Listening by Design

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School of Art + Art History + Design

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Abstract

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Listening by Design

Let's change the culture of pain

Coreen Callister, MDes Thesis 2019
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ABSTRACT

With an estimated 7–10 million Americans currently opioid dependent, it's clear that our attempts to kill pain have paradoxically created the largest epidemic in U.S. history. We can't understand the opioid epidemic without unpacking pain—which is saturated in culture, history, and emotion. From neurosurgeons to addicts in recovery, *Listening by Design* is a collection of audio stories that reveal powerful insights about changing the culture of pain in America. Instead of killing pain, how might we manage it? Listening is a good way to start.

INTRODUCTION

"*Chronic pain now grips so many people in the postmodern era that it is commonly and justifiably described as an epidemic.*"

—David B. Morris, Illness and Culture in the Postmodern Age (1998)

To me, there's nothing more interesting in the world than other people. My experience as an HIV test counselor and palliative care researcher, initially taught me the monumental value of listening to people's stories. Not only did I learn a lot from folks I tested who used drugs, but I also developed a passion for reshaping sociocultural narratives about substance misuse that no longer serve us.

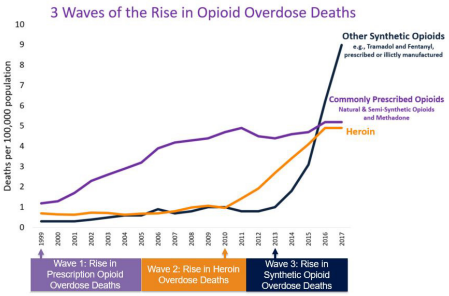
Listening is so much more than being quiet while another person speaks. It is a powerful way to connect with experiences that differ from our own. Listening is an essential skill for designers. It is the first step in creating engaging stories, which capture attention and ideally build empathy for others' lived experiences. By designing interactive listening experiences and capturing audio stories, my thesis explores how we might change the culture of pain in the United States today, through a focus on listening.

Over a nine-month span, I collected and produced a series of audio narratives, each told from a unique personal or professional perspective. From neurosurgeons to addicts in recovery, my thesis is a collection of stories that reveal powerful insights about changing the culture of pain in America. Throughout my research and design process, I wonder—***Instead of killing pain, how might we manage it?*** Ultimately, I believe that listening is a good way to start.

The human voice is unique in its ability to simultaneously emote and preserve anonymity, positioning it as a rich design medium for imparting empathy and reducing visual bias. My thesis explores how audio storytelling—the experience of recording and listening to oral narratives—can help create a more compassionate conversation about pain management. By listening to stories about various types of pain, addiction and recovery, and the constraints of the U.S. medical system, my goal is to inspire a more human-centered response to the opioid epidemic. This design challenge is ultimately about destigmatizing through storytelling and leveraging audio, the most "blind" medium, to demystify existing mental models.

BACKGROUND + PRECEDENCE

i. *Historical context*



3 Waves of the Rise in Opioid Overdose Deaths
National Vital Statistics System Mortality File

Our attempt to kill pain has paradoxically created the largest epidemic in U.S. history. We can't understand the opioid epidemic without unpacking pain—which is saturated in culture, history, and personal experiences. Throughout my research, I've learned that there are several nuanced ways to define pain. Pain can be a reflex, a habit, a memory or an emotion. However, there is a universally agreed upon definition of pain, promulgated by the International Association for the Study of Pain (about 40 years ago): "*Pain is an unpleasant sensory and emotional experience related to tissue damage, or described in such terms.*" According to neurosurgeon and world-renowned pain expert Dr. John D. Loeser (in an interview for this thesis), the last phrase of this definition is critically important: "'*or described in such terms.' Somebody has pain if they say they do, whether or not you can find the cause. And in many cases, you can't find the cause*" (recorded interview, April 2019, University of Washington, Seattle). In other words, we cannot understand chronic pain through a paradigm of "tissue damage" alone. Because "*all pain is generated in the brain*," pain is always a psychological state (Loeser, 2019). Unfortunately, a deeply rooted historical stigma about the validity of mental pain still persists. As David B. Morris writes in *Illness and Culture in the Postmodern Age* "*Mental pain becomes another name for 'no pain.' Like the Victorian women whose pain was dismissed as merely 'hysterical,' many patients today go through a demoralizing experience with doctors who conclude that the pain is not real because they cannot discover an organic lesion*" (Morris, 1998, p. 112). This pervasive and flawed cultural myth distorted the type of thinking that sparked America's opioid epidemic.

ii. *Current landscape*

"*Chronic pain now grips so many people in the postmodern era that it is commonly and justifiably described as an epidemic*" (Morris, 1998, p. 108). Pain is the number one symptom that brings patients to doctors and yet, no medical school has a chronic pain curriculum. A 2011 study found that U.S. medical school's spend a median of seven hours focusing on pain (Tauben, D. & Loeser, J., 2013). "*Many chronic pain sufferers discover that when drugs prove ineffective, conventional biomedicine, has little to offer them*" (Morris, 1998, p.112).

