at various angles to be manipulated further digitally. I converted the image to black and white and digitally removed the glued seam so the mobius strip would have no trace of a beginning or end.

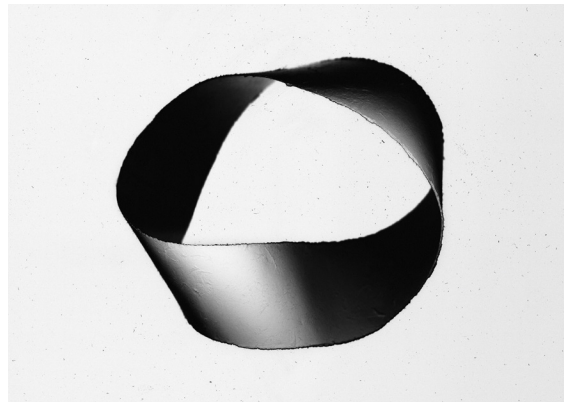


Fig. 14. Carter Pryor, *Möbius Strip*, 2021, digital image.

With abstract imagery, a typeface, and a mobius strip explored I began to implement the ideas into a book. Initially I tried to combine all visuals into a single book, in doing this the content and narrative seemed too fast paced and complex. To reduce the complexity, and allow more space to explore visualizing my ideas, I decided to take up each idea in its own book: *I Can't Sleep—Thoughts* (typographic progressions), *I Can't Sleep—I Feel* (abstract progressions & typographic), and *I Can't Sleep—Everyday* (timeline of mobius strip imagery). The text in each of the books is set in the *Specire* typeface. The series works together to visualize different aspects of my experience sleeping as a tinnitus sufferer.

The first book, *I Can't Sleep—Thoughts*, is entirely typographic. The book visualizes how falling asleep is long process for me, I experience discomfort in quiet environments, and the experiential tinnitus affect is repetitive and predictable. My autoethnography recorded that my experiences of tinnitus affect can be repetitive, sleep issues being one. Reoccurring thoughts of being unable to sleep are common for me, especially if my tinnitus is aggravated. If my attention is on tinnitus, I am uncomfortable and have difficulty sleeping.

In the book, two lines run horizontally throughout the centre of every spread, acting as an anchor for letterforms. All letter modules are connected to the centre of the book using a grid of horizontal lines. Throughout the book there is a strong left to right forward moving momentum, this is emphasized early on by bleeding characters off the right side of the recto and continuing the letters on the left side of the verso on the following spread.

The introduction slowly reveals the phrase “a kettle of static whistling at boil.” This metaphor is based on what my tinnitus can sound like sometimes and sets an auditory context. The phrase is pieced together by revealing a few letter modules at a time over several spreads to replicate the experience of my focus shifting towards listening my tinnitus. Following this introduction, the main content of the book repeats the phrase “I can't sleep.” The typography begins in all caps set at a large scale with letter modules varying in swell size, vibrating on the page. As the spreads progress, the typography decreases in scale, modules become smaller and more consistent in swell size, and the case switches from all caps to lowercase. This typographic progression creates a loud and dissonant rhythm which recedes to a consistent calmness. The book concludes by reversing the introductory progression, the phrase “I can't sleep” slowly loses modules and lines over a series of spreads until all that remains are the two horizontal lines.

The second book, *I Can't Sleep—I Feel*, has typographic introductory and concluding text, and uses the abstract wet-on-wet ink and water visuals combined with the noise wave imagery to visualize the role of sound in my sleeping environment. Every entry in my autoethnographic journal that was taken before falling asleep notes that I employ masking sounds to fall asleep. In the book, all spreads are symmetrical to tie into my case of tinnitus

being bilateral. The introductory text reads “there is no comfort in silence,” set with inconsistent spacing and employing the same line styling as *I Can’t Sleep—Thoughts*. These spreads are followed by a digital image contained in white margins spanning across one spread. The image has two waves of noise texture, a white line running centred horizontally, and a black background which dominates the image. The black background is resonant of absence, a silent void, and is pierced by the white line. The waves of noise-texture briefly interrupt the white line, but it immediately comes back to prominence after passing through. For me, the white margins and use of digital imagery visualize that this is an internally processed and contained experience, this is how I understand sound interacting with tinnitus inside my head.

Next comes a progression of the wet-on-wet ink and water imagery overlaid with the noise-wave textures. The progression begins with a spread that covers little of the page, and the white line in the imagery runs centred horizontally across the spread. The volume of imagery increases over the eight spreads. The last spread reaches a crescendo of full coverage and provides extensive texture and rhythm to lead the eye around. Sounds which shift my attention alleviate my tinnitus perception, this is how I manage to sleep. Although there is alternate stimulus, tinnitus remains, just as the horizontal line is present throughout this progression. Following the crescendo, a second digital noise-wave image contained within white margins ends the abstract visualization. This image spans across the spread but now has very little darkness. Noise waves occupy the entirety of the image and the white line that once pierced through a dark void is flowing harmoniously along the rhythm of the waves. The book concludes with a reference to the introductory text: “I rest and sleep in the embrace of noise.” The typography remains set in the same style except for the last word “noise” being emphasized in a heavier weight with heavier lines on its own spread.

The third book in the series is *I Can’t Sleep—Everyday*. This book represents an annual timeline of my perpetual difficulties sleeping with tinnitus. The timeline consists of 365 repetitions of a single source image of my mobius strip. Repeating the mobius strip imagery in this abundance emphasizes how my experience is overwhelmingly repetitive. All

my journal entries that are recorded before falling asleep note that tinnitus plays a role in my process of falling asleep. Every night when my house and bedroom are quiet, I hear my tinnitus. This means every night I have to mask in order to fall asleep comfortably. One year is visualized but I have been a tinnitus sufferer for approximately ten years and expect to live the remainder of my life as one.

Each mobius strip image is made slightly unique by altering crop, rotation, and scale—no two images are duplicated without minor modification of these attributes. This variation shows visual difference while at the same time maintaining the repetition of experience. I do this because although tinnitus is always in my head, its affect can be slightly different every day. Each night falling asleep can be different, my tinnitus may be aggravated to various degrees and I will need to use louder masking sounds, I may employ different masking sounds depending on the night, I may be able to fall asleep quickly, it may take a long time, and other variables might affect the experience. This is further emphasized by setting the images into spreads which do not use a grid. No spread compositions are the same, they are sporadic and make the timeline path somewhat aleatoric. Images at the left and right edges of spreads employ the same treatment as the bleeding letters in *I Can't Sleep—Thoughts*. Bleeding from one spread to the next creates a continuity and makes the experience uninterrupted as spreads are flipped.

The three books have the same covers, end pages, and title page, except for the subhead on each title page. The covers are dark with a dusty texture and the title, “I Can’t Sleep,” set in white *Spectre* running horizontally through the centre. Only two lines anchor the letterforms leaving the remainder of the modules free. The end pages are mirrored images of the noise-wave texture created using the Photoshop action (see Appx. F for *I Can't Sleep* covers and end pages). The title pages continue the alignment of the two lines from the cover, repeat the title with subheads falling underneath.

2 — BOOK ARTEFACT

I Can't Sleep is a three-book series that visualizes different aspects of my sleep experience as a tinnitus sufferer. The repetitive thoughts, the need for noise in my sleeping environment, and the unpredictable and perpetual nature of the experience is visualized. All books in the series are designed at the same size, 12"×18" for a 36" spread. Their scale demands a large space from the reader and make the books difficult to hold. The soft covers, just like *Keeping the Ghost at Bay*, make the books vulnerable to damage if mishandled. When beginning to flip through any of the three books there is a visual familiarity found in the identical covers, end pages, and title pages (aside from the subheads) (Figs.16).

I Can't Sleep—Thoughts (Fig. 15) begins slow paced, making the reader flip through multiple spreads before the introduction is pieced together and able to be read. The phrase “a kettle of static whistling at boil” gives the reader an unfamiliar combination of imaginable sounds to set an auditory context. The reader is then bombarded with loud and distorted typography which can only display a few letters per spread. The first instance of the *I Can't Sleep—Thoughts* text is so loud and obscure that it occupies two spreads, bleeding letters from one recto to the following verso. This type treatment asks the reader to flip to the next page to reveal the remainder of the letter and thus the remainder of the phrase. The reader must flip through several pages before this short phrase can fit to one spread and begin to read the text a little more clearly. As pages are turned, the capital letters turn to lowercase, the scale of letterforms decreases, and the module swell sizes settle. With this there is an increase in negative space along with feeling a descent to calmness. Once the type reaches its smallest size the letterforms deteriorate over a series of spreads, reversing the introductory progression. The reader undergoes a long repetitive experience and a slow descent from loud distortion to a toned-down calmness.

I Can't Sleep—I Feel (Fig. 16) welcomes the reader with the phrase “there is no comfort in silence,” to set an uneasy auditory context. This phrase is flipped by quickly and is followed by a symmetrical spread containing a dark void with a horizontal white line penetrating two noise-waves. The white line is unignorable when against the dark void. The

next spread introduces the abstract noise-wave progression, showing mirrored imagery of a white line emitting textures running across the spread. There isn't a lot of visual stimuli, looking unkempt and interruptive. As the reader flips through the next few spreads the noise-waves occupy more and more of the pages and provide rich texture and movement to stimulate the reader. Each spread in the progression asks for more and more time to be spent to take in the visuals. Once the noise-waves reach full coverage the reader can become entranced in a mass of rich texture which continuously pulls their attention away from the ever present horizontal white line. After leaving this spread the reader is brought to a concluding phrase which trails from the introductory: "I rest and sleep in the embrace of noise." Noise is confirmed as a necessity, visualized in this experience as a rich and beautiful harness for attention in the context of sleep.

I Can't Sleep—Everyday (Fig. 17) abruptly brings the reader into an overwhelming experience. Mobius strip images are set with dissonance in spreads to encourage multiple eye paths, there is no one way to navigate the imagery. Throughout the book there are 365 mobius strip images, nodding to an annual timeline of a repetitive experience. Although the number of images has this significance, the reader is not expected to count or catch on to this fact. Rather, the visualization uses this number to create an overwhelming experience, to show variety in repetition and an unease of navigation. A qualitative representation depicting potential variation of experience and abundance is communicated through these attributes as oppose to a quantitative calendar of information related to particular days, leaving affect subject to chance.

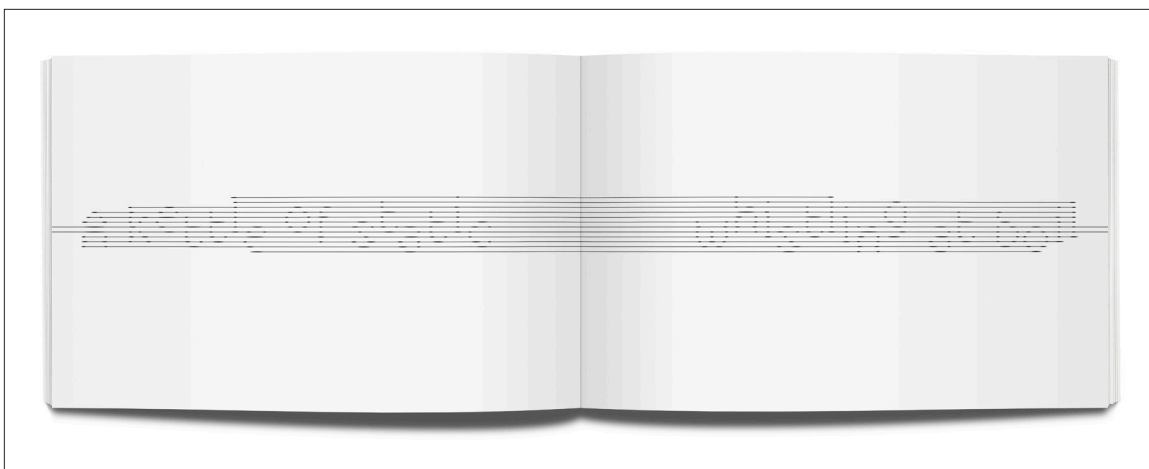


Fig. 15.1. Carter Pryor, *I Can't Sleep—Thoughts*, 2021, book, 18"×12".

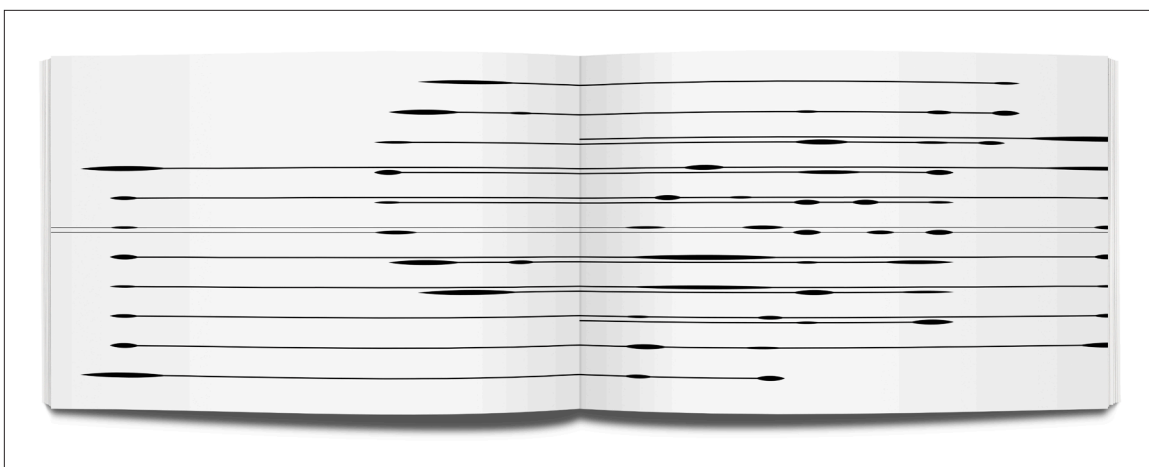


Fig. 15.2. Carter Pryor, *I Can't Sleep—Thoughts*, 2021, book, 18"×12".

