Curating Stories, Caring for Selves:
Bioethical Dimensions of Narrative Stewardship

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Abstract

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Social practices of storytelling help shape who we are. The recognition and uptake we grant others' stories shapes our understandings of ourselves and our responsibilities to those around us. In this way, I take personal identity formation as a social, or relational, practice. Understanding the ways we make sense of these stories and the ways our stories are told is critical to the ways we care for others. The co-creation and uptake of these identity-stories, then, critically shapes our agency and how we are able to be in the world. This dissertation is a compendium of three papers that explore the ways these social story sharing and building practices affect our ability to empower and care for one another.

First, I explore how relational approaches to identity illuminate the roles loved ones can play in medical decisionmaking for patients with amyotrophic lateral sclerosis. Second, I consider how current data-sharing norms

surrounding de-identification may be ill-fit for sharing participant narratives within qualitative research. Finally, I explore how, given varying epistemic resources, we might approach continuing to animate the stories of loved ones who have passed away, in order to integrate them into our own, and to hold their identities even after they have died. Taken together, these papers consider the bioethical dimensions of narrative identity-building practices and the ways the social webs and systems around us shape how we live out those stories. Through considering these narrative construction practices, this project centers how we can better provide stewardship over the narratives of others, and care for each other and ourselves in the process.

A Dedication

When I told my grandpa, Dodo, that I was pursuing a PhD in philosophy over medical school, he said:

"But I thought you were going to actually help people."

Dodo, this one is for you.

Thank you for all the bedtime stories.

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And, within all those who hold me here, I am grateful and accountable to myself. Thank you to all the versions of me that led to me being here as I am. It has been a confusing and wild ride. I am so proud of us, and I promise to get some sleep.

Introduction

Storytelling is a fundamentally social practice: there is a teller and a told to. Often implicit in that exchange is a display of trust. The teller is entrusting that story to the intended listener(s). What is expected in return varies: a patient and listening ear, an invitation to build upon, an openness to pushback, a request to share, a desire to learn. Beyond being avenues for social connection, these practices can be byways for self-understanding and self-advocacy through the ways they are taken up by those around us. A student recounts a difficult experience and someone discounts them. Someone shares expectations and another person nudges them towards what they think is possible. A friend leans on another to make sense of what is happening around them. Depending on the parameters in place, engaging in these shared story-building practices can be expressions of care, or a constriction point for the kind of agency we are able to exert.

Here in this dissertation, I explore some of the epistemic, ethical, and ontological dimensions of storytelling practices in bioethical spaces.[1] The kind of uptake we grant different stories shapes where we draw our attention and what we take to be important factors for consideration. Take, for instance, the frequent dismissal of women's pain testimony within the US medical system. And, consider the attempts to spotlight stories of women who have suffered as a result in hopes of increasing recognition of the need to address these disparities.[2] Here, the intersection of the epistemic, ethical, and ontological dimensions

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[1] For non-philosopher readers: most roughly, think of epistemic as "what we take to be true." ethical as "what we take to be right," and ontological as "what we take to be real."

[2] Consider: (1) Serial Production's 2023 podcast "The Retrievals" as it chronicles the ways dismissal of women's pain testimony enabled the harm done to egg retrieval patients; (2) *The Washington Post*'s 2022 piece "From heart disease to IUDs: How doctors dismiss women's pain"; (3) the 2018 *Vogue* piece on "Serena Williams on Motherhood, Marriage, and Making Her Comeback" describing the degree of self-advocacy Williams required to have her life-threatening pulmonary embolism diagnosed; (4) *The Atlantic*'s 2016 eight-part reader series recounting the misdiagnosis and dismissal of women's pain.

reveals itself– we have moral responsibilities regarding taking these testimonies as important sources of information that reveal the reality of pain that has all too often been dismissed or miscategorized. The ways stories are constructed and taken up can affect how we understand the world around us, who we take to be sources of knowledge, and how we build our shared realities.

In these ways, then, I take the social negotiation practices surrounding personal narratives to be key ways people exert their agency. Enabling people's autonomy then requires critically examining the social practices surrounding the formation, curation, and propagation of these stories. This dissertation comprises three papers that explore these practices within bioethical contexts– some of which occur immediately within medical care and research systems, and others that occur through more intimate and non-institutional care exchanges. Interpersonally, these dynamics are complex enough. When they occur within biomedical spaces, what it means to properly provide stewardship over and empower these storytelling practices becomes all the more fraught given the unique histories, power, and policies at play.