The opioid epidemic is effectively a result of high doses prescribed in the 1990's, a symptom of ineffective medical training. By treating various types of pain with pain killers, our medical and pharmaceutical systems effectively hooked millions of Americans on highly addictive prescriptions. While "*there is no place for opioids in the treatment of chronic pain*" (Bruce Callister, PA-C, Family Practice Medicine,

recorded interview, March 2019), we find ourselves in an era when the focus has shifted from treating pain to treating drug dependency.

In 2017, more than 72,000 Americans died from drug overdoses, far surpassing both car accidents—about 40,000 fatalities, and gun violence—nearly 17,000 fatalities (CDC, Morbidity & Mortality Weekly Report, 2017). Americans are in the throes of an opioid epidemic. As designers, we might recognize this public health crisis as a "Wicked Problem"—a unique societal challenge that is actually the symptom of another complex problem (Rittel & Webber, 1973). In this case, the opioid epidemic is a symptom of pain and a fundamental mix-up between how we treat it and how we manage other types of human suffering. By its medical definition, pain is "discomfort caused by injury." Physical pain causes suffering, but so does emotional hardship, such as grief or trauma. When doctors take the Hippocratic Oath, they swear to "prevent or reduce human suffering." But the primary care system is overloaded, meaning general care practitioners can usually spend only 10-15 minutes with each patient. "*Doctors who average seven minutes per patient simply lack the tools and time necessary to hear what chronic pain patients could tell them*" (Morris, 1998, p.112). This sliver of time makes it nearly impossible to distinguish between patients who have "discomfort caused by injury" and those who report (and feel) pain as a result of suffering the complexities of emotional distress. In either case highly addictive pain killers are being thrown at people who report pain to their doctors, and the consequences are devastating.

"*Doctors who average 7 minutes per patient simply lack the tools and time necessary to hear what chronic pain patients could tell them.*"

—David B. Morris, Illness and Culture in the Postmodern Age (1998)

iii. *Why design?*

Surgeon General's first ever report on addiction and recovery in America (2016).

In 2016, the United States Surgeon General released the first ever report on addiction and recovery in America—a three-pound, phonebook-sized review of what we know about substance misuse and a call to shift the way addiction is looked upon and responded to in this country. "*We're going to stop treating addiction as a moral failing and start seeing it for what it is: a chronic disease that must be treated with urgency and compassion*," said Dr. Vivek H. Murthy, former Surgeon General (under the Obama Administration). Chapter 7 of the report, "Specific Suggestions for Stakeholders," calls on a range of disciplines to "*do their part to change the culture, attitudes, and practices around substance use and to keep the conversation going until this goal is met.*" Of the many disciplines that could tackle the stereotypes and attitudes that plague addiction, designers are especially well-poised to respond.

We know that design isn't just problem solving. A successful design practice combines rational, wicked problem-solving with emotional storytelling to invite curiosity and draw people into engaging with products, systems and experiences. Moreover, complex societal challenges like the opioid epidemic require multiple, sophisticated solutions. Including, a significant understanding and communication of its nuances and root causes. Herein lies the immense value of leveraging creative skills to synthesize and represent a complex problem into more digestible components. In other words, "*the process of solving a problem is identical with the process of understanding its nature*" (Rittel & Webber, 1973).