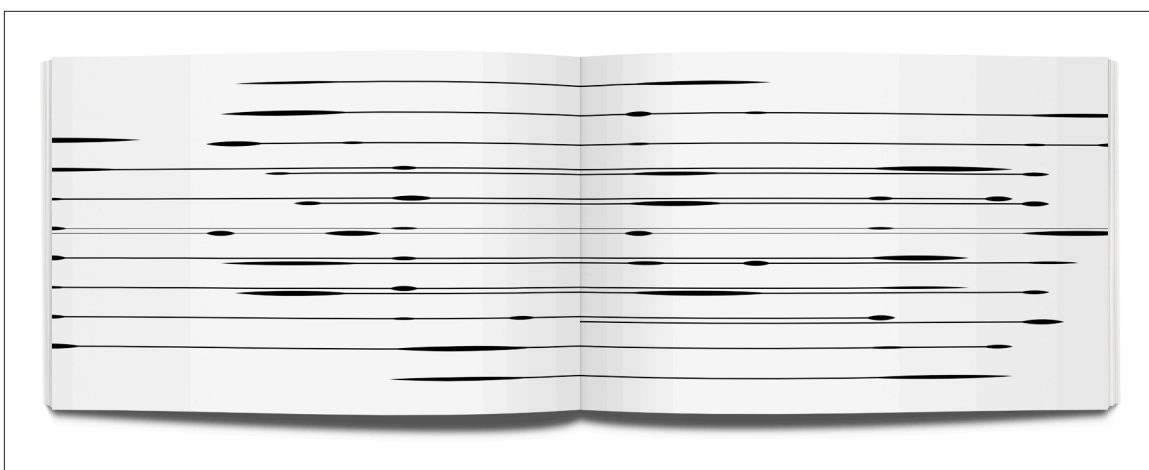


Fig. 15.3. Carter Pryor, *I Can't Sleep—Thoughts*, 2021, book, 18"×12".

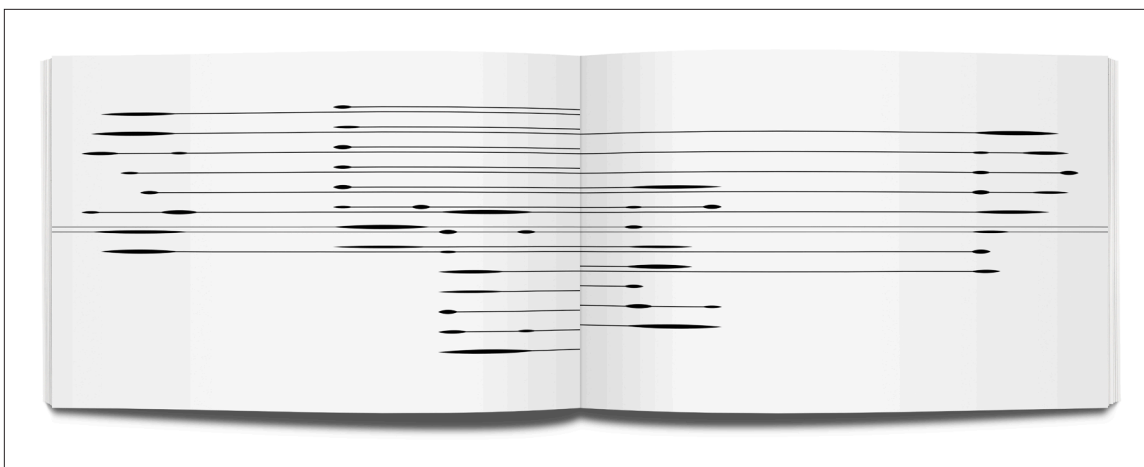


Fig. 15.4. Carter Pryor, *I Can't Sleep—Thoughts*, 2021, book, 18"×12".

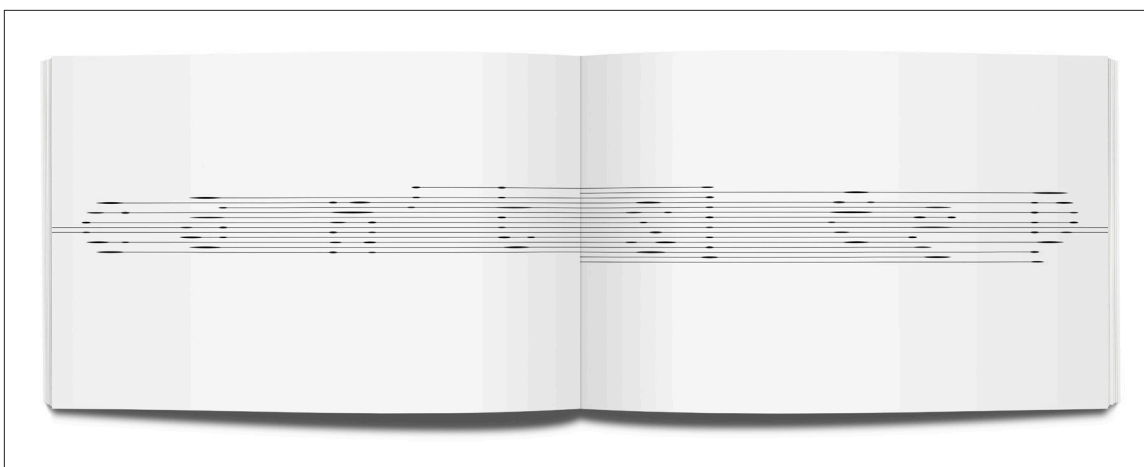


Fig. 15.5. Carter Pryor, *I Can't Sleep—Thoughts*, 2021, book, 18"×12".

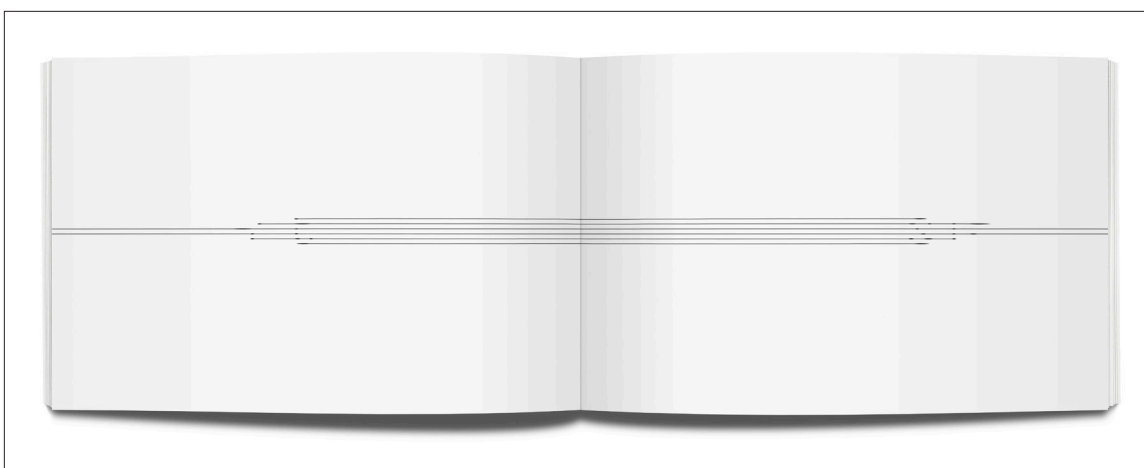


Fig. 15.6. Carter Pryor, *I Can't Sleep—Thoughts*, 2021, book, 18"×12".

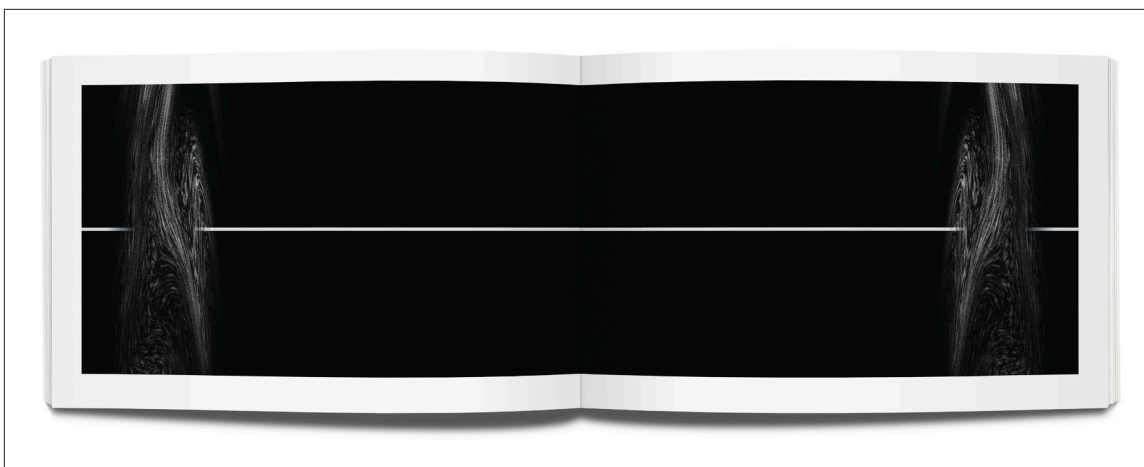


Fig. 16.1. Carter Pryor, *I Can't Sleep—I Feel*, 2021, book, 18"×12".

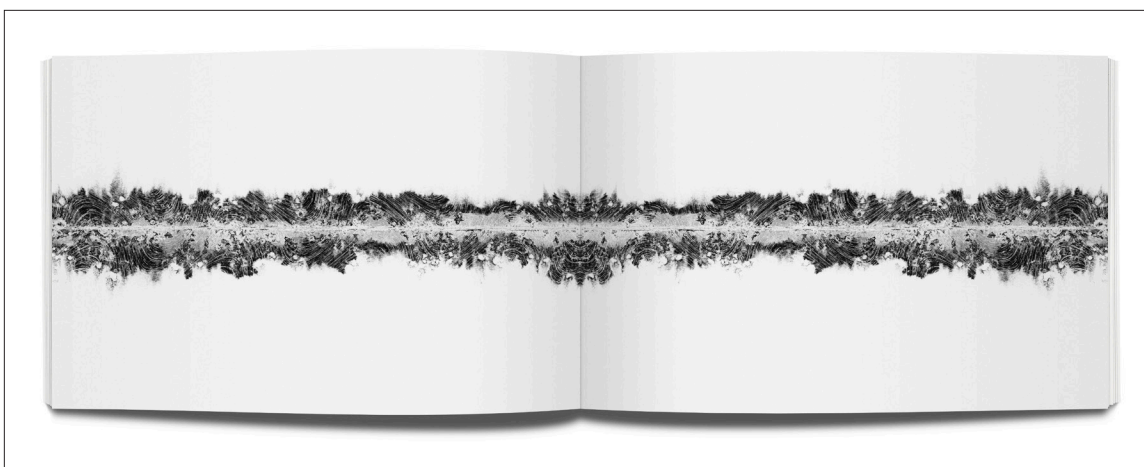


Fig. 16.2. Carter Pryor, *I Can't Sleep—I Feel*, 2021, book, 18"×12".



Fig. 16.3. Carter Pryor, *I Can't Sleep—I Feel*, 2021, book, 18"×12".

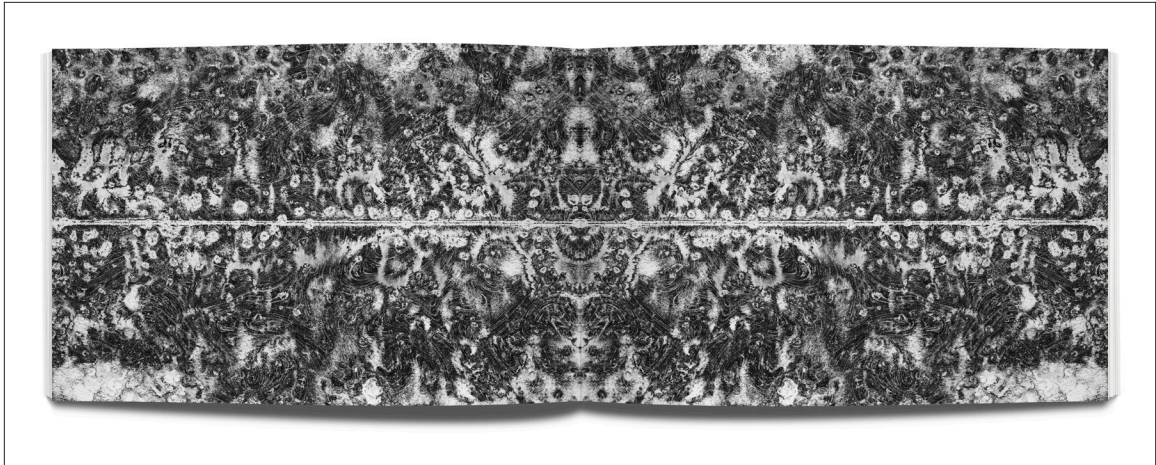


Fig. 16.4. Carter Pryor, *I Can't Sleep—I Feel*, 2021, book, 18"×12".

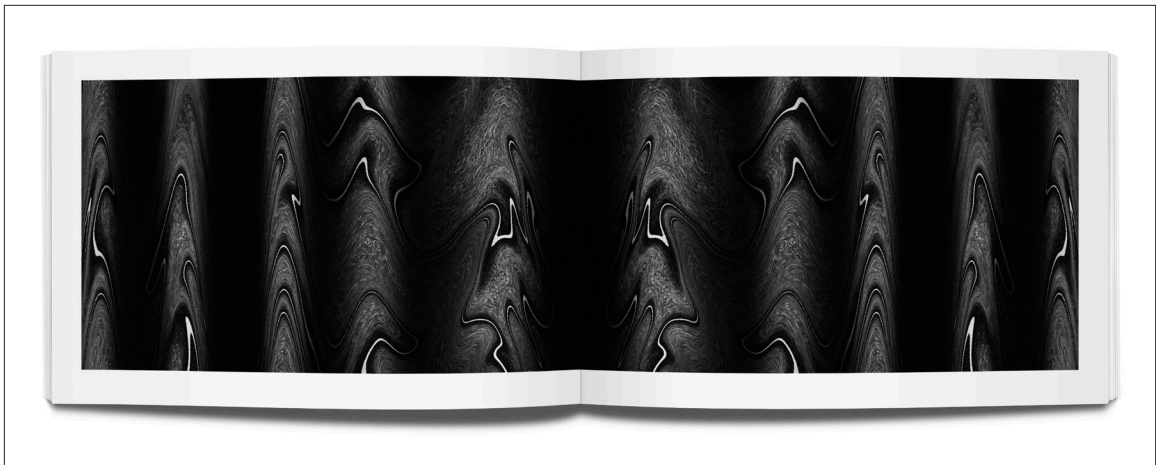


Fig. 16.5. Carter Pryor, *I Can't Sleep—I Feel*, 2021, book, 18"×12".

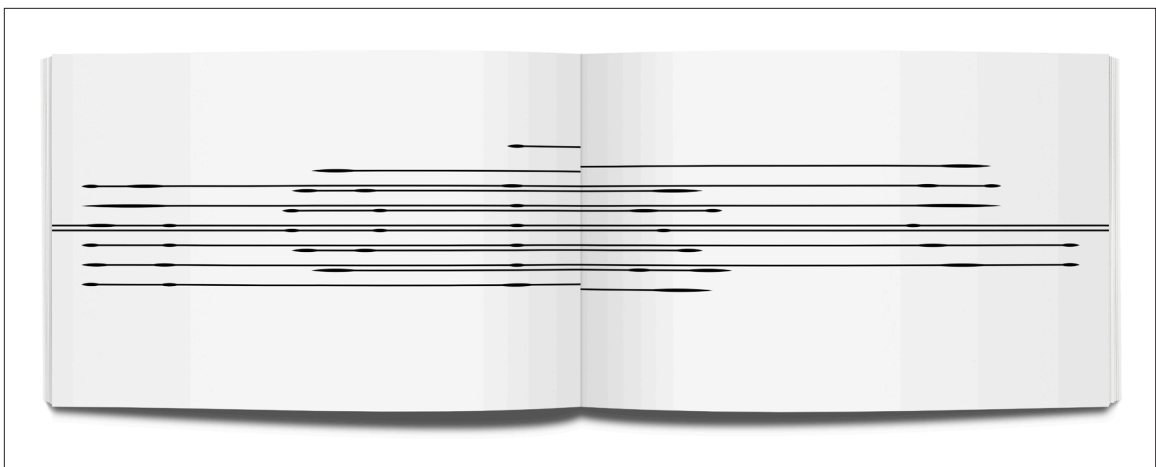


Fig. 16.6. Carter Pryor, *I Can't Sleep—I Feel*, 2021, book, 18"×12".

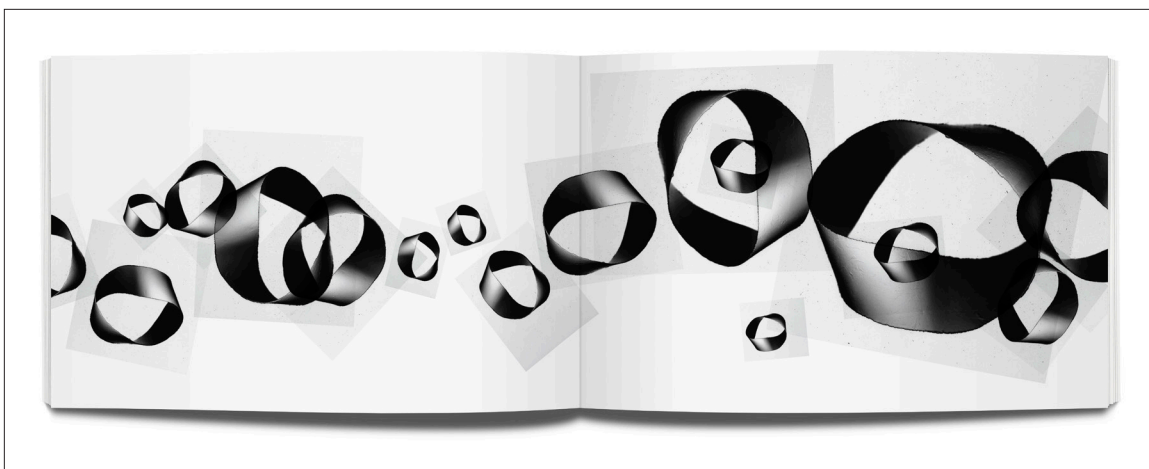


Fig. 17.1. Carter Pryor, *I Can't Sleep—Everyday*, 2021, book, 18"×12".

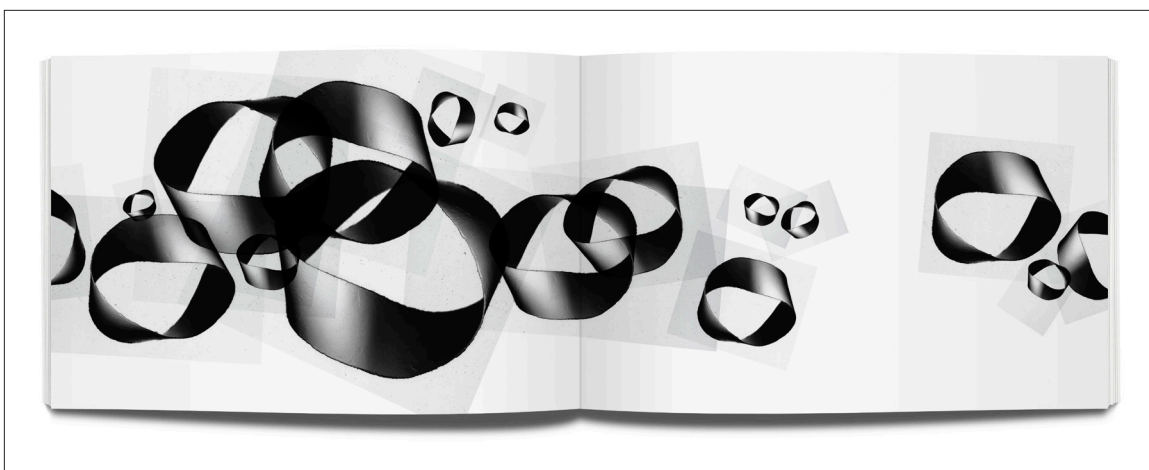


Fig. 17.2. Carter Pryor, *I Can't Sleep—Everyday*, 2021, book, 18"×12".

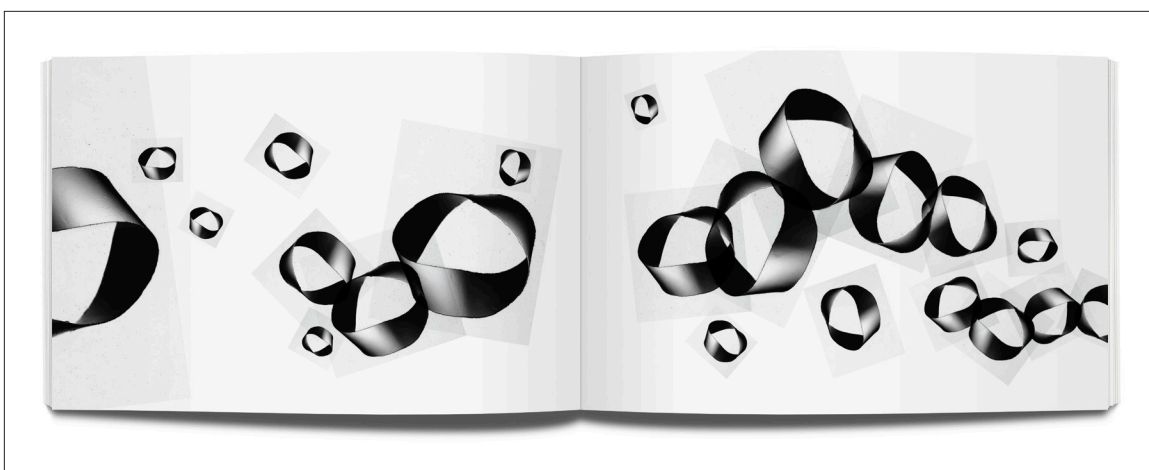


Fig. 17.3. Carter Pryor, *I Can't Sleep—Everyday*, 2021, book, 18"×12".

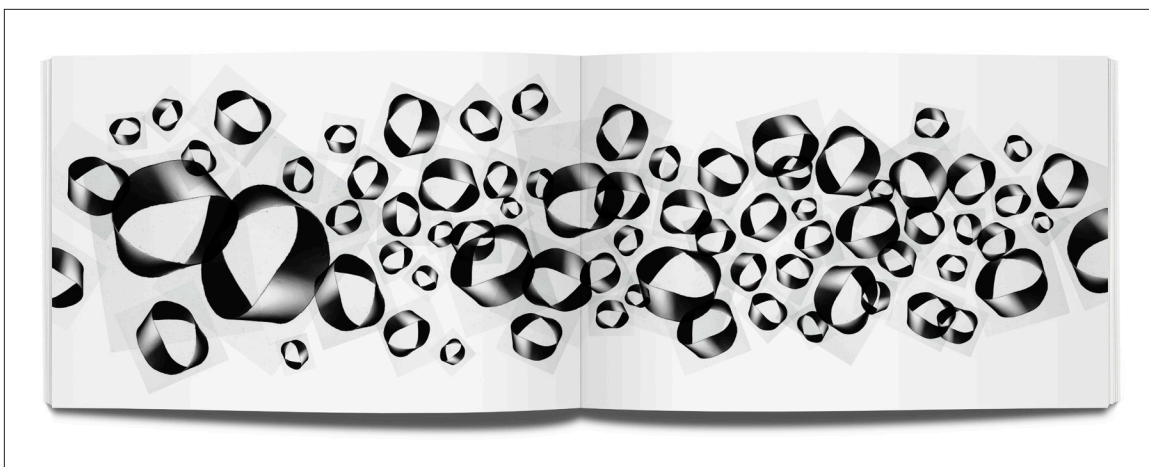


Fig. 17.4. Carter Pryor, *I Can't Sleep—Everyday*, 2021, book, 18"×12".

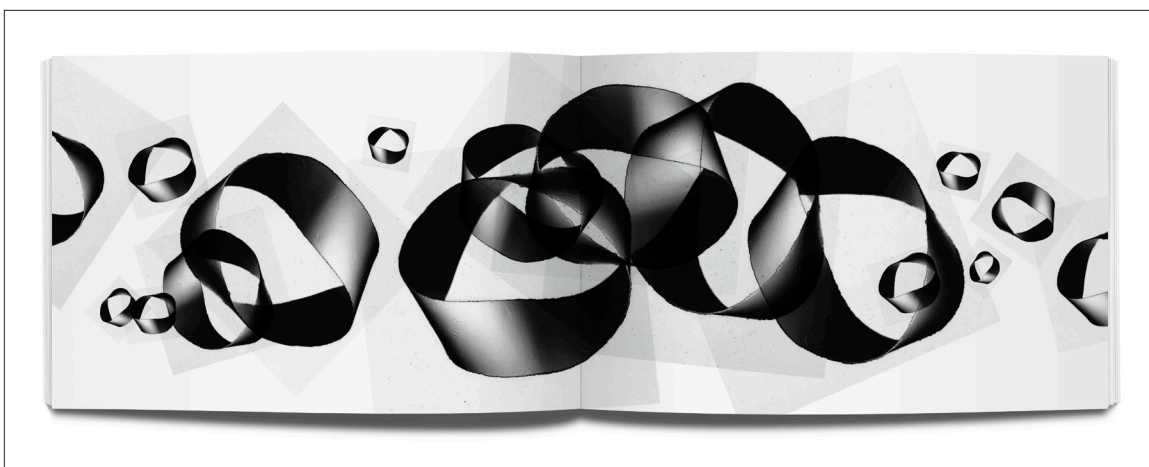


Fig. 17.5. Carter Pryor, *I Can't Sleep—Everyday*, 2021, book, 18"×12".

BOOK 3 — OBSTREPEROUS

My tinnitus deeply affects how I experience reading and writing. While most people tend to prefer reading and writing in quiet environments, they can be problematic spaces for me. When I read or write tinnitus draws my attention and I lose concentration on the task at hand. The dissonant tones in my head slowly overwhelm and corrupt my focus and my attention shifts to tinnitus. Coinciding with Colagrosso, et al.'s findings on the relationship between tinnitus and attention, my experiences affirm that "tinnitus seems to play a central role by drawing or monopolizing attention."¹¹⁶ Once my attention shifts, I have to stop, go back, reread what I have just read or written, and continue where I left off. Reading and writing are a two step forward, one step back process for me.

My third book, *Obstreperous*, meaning 'noisy and difficult to control,' visualizes my experiences of reading and writing. The book captures how tinnitus interferes with my concentration, resulting in a growing sense of frustration. This is another instance where a loss of silence has debilitating connotations, and it is this odd difficulty that I take up in the book *Obstreperous*.

3 — MATERIAL EXPLORATION & MAKING PROCESS

To begin material exploration, I reverted to earlier studies: sewing string through paper and the scoring book. Sewing white string through white paper created a visual and material interference using 'blank' materials, unified by piercing the page. I sewed lines into sheets of paper to investigate how this process could be used to block out the visibility of a page. I found that sewing multiple horizontal lines of string that gradually decrease in vertical spacing can reach a point where the paper underneath is no longer visible.

Thinking back to the scoring book, I created a second version to explore if the structure of a book could function as content (Fig. 18). I continued to use score lines to

¹¹⁶ Colagrosso, et al., 639.

damage white French-folded pages. I also continued to use the ear images as inserts, centred in every spread. I converted the ear images to black and white and obstructed the values to distort their expected appearance. All spreads remain identical to make the experience repetitive. The book is bound with an accordion fold which allows it to open 360 degrees. I then bound the book in hardcovers with embedded magnets. The magnets hold the book open at 360 degrees, this allows for a continuous reading experience in which it is easy to lose your place, become confused, and frustrated. The reading experience harmonizes with how tinnitus interferes with my experience of reading and my perpetual perception of tinnitus. This development of the scoring book brought me to consider how content can be a counterpoint to structure in visualizing an experience.

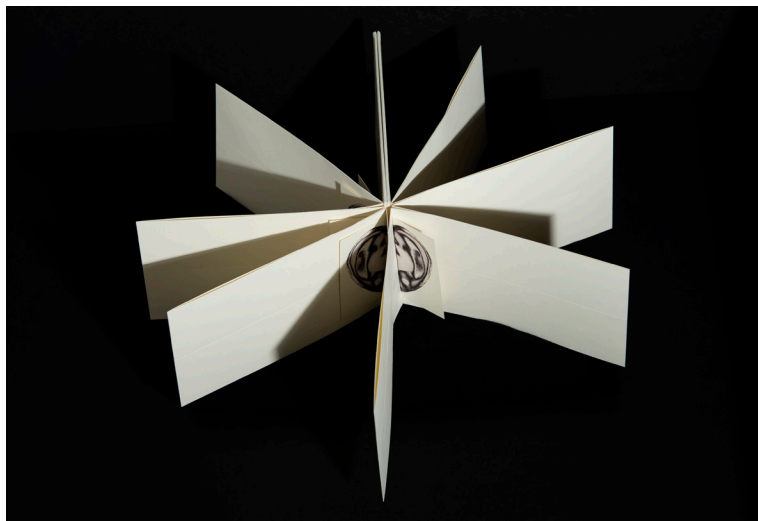


Fig. 18. Carter Pryor, *Scoring Book Version 2*, 2021, book, 8"×5".

I began to test sewing in spreads to explore how structure and content could be unified. Looking back to the scoring book again, I realized the French folded pages could hide string maneuvering between spreads. I could strategically plan the book to sustain one length of string sewn through every page. Furthermore, I could implement a binding method which used sewing so the string acts as both content and binding method. For me, the string becomes a representation of tinnitus interference that is inseparable from the book structure.

changes are added modestly to each drawing until I got to one that looked very frustrated, then I did one more to reach a cacophonous peak (Fig. 19.2). In total, I drew 16 asemic writings for the series (see Appx. G for asemic writings 1-16). Not all drawings were used in the book; over 50 drawings were created in total. I scanned my series of asemic writings and implemented them into the book design along with the sewn string.