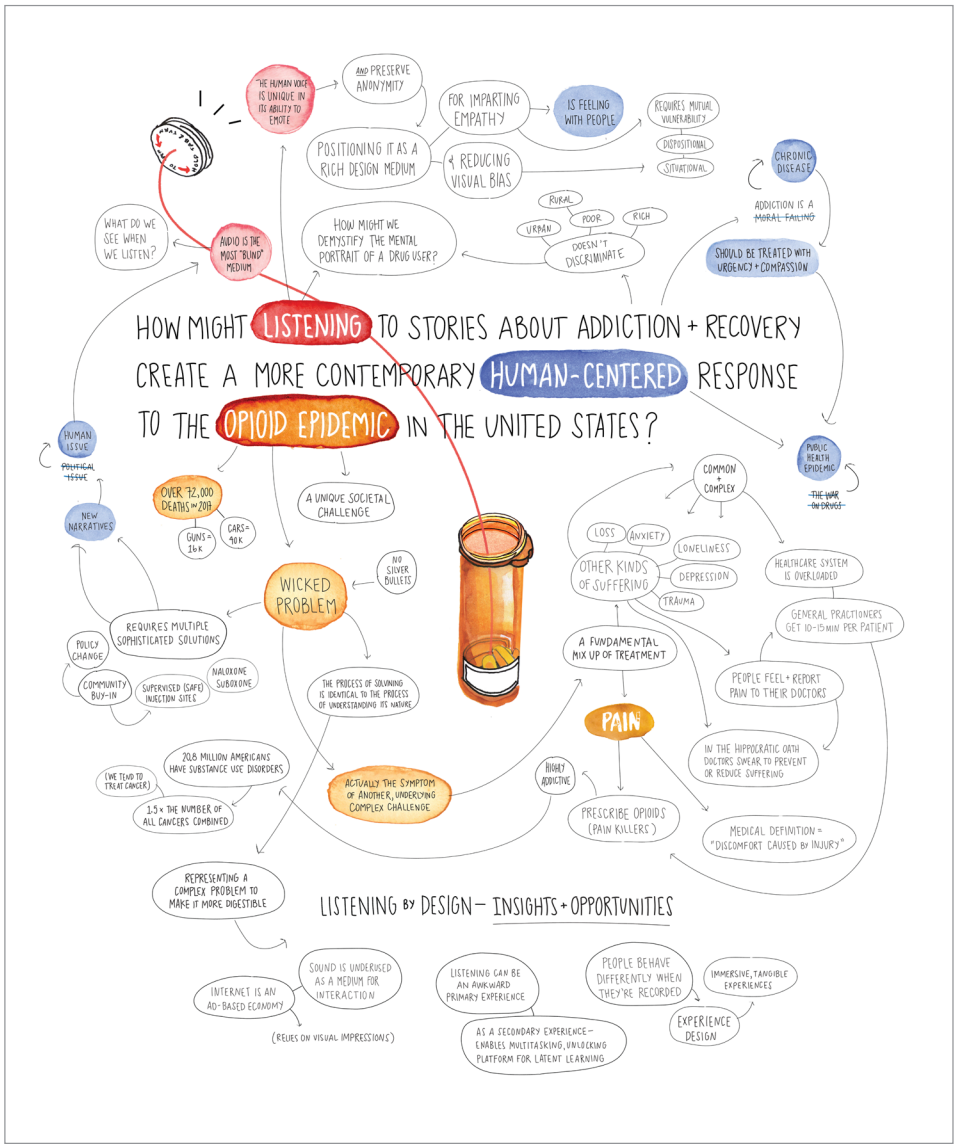
Ellen Lupton's 2017 manifesto

Designers are also experts at leveraging narrative to increase awareness of others' lived experiences—an effective strategy for cultivating empathy. In her recent (2017) manifesto Design is Storytelling, Ellen Lupton thoughtfully holds an emotional lens to systems and experiences that may appear purely practical or transactional at first glance. "*A subway is more than a rational system. It is a place where people fall asleep, fall in love, get drunk, get lost, and sometimes take their lives. Trains rumble,*

platforms murmur, and ads hawk everything from underpants to wrinkle cream." By reframing a people-mover as a system that also moves people, Lupton reveals a rich landscape for designing with inner, emotional worlds in mind, ideally building more dynamic and meaningful relationships between people and experiences. Lupton points out that a rational approach to design leaves far too many tools on the table. "*What about beauty, feeling, and sensation? What about humor, conflict, and interpretation?*" she asks.

PROCESS + PROTOTYPES

I conducted thesis research in San Francisco, Seattle, and Copenhagen. I interviewed people about their personal and clinical experiences with pain and opioids—recording audio stories and building them into a podcast called *Changing Pain*. To learn the technical craft of audio production, editing, and storytelling, I participated in a podcasting fellowship through a *University of* Washington Library Sciences Fellowship. Throughout the fellowship, I learned how to capture quality audio, gained experience with creatively editing around glitches, developed a process for converting many hours of interview "tape" into audio transcripts, and eventually into compelling short form stories with music as a supporting element (e.g. for



Research poster illustration, University of Washington MDes Process Show (December 13, 2019).

points of transition in a story or tone). Ultimately, my greatest learning was creating a method for radically synthesizing long form interviews (often more than one hour in length) into bite-sized, engaging and informative stories of 4-8 minutes that I featured in my final thesis installation.

Given the narrative element and complexity of pain as a topic, I took visual notes as a way of synthesizing the diverse interviews—recorded with family and friends, addiction and public health experts, and the medical community—as well as the rich body of written research on pain within culture. This process helped me map complexities, find common threads, and connect nuances across a heavy amount of content. What took hold was a drawn journalism practice, the result of which became the visual identity of my thesis and a quick way to communicate the complex relationships nested within a wicked problem space.

During autumn quarter 2019, I lived in Copenhagen Denmark as part of the University of Washington College of Built Environments *Scan | Design Fellowship*. Over the course of three months, I learned from the coHERE research team at Copenhagen Institute of Interaction Design (CIID). Based on the insights of the team's long-term project, which focused on listening as a key interaction in the context of museum and through contemporary narratives about European heritage, I explored what it feels like to share personal stories in public places. I learned that stimulating engagement, especially with sensitive content, often requires three essential ingredients—an invitation, mediation, and context setting. In other words, converting interest into contribution (in a public setting) requires: a push, a pull, or possibly both.