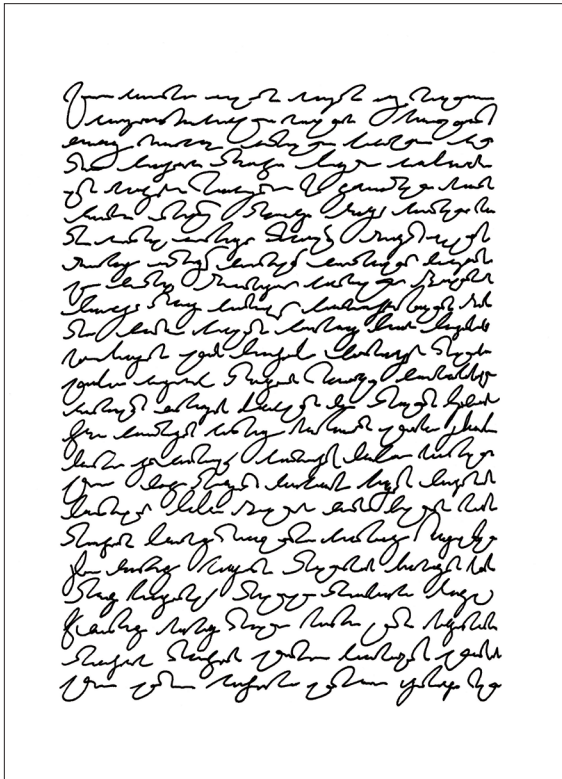


Fig. 19.1. Carter Pryor, Asemic Writing (Calm), 2021, ink drawing, 8.5"×11".

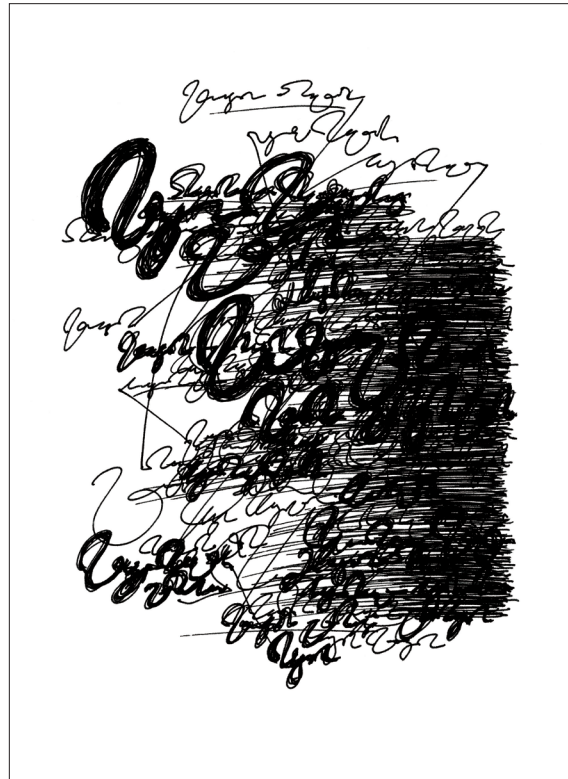


Fig. 19.2. Carter Pryor, Asemic Writing (Frustrated), 2021, ink drawing, 8.5"×11".

Obstreperous visualizes an abstract narrative of my experiences with reading and writing that begins calmly and progresses to crescendos of frustration. I begin the book with a small section of calm asemic writing revealed on the verso and string sewn horizontally across the spread leading into a descending downward step pattern on the recto. As the next few pages are flipped more of the asemic writing is revealed, maintaining a consistent tone, and the step pattern decreases to a flat line. Once the sewn line runs straight across

the spread, the asemic writing begins to integrate distortions and the string covers more and more of the recto. This progression builds to a crescendo of frustration where attention has been monopolized and concentration lost, at this point the spread pattern breaks. The asemic writing increases in size, bleeding across the spread, the string progression inverts and spans both pages symmetrically. The pages which follow are an intermission where distortion decreases, and string tones down to have less presence on the pages.

The book visualizes a second progression, then a final progression reaches the end of the writing before another instance of frustration can occur. This concludes the reading and writing experience. The book ends by displaying the full calm asemic writing drawing on the recto bleeding out to the right. The string emerges from the verso, stopping to highlight the left vertical alignment of the asemic writing. The experience of this reading or writing session is complete, but the interference of tinnitus and coinciding frustration will return, this is an ongoing struggle.

The book employs just a few key design elements, sewing and asemic writing. I use the elements to describe progression, calmness building to a crescendo of frustration, and interference in the context of reading and writing. A reality of how tinnitus affect is present, disclosing how the sounds I perceive in my head drastically alter these everyday experiences, experiences which I think should be peaceful and not require constant backtracking with negative psychological responses. The exploratory processes revealed how a book can communicate an experience by integrating structure and content, and how I can employ asemic writing to work in an abstract progressive narrative to formulate written meaning void of semantic content. The omnipresent string representing tinnitus interference does not break, it remains persistent throughout whether hardly noticeable or built up to a peak of frustration.

3 — BOOK ARTEFACT

Obsstreperous visualizes my personal experience of tinnitus affect as interference and progressive frustration occurring while reading and writing. The book makes my subject position explicit through a reflective making process that builds on the visual exploration conducted for the *I Can't Sleep* book series, and how I use autoethnographic data to inform the narrative. My data revealed a correlation of progressive experiences of frustration which are present in both reading and writing. Frustration is caused by tinnitus affect monopolizing my attention which brings a predictable difficulty to these activities.

Obsstreperous (Fig. 20) is a handmade Japanese-stitched hardcover book with heavyweight French-folded pages. The book is designed to a scale of 9.5"×8", for a 16" spread. The French-folded pages allow me to hide string maneuvering from one spread, so it does not interfere with the spreads that precede or follow it; the maneuvering of the string is hidden in folds. The book is strategically designed to use one unbroken length of string as both content and as a binding method, reflecting my tinnitus as a chronic condition—it does not stop. Aside from the black asemic writing, the book uses white on white with string and paper to have a subtle yet interruptive visibility. The book itself is difficult to handle, like tinnitus. The binding method and paper thickness asks for an unusual amount of effort to be used when flipping through the pages. The book cannot rest comfortably open on a spread; it closes on its own, making the reader lose their place, and have them find their way back to where they left off.

When a reader handles the book, they see the string which binds the pages and cover feeding in through the front cover. The string is sewn through the first few pages with a slight descent occurring in each spread. When flipping the pages, the reader will find that no spread can fully open. The string is measured and sewn to pull tight before it reaches a horizontal state, forcing spreads flat risks tearing the holds that position the string. The string is a constant interference for the reader, either by hindering their ability to hold pages open, or by covering parts of the pages. The calm asemic writing slowly reveals itself to the reader over a few spreads as a sewn descending step pattern comes to a flat line. The build to frustration

begins. As the reader flips through the next few spreads, they will see the asemic writing become more distorted as the string builds in coverage until they reach a visual crescendo of frustration. Two spreads follow the crescendo in a descend back to a visual calmness before a second build to frustration begins, but now beginning part way through the asemic writing rather than the beginning. The reader will reach a second crescendo of frustration, followed by another set of calm descending spreads. A third build begins but before frustration can occur the reader reaches the end of the asemic writing. Their progress through the visualized reading or writing experience has completed. The interference of string remains even after the asemic writing has finished. The reader follows the string as it feeds through blank spreads toward the end of the book, out the back cover and into the book spine where it began. The reader works their way through pages stung with tension, calmness progresses to frustration, and they conclude realizing that although this reading or writing session is complete, it will all happen again (see Appx. H for detail images of *Obstreperous*).



Fig. 20.1. Carter Pryor, *Obstreperous*, 2021, book, 8"×9.5".



Fig. 20.2. Carter Pryor, *Obstreperous*, 2021, book, 8"×9.5".

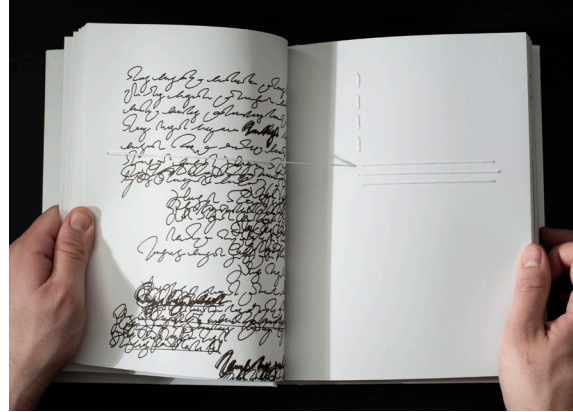


Fig. 20.3. Carter Pryor, *Obstreperous*, 2021, book, 8"×9.5".



Fig. 20.4. Carter Pryor, *Obstreperous*, 2021, book, 8"×9.5".



Fig. 20.5. Carter Pryor, *Obstreperous*, 2021, book, 8"×9.5".



Fig. 20.6. Carter Pryor, *Obstreperous*, 2021, book, 8"×9.5".

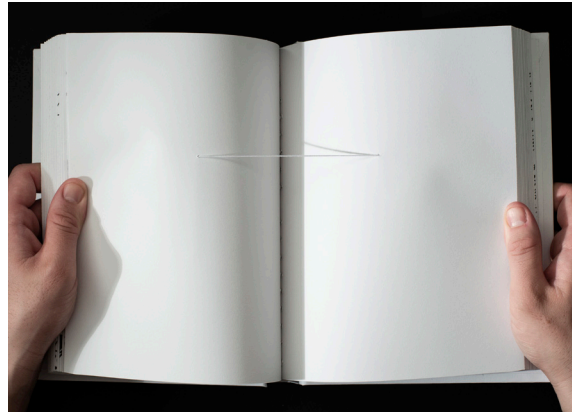


Fig. 20.7. Carter Pryor, *Obstreperous*, 2021, book, 8"×9.5".



Fig. 20.8. Carter Pryor, *Obstreperous*, 2021, book, 8"×9.5".



Fig. 20.9. Carter Pryor, *Obstreperous*, 2021, book, 8"×9.5".



Fig. 20.10. Carter Pryor, *Obstreperous*, 2021, book, 8"×9.5".

Conclusion

My thesis deploys graphic design to represent non-visual phenomenon, using my everyday experiences of living with the auditory disruptions of tinnitus as a basis for inquiry. The visualizations I developed are representations of personal tinnitus experiences which bring a material legibility to a non-visual disability. The visualizations are intended to inform public understandings of how experiences of tinnitus-affect debilitate its sufferers. My work is self-referential, the experiences explored are my own and do not speak for any tinnitus sufferer other than myself. While self-representation is an intimate exploration, by making my experiences materially legible and open for interpretation they can illicit relational experiences for fellow tinnitus sufferers and provide a visual understanding of tinnitus for the non-sufferer. Furthermore, though my thesis is local to my own non-visual disability, the research and methodologies participate in the broader discourse of how to bring a visual legibility to non-visual disabilities.

I locate my research in the body of contemporary design investigations at the intersection of design practice, disability studies, and qualitative research of tinnitus experiences. Feminist and sound visualization theories inform an RtD making process that employs autoethnographic data to visualize experiential knowledge. These synchronous methods and theories recognize and value subjective perspectives, validating my role as a hybrid researcher-sufferer (participant), and accept my knowledge of tinnitus as expertise acquired through approximately a decade of lived experience. My thesis design outcomes manifest as exploratory making processes and a series of three books which visualize personal experiences of tinnitus affect. The cumulative research provides an instance of how to visualize non-visual phenomenon using graphic design.

My process of visualizing non-visual phenomenon addresses a broader context of how the non-visual affects experience. I investigate how to visualize experiential affect, and acknowledge that the non-visual phenomenon is central to how the experience unfolds over time. My work visualizes how tinnitus affect as a non-visual disability participates in personal

navigation of common daily activates, and how this affect is a hindrance on my daily life. Nobel and Bestley vouch for personal exploration in stating,

*“the exploration of a theme that interests the designer, and the graphic response to that theme which might enlighten and help to describe new visual languages that are applicable to other graphic solutions, is a core part of the research agenda. In effect, this places the design methodology itself as a central component of the design process. The testing and development of a visual vocabulary relevant to a specific context may then be further developed in order to address a number of problems within that same context.”*¹¹⁸

The context of my thesis exploration, processes and outcomes can inform future investigations of subjective tinnitus experiences and the visual legibility of other non-visual disabilities. The subjective and non-reproducible aural experience of tinnitus makes my work particularly relevant. My years of living with tinnitus has given me experiential knowledge local to my own case that is impossible for anyone else to possess. I use my unique experiences to begin building visual languages and employ methodologies that can be referenced for future investigations in similar contexts.

My also work helps to expand the (currently) limited research in qualitative studies of tinnitus experiences that investigate the sufferer perspective. In addition to my hybrid researcher-sufferer role, my work (to the best of my knowledge) is the only research in this field that stems from a graphic design perspective. Graphic design is employed as an experiential storytelling and research device to discover possibilities of visualizing these instances of affect. The visual and material exploration becomes as much a part of the research as the book artefacts.

¹¹⁸ Ian Noble, and Russell Bestley, *Visual Research: An Introduction to Research Methodologies in Graphic Design* (Switzerland: AVA Publishing SA, 2005), 99-100.

I encourage more people with disabilities to use their experiential expertise to represent themselves and inform public understandings of valid experiences of disability. I believe our self-representation can work against stereotypical perceptions of disability, acknowledge the complexity of what it means to experience disability, and create relational experiences to evoke empathetic responses from others within our community.

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Appendix: A

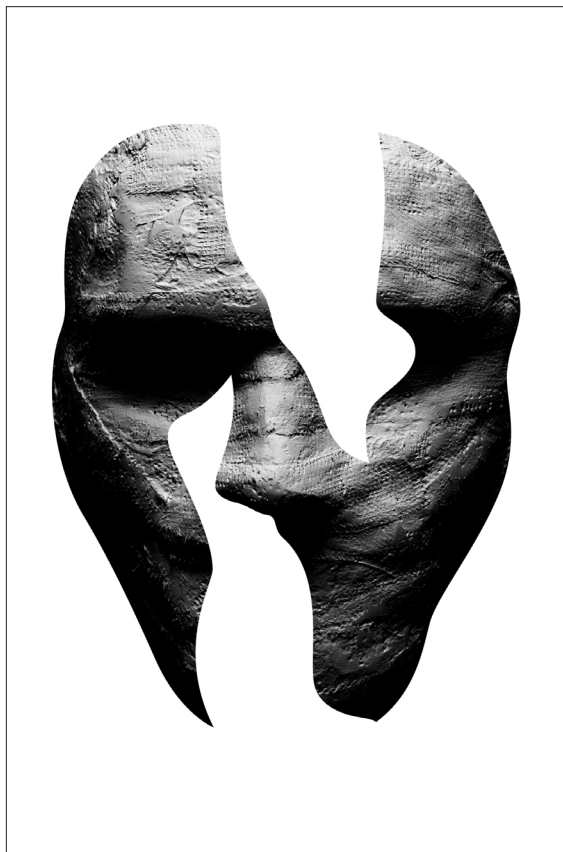
<p>___/___/2020 __: __</p> <p>Activity: _____</p> <p>Situation: _____</p> <p>Notes: _____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>2 TINNITUS JOURNAL</p>	<p>__: __ __/___/2020</p> <p>Activity: _____</p> <p>Situation: _____</p> <p>Notes: _____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>TINNITUS JOURNAL 3</p>
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Carter Pryor, *Tinnitus Journal Spread*, 2020, book, 4"×5.5".