In spring quarter 2019, I audited an undergraduate honors seminar at the University of Washington, focusing on the study of pain. The course has been co-taught for seven years by Dr. John D. Loeser, M.D. (*Professor Emeritus, Neurological Surgery and Anesthesia and Pain Medicine*) and Dr. Jonathan Mayer, PhD. (*Professor of Epidemiology, Medical Geography, and Medicine*). Through this opportunity I interviewed the professors as part of the podcast and audio installation, received recommendation for key literature, and had the chance to learn from class visitors including the litigator representing Washington State in the class-action federal lawsuit against pharmaceutical manufacturers and drug distributors of Oxycontin, Oxycodone, and Fentanyl (taking place in Columbus, Ohio in October 2019).

Through these research endeavors, I learned that while pain is universal, it is always shaped by cultural forces and personal meaning. Narrative is perhaps the most powerful tool we have for unpacking these complexities, and course-correcting a legacy of pain mis-management in America requires us to build a stronger culture of listening. Listening is a powerful and simple method toward replacing ignorance with knowledge. There are many ways to shine a light on the wicked problem of pain in our culture, and as I began mapping its complexities as a way to identify possible design interventions, I became most intrigued by personal stories as means of building empathy. I wondered, how might audio narratives be leveraged as a design medium to create a more human-centered response to the opioid epidemic?

To prototype an initial listening experience, I selected one personally meaningful story as a jumping off point—an interview with my college boyfriend Jon's mother (Celia Harms), who lost her son to an accidental opioid overdose in February 2017. From 48 minutes of this raw audio content, I created an eight-minute audio segment. I commissioned custom music and paired Celia's narrative with a clip of Jon's voice (a

Listening prototype, MDes Process Show (December 13, 2019).

serendipitous recording by a friend in his mid-twenties). Jon's audio bookends his mother's recounting of his lifelong struggle with chronic pain as a result of migraine headaches and the tragic medical response to his condition—a fire hose of prescription pain-killers thrown at him since Jon was in kindergarten. Frustrated doctors simply didn't know how to help him. I paired the story with my research poster in our graduate *Process Show*. During the event, 14 of the 15 people who interacted with my installation, listened to the full eight-minute audio segment (via mounted headphones and an MP3 player). Several listeners asked where they could hear "*the rest of the story*." The insights from this prototype showed that not only is our attention span for audio much longer than video—average is less than two minutes for most adults (Wistia Marketing Analytics, 2011)—but that challenging emotional content can still be consumed in a meaningful way within a public space. In other words, listening to a real and tragic story didn't scare people away. It invited them to lean closer and ask for more. Herein lies the opportunity to leverage audio storytelling as a powerful medium for capturing attention, and perhaps to build empathy.

Listeners at the *Process Show* were also encouraged to provide open-ended written feedback, via note cards submitted into an opaque envelope. In the written responses, some people reminded me I "*picked a complicated topic*," but many said they enjoyed the immersive quality of the audio. One person remarked, "*I felt the audio was more powerful than video because it forced me to imagine the story in a way that was closer to my own life*." Others reflected on the fact that Jon's story had successfully piqued their interest, but wanted to know what I planned to do with their focused attention. By learning how to effectively capture attention surrounding this content, I wondered whether a more interactive experience could spark a level of empathy. However, to build empathy, we have to be vulnerable ourselves. Simply put by empathy expert Dr. Brené Brown in her book The Power of Vulnerability (2012), "*Connection requires mutual vulnerability.*"

These research insights prompted me to explore what types of immersive listening experiences might invite participants to be more vulnerable. Experiences such as Elliot Sharp's "*Volume: Bed of Sound*" (2000), which traveled the world featuring a massive futon-bed with interchangeable audio content. The popularity of such an installation successfully incorporates intimacy in a public (museum and gallery) spaces. Olafur Eliasson's "*The Weather Project*" (2003) at the Tate Modern in London, leverages fairly minimal material to create a feeling of warmth—monofrequency lights, projection foil, haze machines, mirror foil, aluminum, and scaffolding. This ambient glow implicitly nudged visitors to lay together in a large interior space, soaking up a "feeling" together. I also wondered which physical affordances might invite a particular listening posture, inviting us to physically change position or encourage deeper listening. I was particularly inspired by "*Touched Echo*" (2007-2009), designed by the *Digital Media Class* at the University of the Arts Berlin, which leverages bone conduction to mimic the gesture and hear the sound of approaching WWII planes in Bergen by leaning elbows on a railing and covering the ears.

Armed with inspiration, I began to sketch and prototype a listening experience for the audio content I'd gathered. Throughout this process I wondered what type of technology or materials might make the interaction feel most approachable. In other words, what kind of experience might capture attention through as little design as possible, where sensors or screens get out of the way of the story? I also considered which affordances would feel self-contained, which materials would be most content relevant, and which simple gestures could activate audio or encourage a more

immersive listening experience. And, how was activating the audio best signaled? My overall goal was to establish a fit between context and content while acknowledging that listening to personal stories about the pain, addiction, and the opioid epidemic is challenging. Because of this, I wanted to give listeners something they could do as a result—a call to action.

RESULTS + SOLUTIONS

Building on these insights and affordances, I designed a space that invited strangers to engage with challenging content, and to some extent with each other—both intimately alone. Ultimately it was my insights from the process show prototype and Sharp's "*Volume: Bed of Sound*," that inspired my gallery installation at the Henry Art Museum. That this rather simple, yet highly kinesthetic sound-based experience, traveled the globe for many years, is proof that intimacy can successfully be cultivated in a public space. By leveraging the immersive quality of audio, and simultaneously, by sharing a physical, public space, I built an interactive listening experience and place for reflection (in the Henry Art Gallery) that centers around a collective call to action: ***"Let's Change the Culture of Pain."***

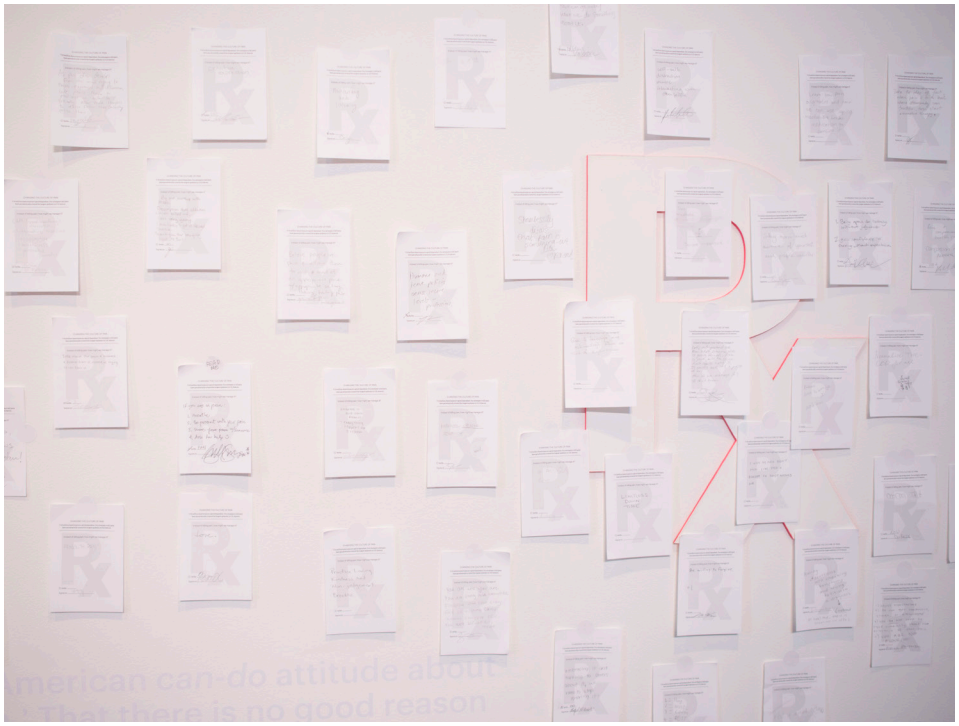
To bring this message and the audio stories I collected to life, I installed a coral pink king-sized mattress listening platform. This soft space contains looping audio in mounted headsets, stationed at four corners of the square bed. Four unique audio stories are featured, which are shorter versions of an evolving audio archive and web platform I created called **changingpain.org**. The site contains audio transcripts, research images, and ongoing documentation of visitors' reflections on the narrative content exhibited in the gallery space. I curated and installed white vinyl quotes and statistics from interviews and research on three white gallery walls. I also designed a wall that serves as a place for collective brainstorming and reflection on the audio stories, where visitors are invited to respond to the prompt "*Instead of killing pain, how might we manage it?*" in the form of a post-able "prescription" pad.

Exhibition responses to "Instead of killing pain, how might we manage it?" Photography credit: Phillip Carpenter (2019).

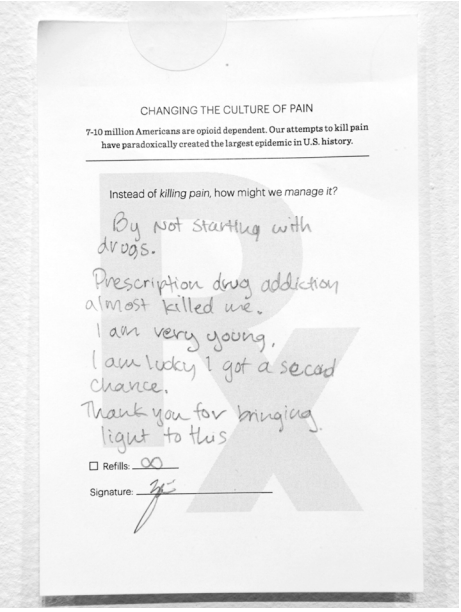
Listening platform and installation. Photography credit: Phillip Carpenter (2019).