Appendix: B—1

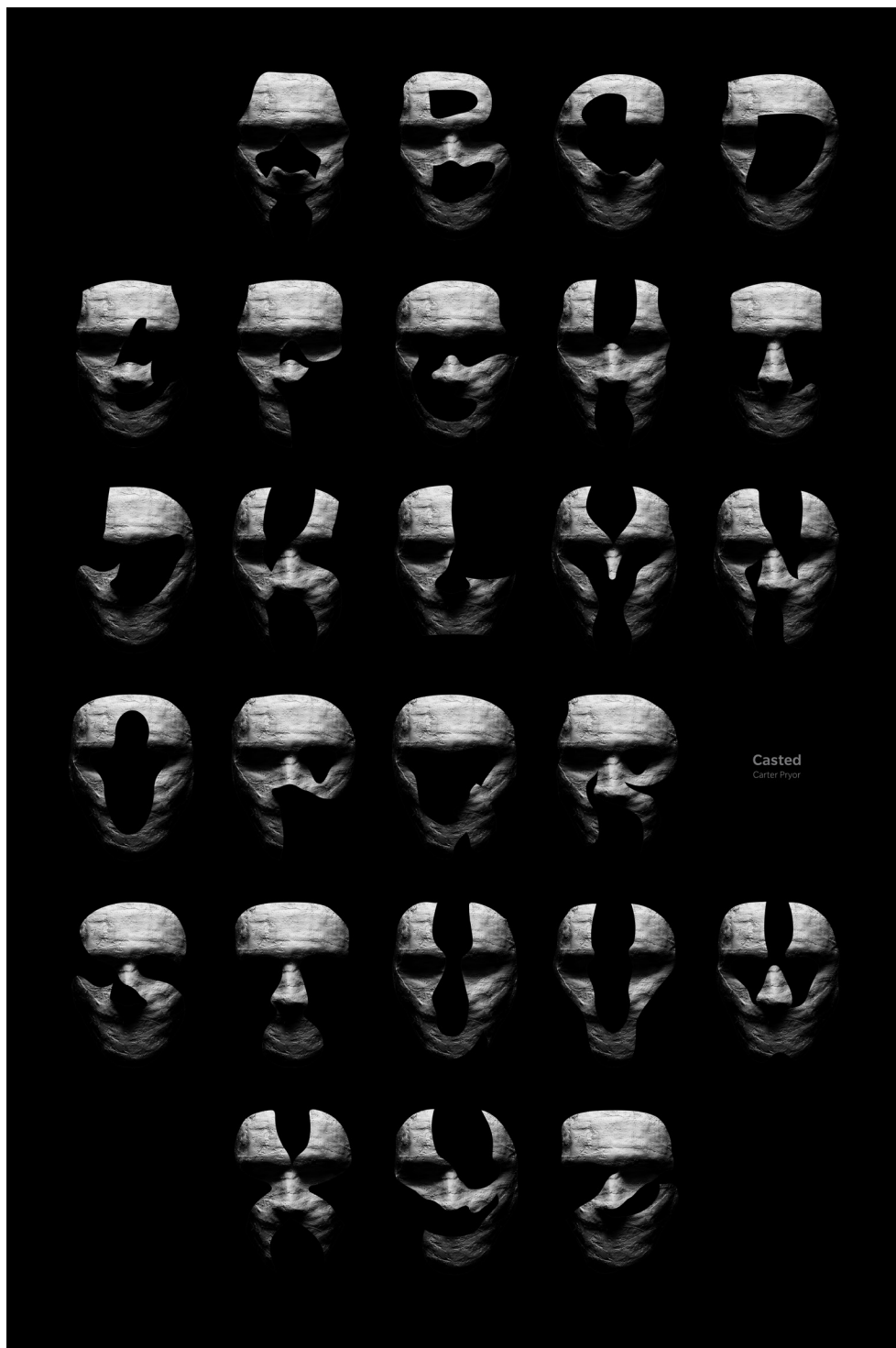


Carter Pryor, *Casted (Full Face Mask Image)*, 2020, photographic image.



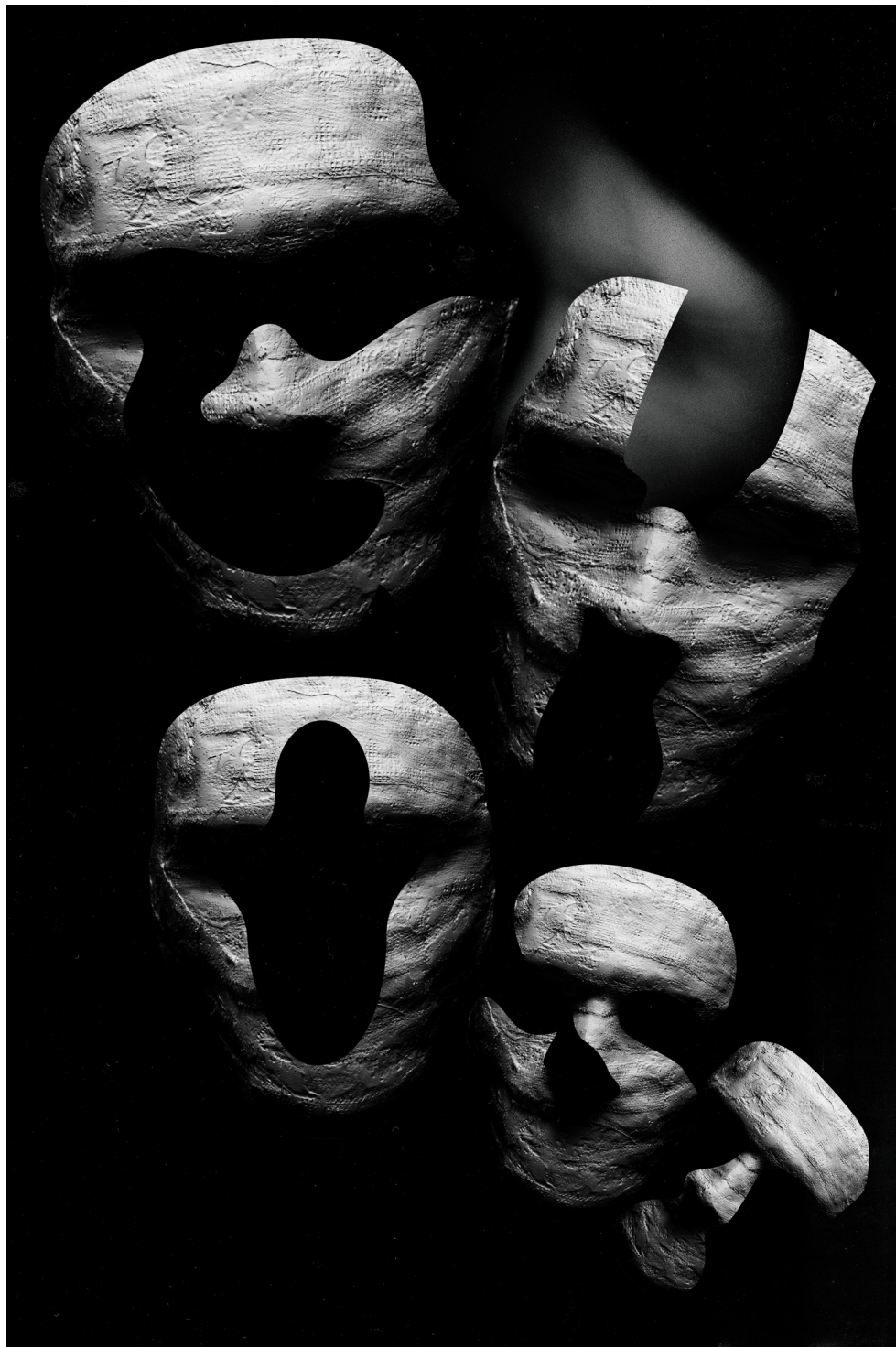
Carter Pryor, *Casted (Cut "N" Letterform Image)*, 2020, photographic image.

Appendix: B—2



Carter Pryor, *Casted Alphabet*, 2020, poster, 20"×30".

Appendix: B—3



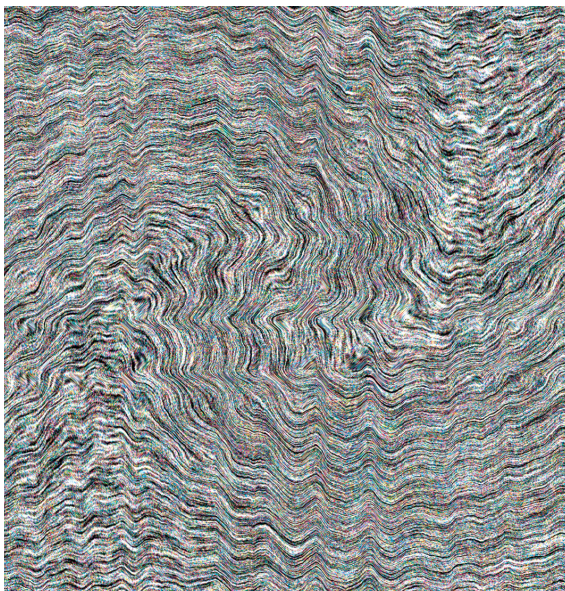
Carter Pryor, *Casted (Testing Letterforms In-use)*, 2020, poster, 20"×30".

Appendix: C

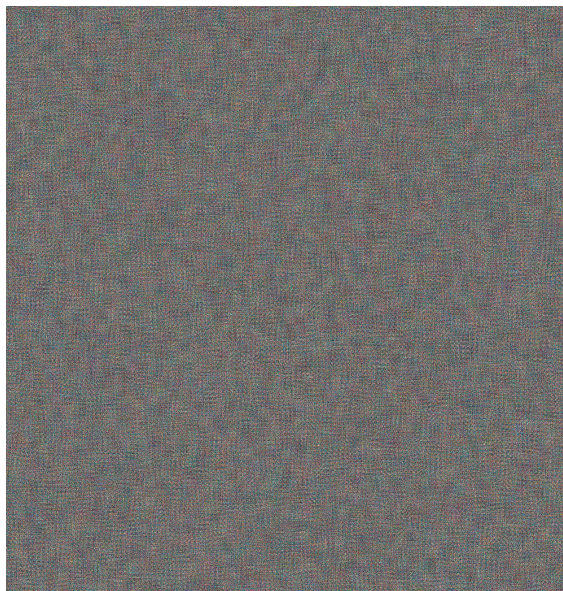
I have a ghost; we're bound for life.
Always present, always haunting.
It lives within, invading every woken moment.
Never alone, in an isolated margin my ghost is maddening company.
My ghost won't let me sleep, won't let me focus.
Moments of peace are pierced by an assailing haunt.
Agitation is inevitable and pacification is hindered.
My ghost lives unseen, non-visible, known only to me.
A moment of perceived silence is confirmation of presence.
Silence is Presence.
My ghost haunts and hinders my being, but I have learned to keep it at bay.
I can eclipse its presence, shadowing the tide of haunting with a mask.
Under this cover, my ghost is abated.
I wear many masks in my day, suiting most occasions.
My mask is a key; used to access sleep, to access focus.
I am calm in my mask, my mind bears clarity and comfort.
My mask is clarity, my mask is comfort.
Don't misread my words, my ghost is not defeated when my mask is on.
Rather, my ghost is patiently waiting.
All masks must come off, and with no intermission my ghost will return.
Invasive and persistent, I am without a modicum of solitude.
I must choose; wear my mask or succumb to the haunting.
Going without, open and exposed; this holds consequence.
My ghost haunts with nothing but anxiety, torment, frustration, distraction and pain.
My ghost is unremitting, attentive, and a glutton for haunting.
Every opportunity is seized.
All being said, I have no fear of my ghost.
I know its vocation and I understand our bond is inseparable.
I cope, I wear my masks to manage the burden.
But I am not happy, I am not at peace.
I'm tired, I am so tired.
The departure of my ghost would bring me no grief.
My masks offer transient relief, a reverie of a broken bond.
I've worn my masks for so long, I wish I could go without.
But alas, we are bound.
They are all I have to keep the ghost at bay.

Carter Pryor, *Keeping the Ghost at Bay Manuscript*, 2020.

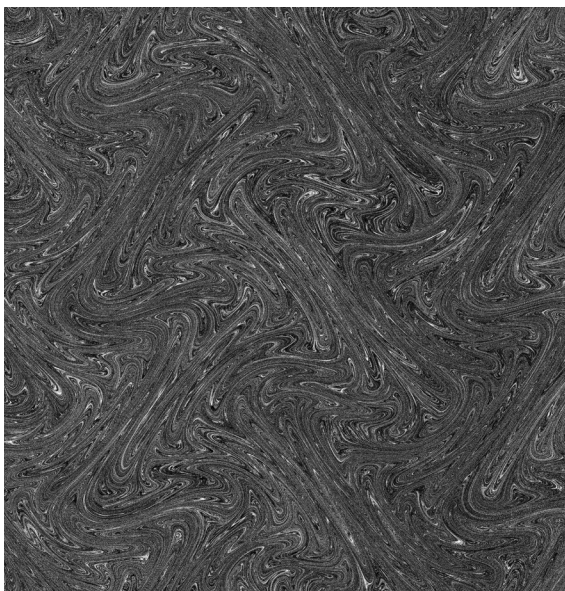
Appendix: D—1



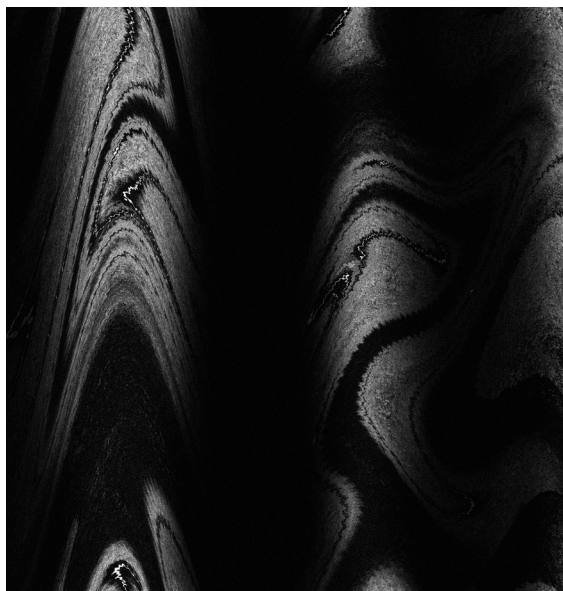
Carter Pryor, *Noise-wave Experiment*, 2020, digital image, 5"×5".