Writing and reflection station. Photography credit: Phillip Carpenter (2019).

Listening station. Audio story by Celia Harms *(4 minutes, 41 seconds).*



Over 50 responses posted to gallery wall. Photography credit: Phillip Carpenter (2019).



Exhibition response posted during the opening reception of MDes Thesis Show, Henry Art Museum (May 31, 2019).

In the first two weeks of the installation, a variety of over 50 responses have been posted on the gallery wall and written in at least three languages—ranging from practical advice, to calls for systemic change, good-natured humorous contributions and profound messages of encouragement and hope. Perhaps most anecdotally pivotal, was a response posted during the opening reception of the show, which answered the wall prompt (*Instead of killing pain, how might we manage it?*) with "*By not starting with drugs. Prescription drug addiction almost killed me. I am very young. I am lucky I got a second chance. Thank you for bringing light to this.*" I believe that an experience which prompted someone to share such an intimate and personal story, during a particularly high-traffic event (of over 400 guests), is evidence of cultivating intimacy in a public space through storytelling.

REFLECTIONS + INSIGHTS

i. *Audio as an interactive medium*

Through interviews with pain experts and advocates, and an exploration of sound-based design projects and listening platforms, I've learned that while audio is intimate and immersive, sound is generally underused as a medium for interaction. *Key research insights and opportunity areas for designing audio interactions:*

There are several reasons why podcasts are increasingly popular. Audio narratives are inherently social. As one podcast enthusiast I interviewed put it, "*I switched (from audio books) to podcasts because they're more conversational. It's like hanging out with folks.*" Yet sound as a medium for interaction is underused in general on social platforms. The internet is an ad-based economy, which relies heavily on visual impressions to generate revenue.

Minimal design effort has been invested in what we actually "see" when we listen. This can also be a benefit in that it eliminates some implicit (i.e. visual) bias. Nonetheless, it's worth noting that digital audio interfaces typically feature progress bars, wave-forms and pause/play buttons, with very little attention paid to the visual experience. From iTunes to Soundcloud, most listening-based interfaces either resemble their analog counterparts or just haven't been considered a visual design opportunity. New listening platform Entale is adding a visual layer to podcasts and also chunking episodes into chapters for well-packaged sharing and bookmarking.

Listening-based experiences enable multitasking—an opportunity to glean information that we might not otherwise dedicate our primary attention to in the way that watching or reading requires. Audio is an immersive, secondary medium that unlocks more time for latent learning or entertainment. "*Hearing their voices you can feel their passions, versus trying to interpret it for yourself when reading,*" said one interviewee of his love for podcasts. Moreover, podcasts are free and highly accessible. "*Experts and super smart people just become more approachable. Podcasts are for anyone, so they know it has to be put in layman's terms,*" remarked another podcast enthusiast.

But listening as a primary experience can feel awkward because it doesn't require our visual or kinesthetic attention. What do we do with ourselves while we listen? Audio-based installations in public spaces (think museums and art installations) present a nuanced experience design challenge. Especially when the content is sensitive, or the hope is to stimulate empathy. Immersive experiences, designed exhibitions for example, can invite connection by asking participants to be

vulnerable in a more direct or tangible way. With these insights in mind, we can recognize both the strong case for leveraging oral narratives as a design medium, as well as the challenge of designing a primary experience for listening.

ii. *Content Reflections*

In many ways the opioid epidemic is the quietest epidemic. Not only because its data is inaccurate—doctors and medical examiners are either not required to report, or are asked by families to intentionally misrepresent overdose as cause of death—but also the silence of this epidemic lies in the deeply rooted shame and stigma that is associated with addiction—a malady that is widely and falsely perceived as a moral failing, versus a clinically proven brain disease. Information about the opioid epidemic, albeit generally underrepresented, is actually not difficult to find. However, the content is challenging to connect with, especially if you or someone you care about hasn't been directly affected by addiction or chronic pain.

Research illustration and final poster. Re-frame of central content and visual language.

Perhaps it is the way we focus on deaths and mortality related to opioids that's ineffective in capturing our attention. It's possible that the primary vehicle for disseminating this information—an emotionally fatiguing, fear-based news cycle—is a mode of delivery that prevents us from really listening and understanding the root causes of this epidemic. As a result some people are getting rather creative about drawing public attention to the systemic and deeply rooted challenges of the opioid epidemic. In February 2019, artist like Nan Goldin organized a large-scale guerrilla protest at the Guggenheim—dropping thousands of fake prescription *Oxycontin* slips from the top floor. Her continued activism targets the Sackler family, whose art patronage is built on the pharmaceutical dynasty of highly addictive pain killers.