Carter Pryor, *Noise-wave Experiment*, 2020, digital image, 5"×5".

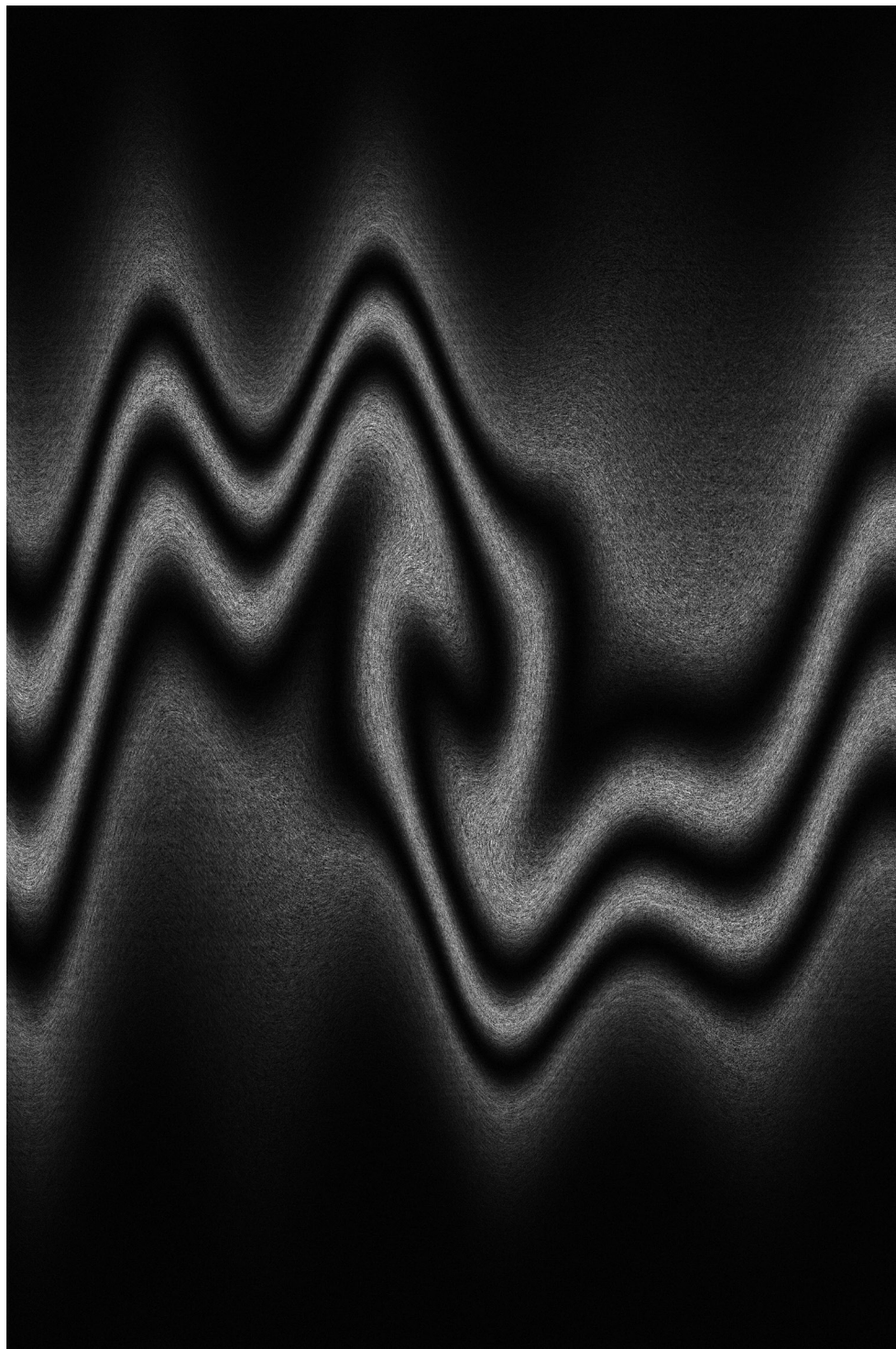


Carter Pryor, *Noise-wave Experiment*, 2020, digital image, 5"×5".



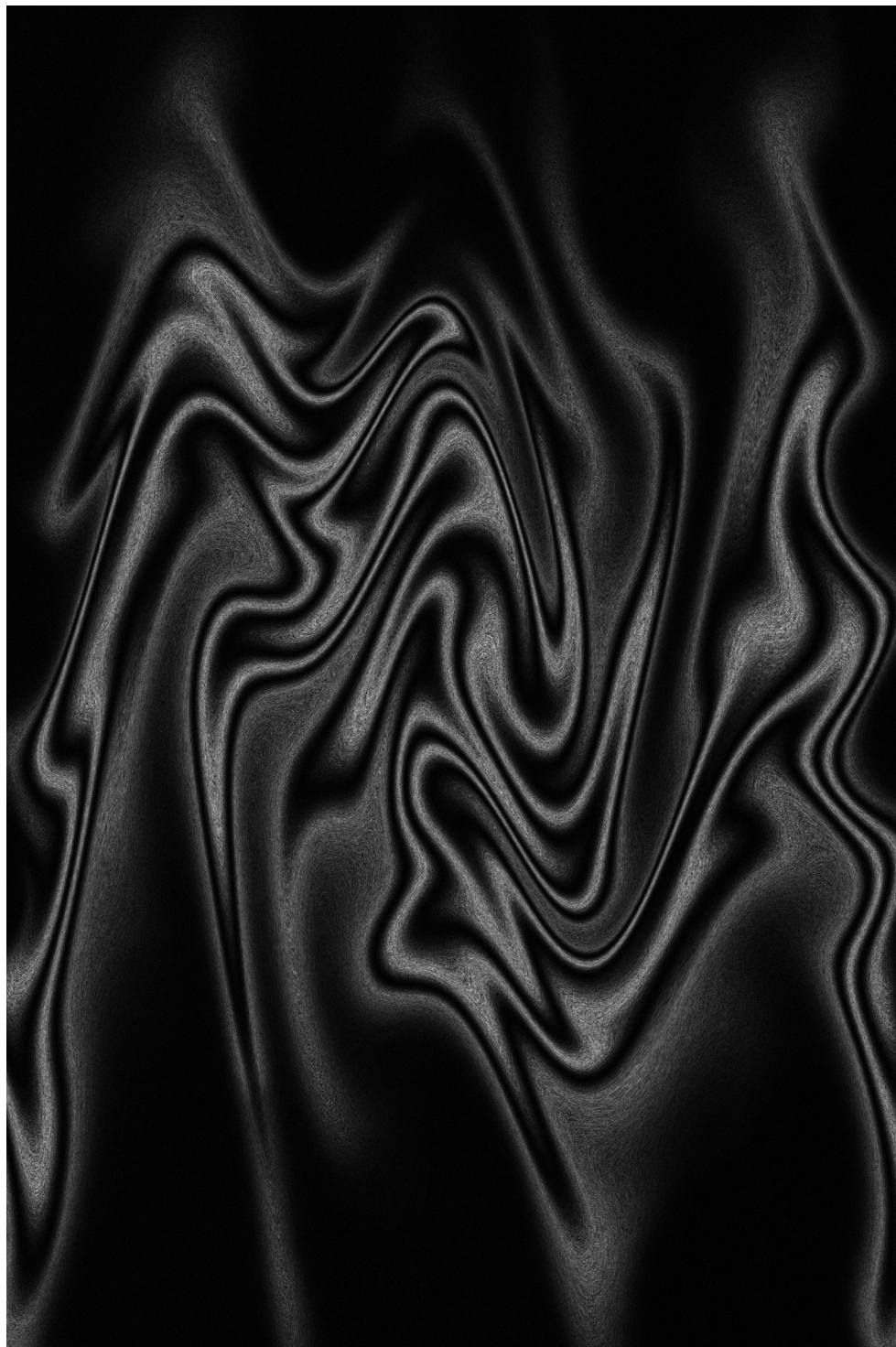
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Appendix: D—2



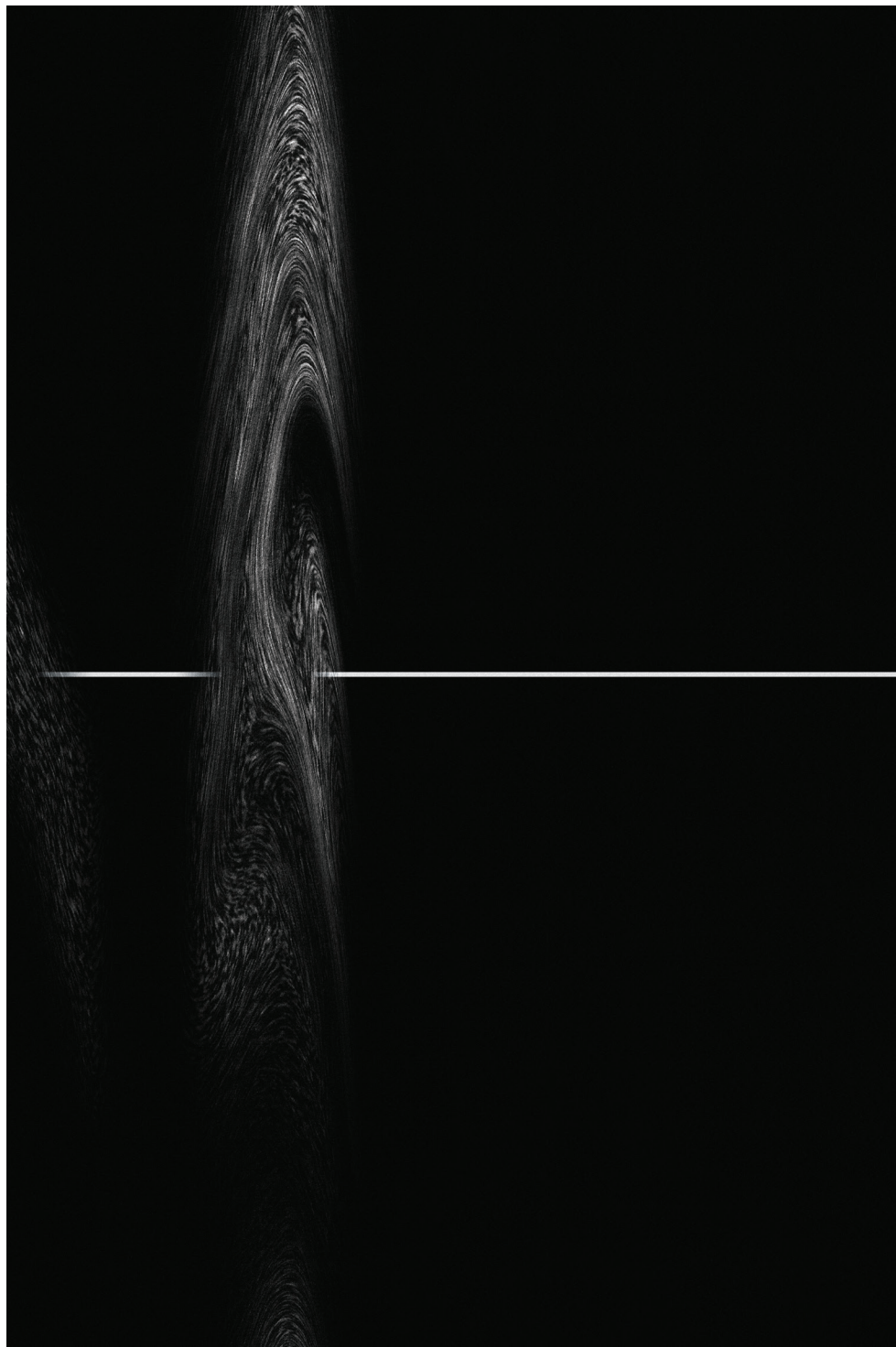
Carter Pryor, *Noise-wave Experiment*, 2021, digital image, 20"×30".

Appendix: D—3



Carter Pryor, *Noise-wave Experiment*, 2021, digital image, 20"×30".

Appendix: D—4



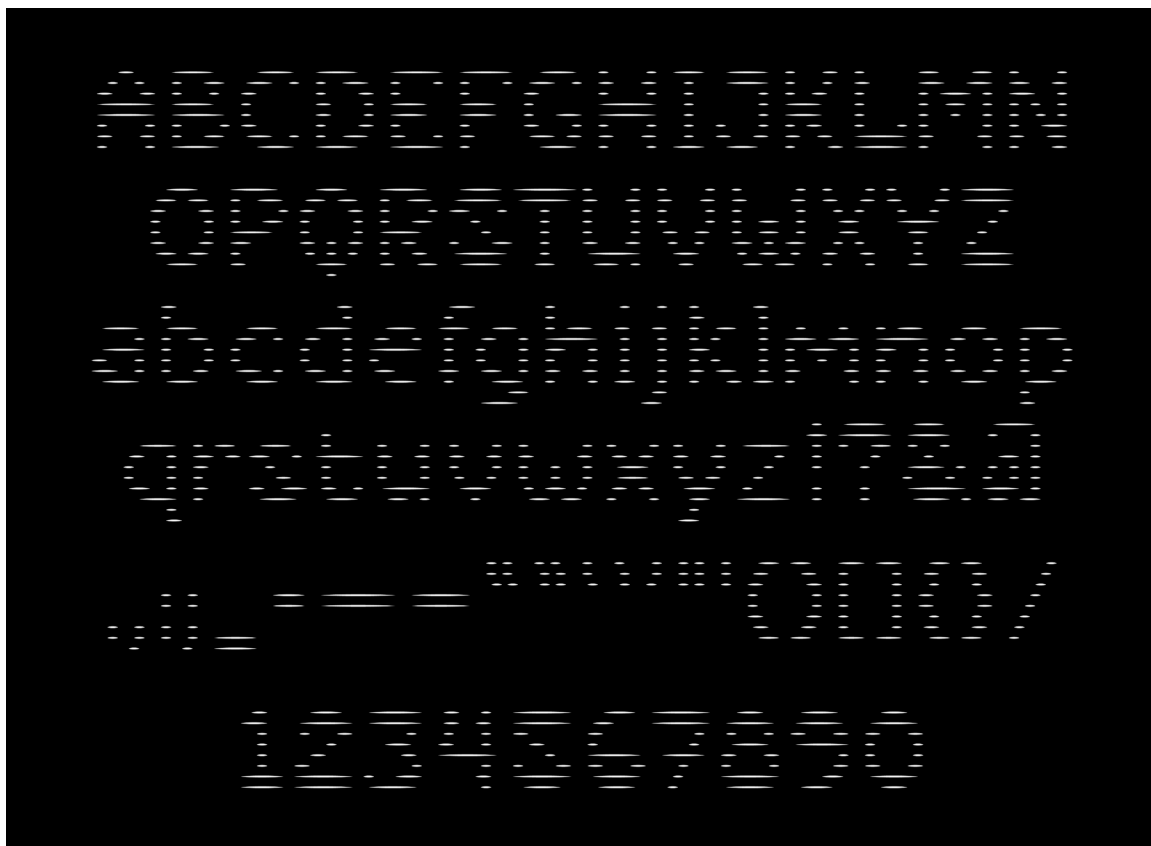
Carter Pryor, *I Can't Sleep Noise-wave Image*, 2021, digital image, 20"×30".