Exhibition listeners, MDes Thesis Show. Henry Art Museum (May 31, 2019).

Along the way I noticed how difficult it was for other people to talk about the opioid epidemic and the topic of addiction and drug dependency in general. Despite how widespread these issues are into our lives and daily newsfeeds, most people had a hard time discussing the issue. This is understandable. Culturally masking pain by not talking about it or carving out space for deeper listening is a large cause of how we created this mess in the first place. Once I reframed the issue to focus on the epidemic's root cause—***Pain,*** rather than its symptoms—*addiction and drug dependency* it dramatically shifted the way people engaged with the topic. Suddenly, everyone had a story about pain to share and it was much easier to talk about, even in a public setting.

As designer, I feel successful when I think that what I've made can create positive impact in the real world. But what's even better is when you empower others to create change because of something you made with them. Nearly two years after her son's death, Jon's mother Celia told me that the interview we recorded gave her the courage to write a letter to Senator Feinstein of California, sharing her experience and asking for civic support. Why was it that verbally relaying her story in an audio recording, no doubt a painful set of circumstances to re-live, prompted her to direct civic action? When we're encouraged to vote, we're often told to "use our voice." But, what if we took this call to action quite literally? How might audio stories about systemic, wicked problems, like the opioid epidemic, be packaged and shared with lawmakers? How might we as citizens be "of service" to our community by dedicating our attention through listening?

December 19, 2018

Dear Senator Feinstein,

On Feb 26, 2017, our beloved son, Jonathan Harms, age 29, was poisoned and murdered by the drug cartels in Mexico. His story is unique in that he didn't purchase street drugs but went to a brick and mortar pharmacy to buy pain medication for an intractable migraine. Jonathan had suffered from migraines since the age of 6 and had run out of his US prescribed medication while vacationing in Cancun. The pharmacy sold him a bottle of pills that was called Migraine medicine. It was manufactured to look exactly like Norco, a commonly used pain reliever. Jonathan was cautious and looked up the pills on the internet to match the color, shape, imprint, size, etc. and the safe dosage before taking them. The pills were not Norco but Fentanyl and he was poisoned.

The day's saga and his intense pain, plane ride to the US where he was taken off the plane in LA as he was so ill, an ambulance to Marina del Rey hospital for treatment, release, was followed by trying to sleep off his migraine in his brother's LA home. As his pain had not decreased even with the ER treatments, he took two "Norco" and died shortly later. His brother's fiancee called 911 as she found him not breathing and the paramedics tried to revive him but he had died. The Coroner's representative, who came to his brother's apartment, also thought the pills were Norco and logged them as such. After the medical examiner (doctor) tested the pills, they were found to be 100% Fentanyl, there was no Norco in them. The pill bottle didn't identify the name of the Cancun pharmacy. Was the pharmacy complicit or duped or threatened by the drug cartels that they had to sell Fentanyl disguised as Norco?

Our family is heartbroken that our youngest son, loving and full of curiosity about life, devoted to making the world a better place, especially the environment, in love with a wonderful woman and doing well in his career is gone.

I am writing to ask for three pieces of legislation to mitigate this tragedy and try to save other lives. With the opiate crisis in the news daily, these measures could make a big difference in keeping our citizens safer. It has taken me 21 months since Jonathan's murder to have the courage to write this letter without being emotionally traumatized.

1. Not all Medical Examiners, hospitals or doctors in all counties in the 50 states are required to report a death by opiates or Fentanyl and its derivatives or drug overdoses (accidental or intentional) to the CDC. How can our country know and address the scope of this scourge if we do not have accurate data on the scope of the problem? The LA Medical Examiner who did the autopsy and blood testing on Jonathan said he was not required to report to the CDC. Legislation needs to be passed to make this reporting a requirement for all of the 50 states, including funding for the administration management of this accurate reporting to the CDC.

2. Some families are ashamed that their loved one has died from a drug overdose and convince their family doctor to put the cause of death as heart failure or another less controversial reason for the death. Families are know to "shop" for a doctor who will put in a reason for the cause of death other than drug overdose. Physicians need to be held to a standard to accurately report the cause of death and be fined a substantial financial amount and risk losing their medical license if they report a death inaccurately.

3. The STATE Department needs to issue warmings to all travelers from the US to Mexico that no drugs are safe to purchase. In speaking with the Chief Medical Officer at Marina del Rey hospital in LA after Jonathan died, he stated very clearly that no drugs in Mexico, prescription or over the counter sold by doctors, hospitals or pharmacies, and especially purchased on the street are not safe and could be tainted with poisonous substances. With many Americans traveling to Mexico to purchase prescription drugs as they are cheaper there, we are putting our citizens at risk without warning them of the dangers.