Appendix: D—5



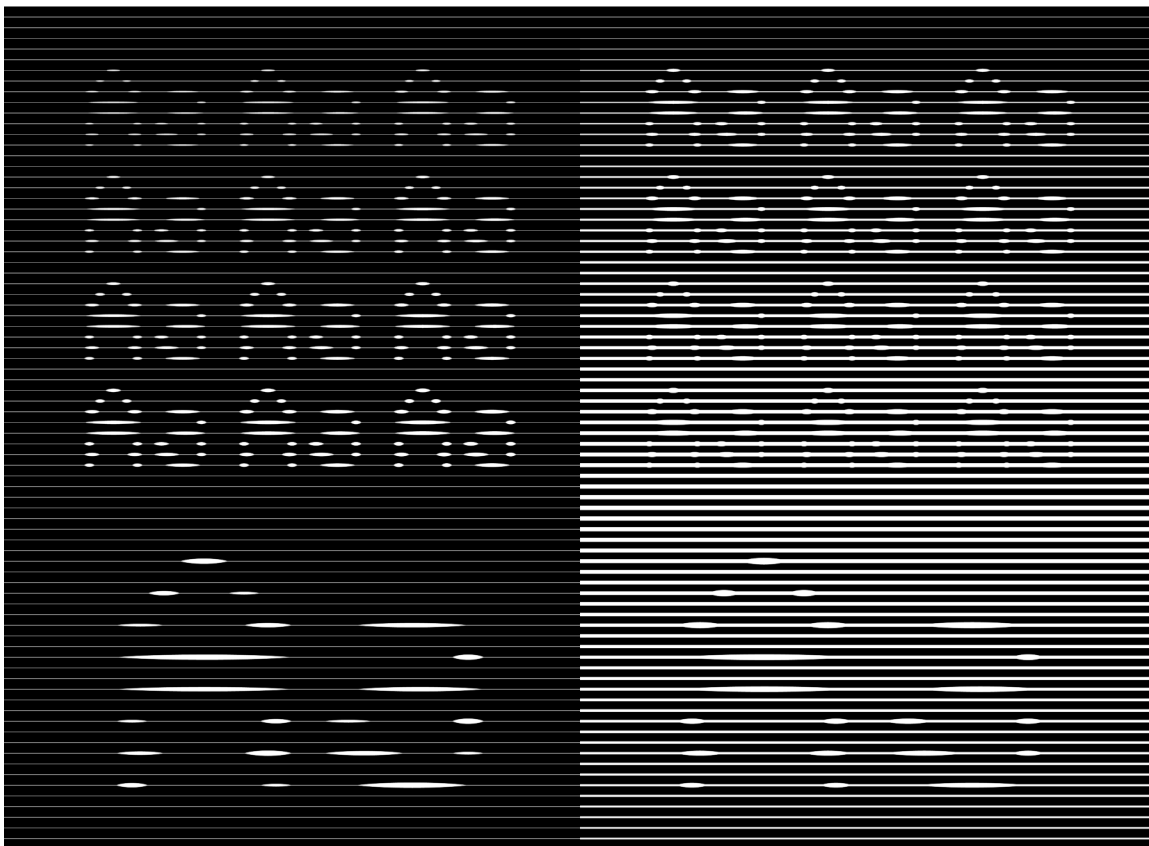
Carter Pryor, *I Can't Sleep Noise-wave Image*, 2021, digital image, 20"×30".

Appendix: E—1



Carter Pryor, *Spectre (Unlined)*, 2020, typeface.

Appendix: E—2



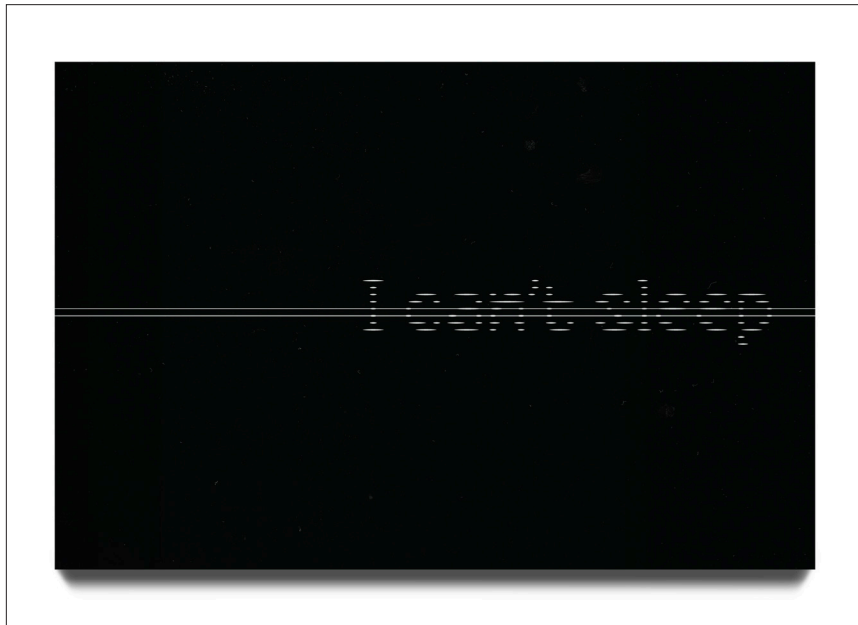
Carter Pryor, *Spectre* (*Variability Detail*), 2020, typeface.

Appendix: E—3



Carter Pryor, *Spectre (Testing Letterforms In-use)*, 2020, poster, 20"×30".

Appendix: F

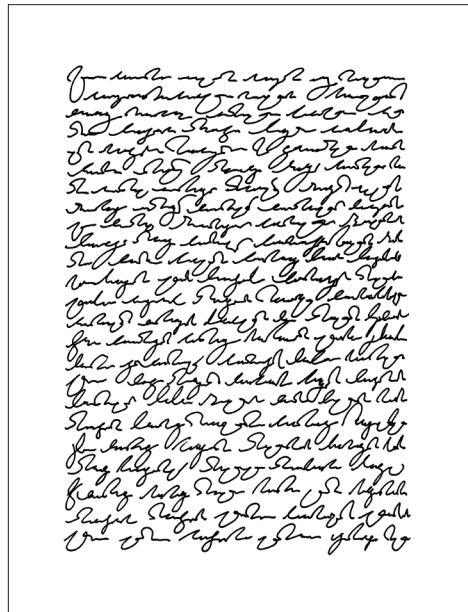


Carter Pryor, *I Can't Sleep Cover*, 2021, book, 18"×12".

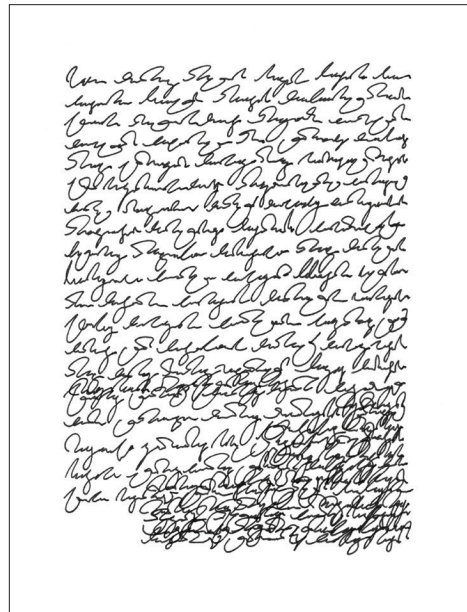


Carter Pryor, *I Can't Sleep End Pages*, 2021, book, 18"×12".

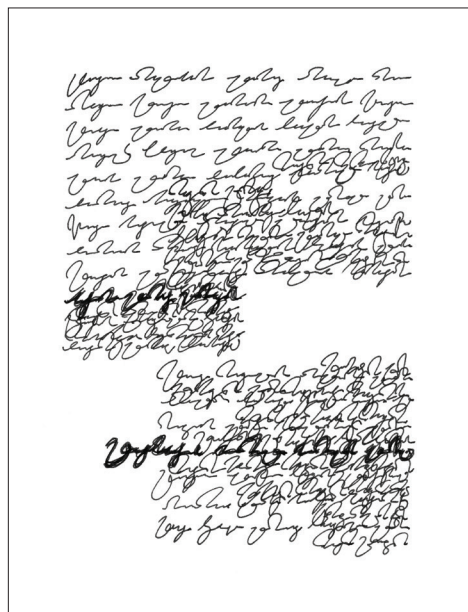
Appendix: G—1



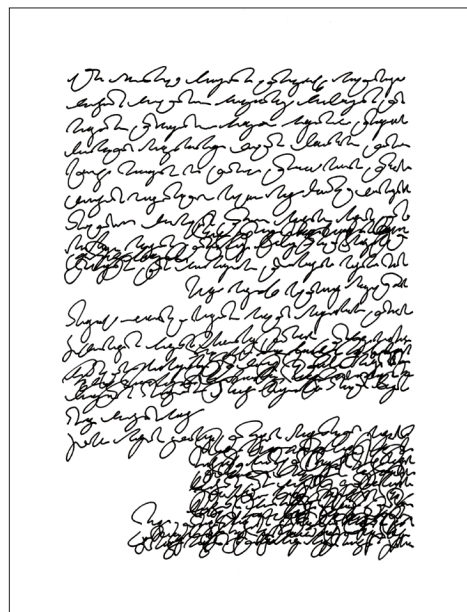
Carter Pryor, Asemic Writing (1 of 16), 2021, ink drawings, 8.5"×11".



Carter Pryor, Asemic Writing (2 of 16), 2021, ink drawings, 8.5"×11".

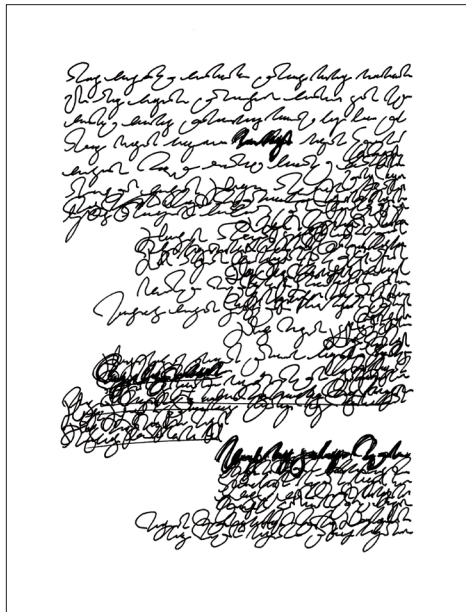


Carter Pryor, Asemic Writing (3 of 16), 2021, ink drawings, 8.5"×11".

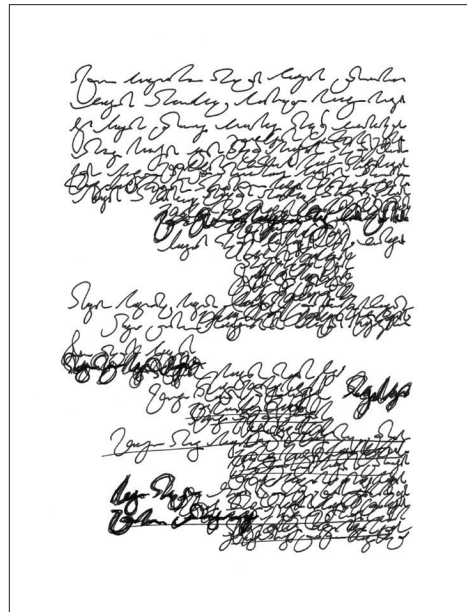


Carter Pryor, Asemic Writing (4 of 16), 2021, ink drawings, 8.5"×11".

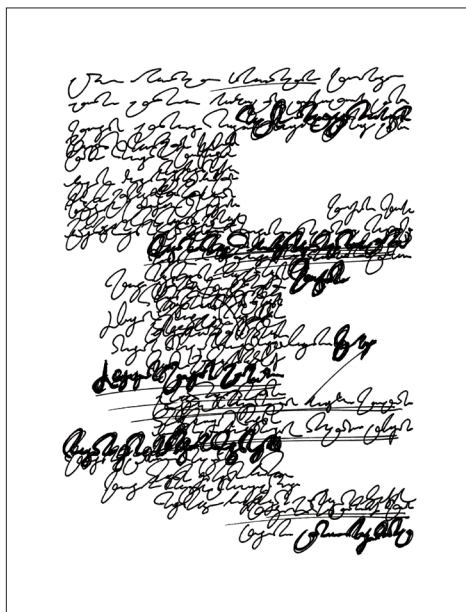
Appendix: G—2



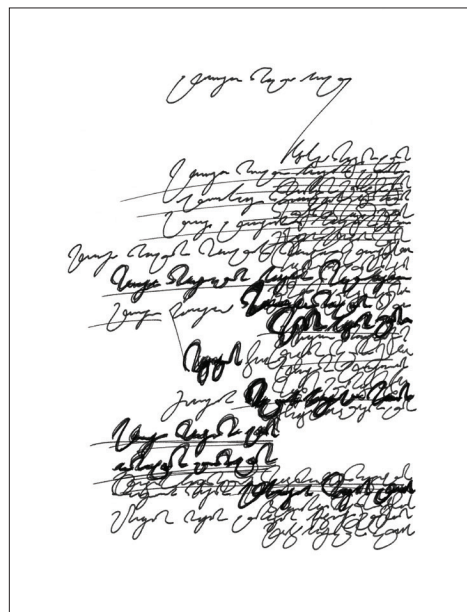
Carter Pryor, Asemic Writing (5 of 16), 2021, ink drawings, 8.5"×11".