In 2016, a DEA Report, was issued that explained the scope of this problem with research that the drug cartels in China are manufacturing Fentanyl disguised as Norco in very large quantities and sending the drugs to Mexican drug cartels who then bring these poisonous drugs into he US. A Forbes article reported the same in 2016. As this is a known problem to our government, why is it not being addressed more proactively to save lives?

Our son, Jonathan, was an innocent victim of evil and greedy drug cartels; he did not deserve to die and the loss has forever changed our family. Our grief is unbounded.

I hope that my letter to you will spur legislative action. I am very happy to come to your local California offices to discuss this issue in greater detail. I am willing to testify about this aspect of the opiate crisis. I understand that you are very busy and if there is a staff person tasked with addressing the opiate issue, I am happy to meet with him or her. If I do not hear from you or a staff person in your office, I will follow up via phone.

I can't bring our son back to life but I hope that I can save other families the heartbreak we have experienced.

In case it matters, I have been loyal Democratic voter for my entire life and voted for you in every election.

Sincerely,

Celia Harms

Cherish your loved ones every moment. Life is precious and fragile.

Celia Harms to Senator Diane Feinstein (December 19, 2018).

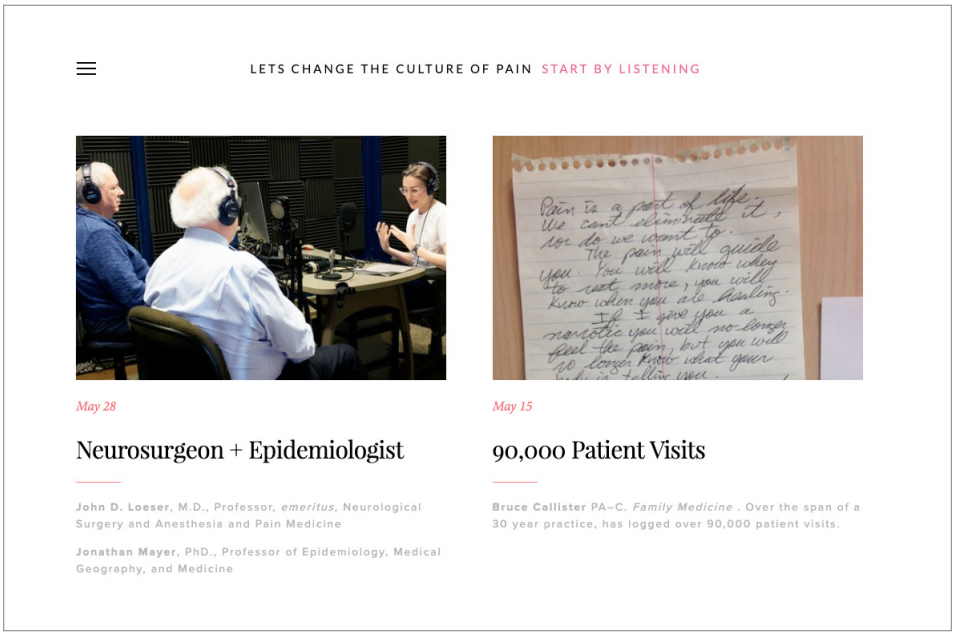
CONCLUSION

Design won't save us from a damaged, archaic culture of coping with pain, especially because pain is always a subjective, interpersonal experience. But the attempt to kill pain (by throwing pills at a problem) certainly won't work either. When it comes to understanding the complex and nested relationships between pain management, addiction, and mental health—we are in urgent need of new perceptions and voices. My thesis research demonstrates that audio is a powerful vehicle for sharing insights and spreading ideas through storytelling. Ideally this means replacing outdated ways of thinking (and the systems that support these mindsets) that no longer serve us. When asked what inspired him to start Story Corps, founder David Isay often replies that "*the soul is contained in the human voice*." Changing the culture of pain requires a more soulful conversation about pain and pain management, if we are to shift our collective health in a positive direction.

Designers are the storytellers of our contemporary time and carry huge responsibility for shaping perceptions—the way a product, system, or service is experienced by others. An important part of this effort is developing language that supports progressive narratives which can directly shape thinking. For example, flipping the syntax from "*the war on drugs*" to "*a public health epidemic*," from "*addiction is a moral failing*" to "*addiction is a chronic disease*," away from any political agenda and towards humanitarian interventions.

Storytelling through design is an emotive technique for relaying human-centered insights and demystifying the nuances of wicked problems to diverse audiences in truly engaging ways. Building compelling artifacts and experiences that bring these stories to life is the core task of a socially responsible design practice. As economist and psychologist Herbert Simon famously said, "*Information isn't a scare resource, attention is*" (1973). Tackling the entrenched and dusty myths that have plagued pain management in the U.S. is not an impossible task. It's a narrative design challenge that starts with listening.

Full audio stories, interview transcripts, and research images available on the evolving web platform: changingpain.org



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