Carter Pryor, Asemic Writing (6 of 16), 2021, ink drawings, 8.5"×11".

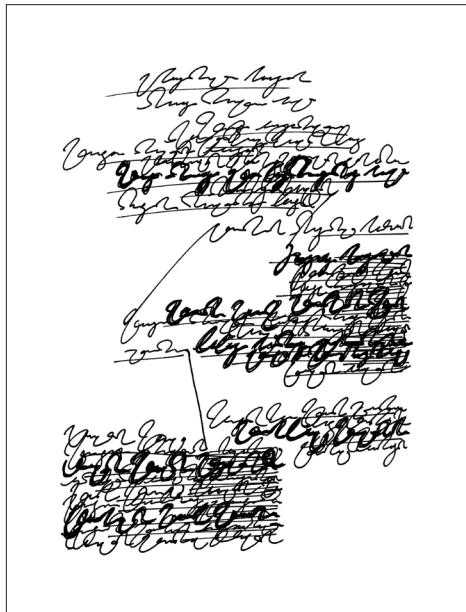


Carter Pryor, Asemic Writing (7 of 16), 2021, ink drawings, 8.5"×11".

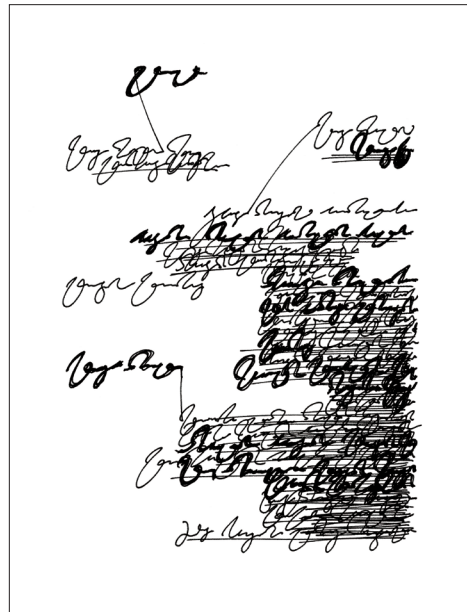


Carter Pryor, Asemic Writing (8 of 16), 2021, ink drawings, 8.5"×11".

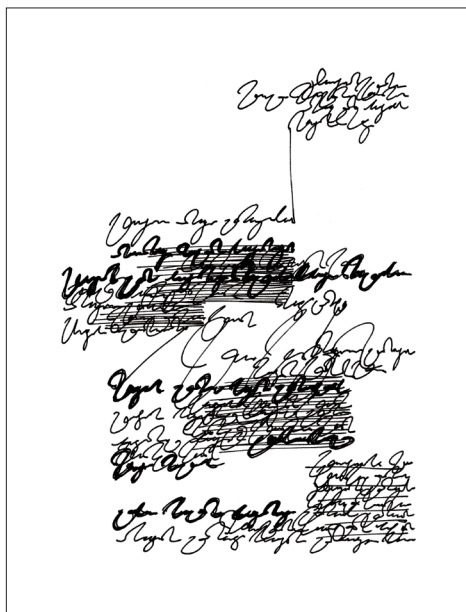
Appendix: G—3



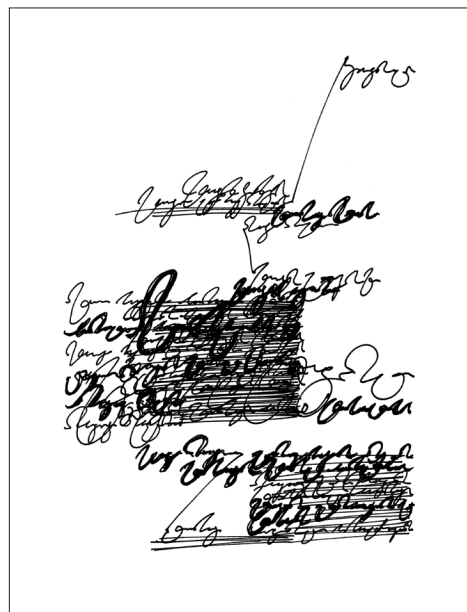
Carter Pryor, Asemic Writing (9 of 16), 2021, ink drawings, 8.5"×11".



Carter Pryor, Asemic Writing (10 of 16), 2021, ink drawings, 8.5"×11".

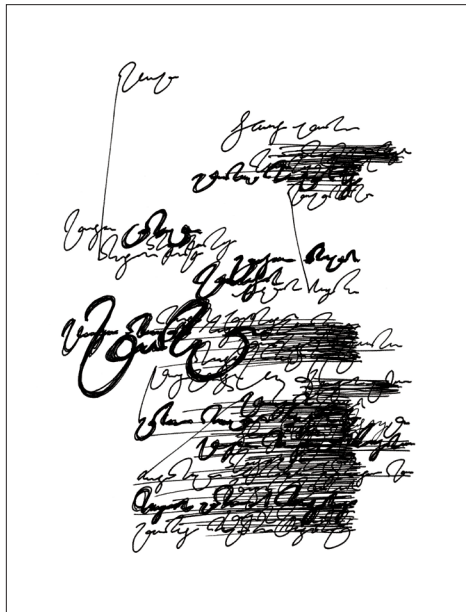


Carter Pryor, Asemic Writing (11 of 16), 2021, ink drawings, 8.5"×11".

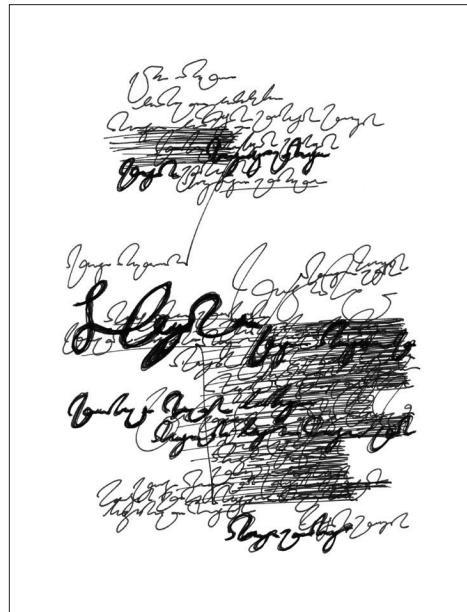


Carter Pryor, Asemic Writing (12 of 16), 2021, ink drawings, 8.5"×11".

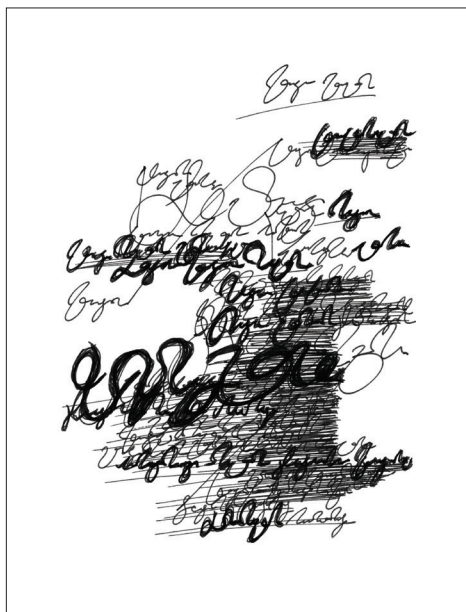
Appendix: G—4



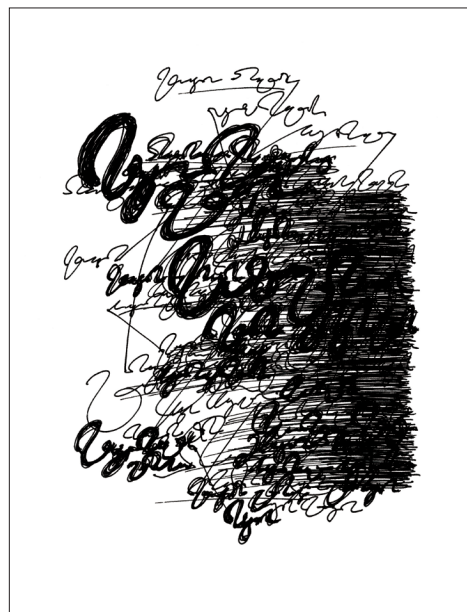
Carter Pryor, Asemic Writing (13 of 16), 2021, ink drawings, 8.5"×11".



Carter Pryor, Asemic Writing (14 of 16), 2021, ink drawings, 8.5"×11".



Carter Pryor, Asemic Writing (15 of 16), 2021, ink drawings, 8.5"×11".



Carter Pryor, Asemic Writing (16 of 16), 2021, ink drawings, 8.5"×11".

Appendix: H—1



Carter Pryor, *Obstreperous Cover and Spine*, 2021, book, 8"×9.5".

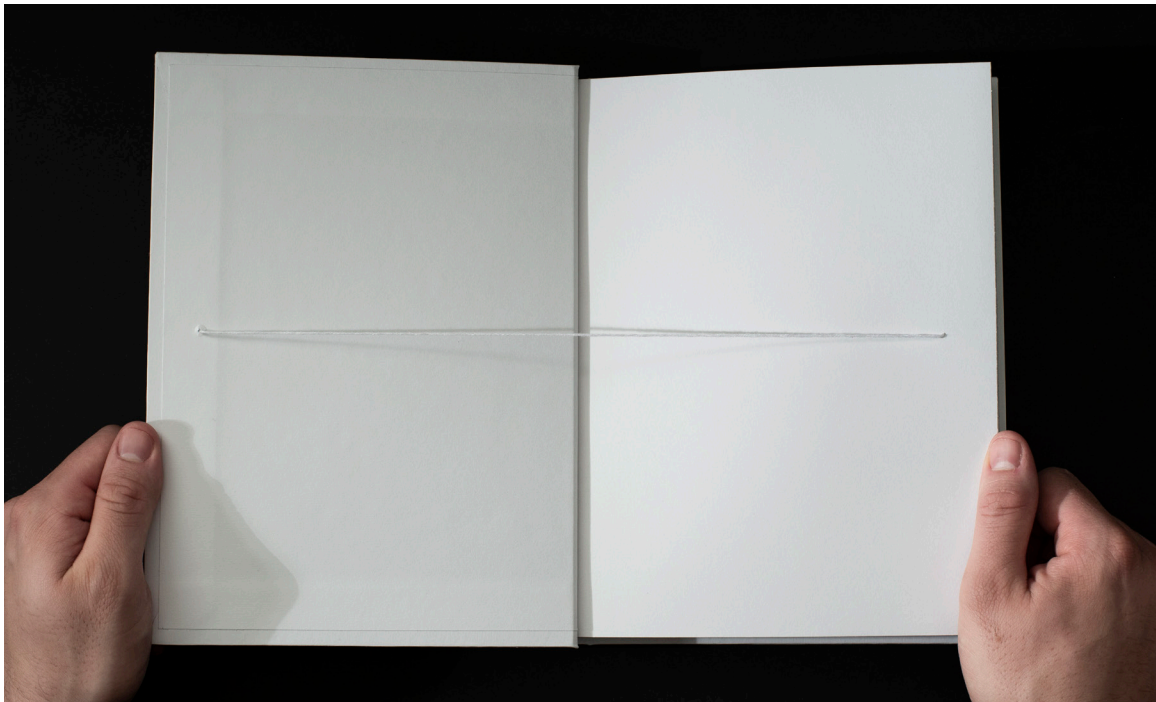


Carter Pryor, *Obstreperous Binding Detail*, 2021, book, 8"×9.5".



Carter Pryor, *Obstreperous French-fold detail*, 2021, book, 8"×9.5".

Appendix: H—2



Carter Pryor, *Obstreperous Inside Front Cover*, 2021, book, 8"×9.5".

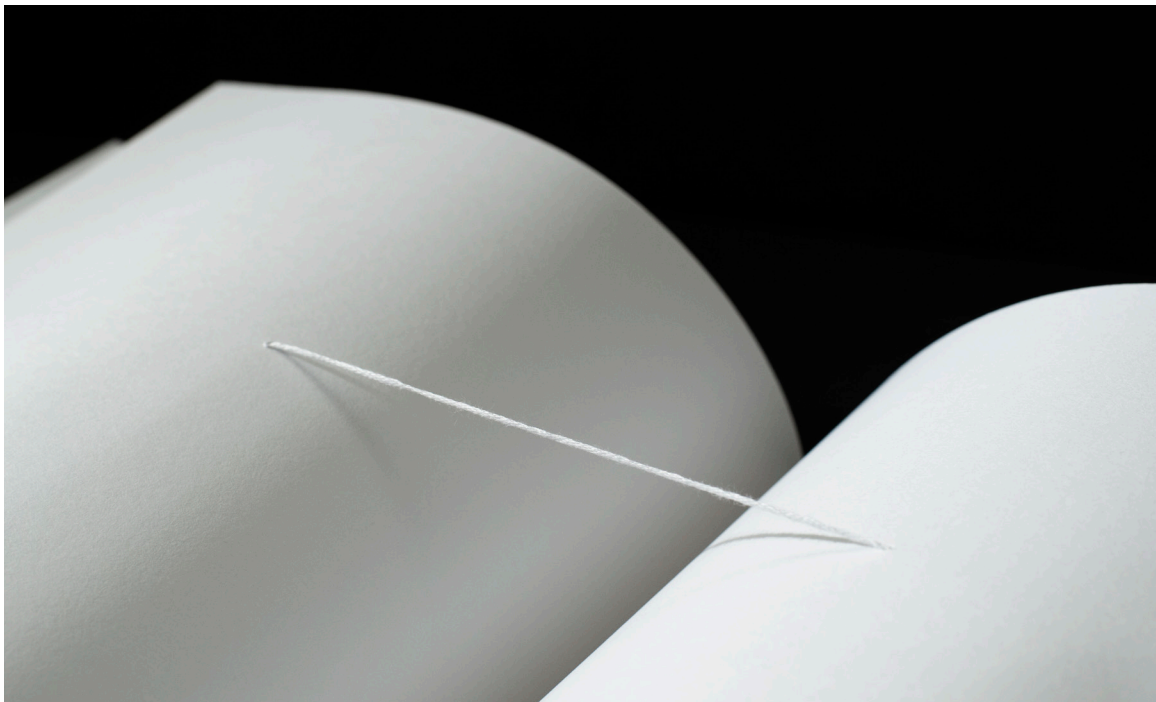


Carter Pryor, *Obstreperous Sewing Detail*, 2021, book, 8"×9.5".

Appendix: H—3



Carter Pryor, *Obstreperous Sewing Tension Detail*, 2021, book, 8"×9.5".



Carter Pryor, *Obstreperous Sewing Tension Detail*, 2021, book, 8"×9.5".