I approach my projects here as a philosopher, medical ethicist, and qualitative researcher. It is these three orientations that guide the territory these papers cover as I explore different aspects of storytelling, storysharing, and storyholding practices: (1) How can we understand the roles care partners play in providing support navigating the time-sensitive decisions ALS often requires?; (2) How are the data-sharing norms surrounding de-identification ill-fit for the narrative sharing that qualitative research often entails?; (3) How can we approach continuing to care for and animate the identity-holding stories of those we have loved and who have passed away?

In the first, I use qualitative data from a project conducting interviews with veterans with amyotrophic lateral sclerosis (ALS) on the ways caregiver dynamics often surpass the more peripheral support roles they are often cast within. Going beyond being providers of support when needed, caregivers served as co-builders of participants' sense of self as they progressed through the disease. Through identifying the ways these shared story-building practices can operate, we can better appreciate the roles loved ones play in medical decision-making and empower them in the process.

The second came from frustrations with a barrier my neuroethics research group faced in attempting to publish results from a study that consulted those in treatment for substance use disorders on concerns and considerations that should be taken into account for clinical trials into deep brain stimulation as a treatment option. After successfully diversifying and broadening participant recruitment, we were met with a request from a prominent pre-publication database: interview excerpts must be de-identified to the extent that the *participants themselves* would not recognize themselves in the data. In a story all too familiar to those doing qualitative research, a standard created for metric-oriented quantitative research was being uncritically applied to a qualitative project. Here, we found one more barrier to trying to get uptake of participant testimony within medical research. This paper is a response-letter of sorts. It is my hope that it can be a tool for others who face similar barriers to push back against these research norms, and for me to cite in response going forward.

The third paper takes these investigations into more personal territory as it considers the epistemic and ontological dimensions of the roles storytelling can play in identity holding after those we love have passed away. It centers around my experiences grieving the loss of my two grandfathers and considers how these identity holding practices may look when the person anchoring that identity relation is no longer alive. In contrast to an approach of 'preservative love' that centers on archiving the stories of those we loved as we knew them, I call for a 'summoning love.' Through maintaining an open curiosity about how we knew those we loved and engaging in embodied care practices, we may re-animate some parts of the worlds we shared with those we loved. My work in medical ethics has made me acutely wary of the ways we can struggle with how to talk about, engage with, and acknowledge death. I offer this paper as practicing writing about death. This paper has been by far the most difficult to write, not just due to the subject matter, but to the ephemeral nature of death, dying, and how to approach the processes that come after.

These papers vary in both their setting and the point-in-time of focus. While individual-level and systemic shaping factors are always present in these practices, the papers here toggle between different layers of analysis. In the first paper, the focal frame is primarily dyadic, intimate dynamics as two people navigate the uncertainty and opportunity afforded through our US medical system as they face a progressive, life-altering illness. The second considers structural norms within the medical research ecosystem that shape the ways patient and research participant stories are able to be shared in medicalized spaces. The third considers practices that happen largely outside of (though not exclusively away from) clinical spaces; it inhabits the world-building practices that occur in the most quotidian, seemingly 'everyday' practices of interpersonal spaces. Temporally, these papers vary as well, as they shift between future, present, and past. The first considers the ways relational identity-building practices shape the ability to make sense of future possibilities and draw forward our future selves. The second focuses on real-time story sharing practices. The third largely inhabits reflections on the past, focusing on who we have been and the things we miss, and the ways we might revive them in our present.

Across these settings, I consider some of the implications from taking these storytelling practices seriously and viewing personal narratives as conduits for human agency. In these ways, all three papers touch on different aspects of narrative stewardship. Ultimately, I hope that in learning more about what comes with being entrusted with others' narratives, we can learn how to better care for another in the process.

(I)

“Who Will I Be?”: Relational Identity, Living with Amyotrophic Lateral Sclerosis, and Future-Oriented Decisionmaking

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Abstract: Patients with amyotrophic lateral sclerosis (ALS) face many difficult, timing-sensitive decisions over the course of their illness, weighing present versus future harms and benefits. Supplemented by interviews with people with ALS, we argue for a relational approach to understanding these decisions and their effects on identity. We highlight two critical aspects of the patient–caregiver relationship: (1) the extent to which each may rely on the other leaves their wellbeing intimately intertwined and (2) patients often require others to help with the imaginative task of considering possible futures for each therapeutic option. We show why family involvement in decisionmaking practices can be so critical, and shed light on the ways intimate others help preserve and protect people’s identities amidst the destabilizing uncertainty illness and treatment can bring.

Introduction

Patients with amyotrophic lateral sclerosis (ALS) (also known as motor neuron disease) face many major medical decisions over the course of their illness. ALS is a progressive illness without a cure but with treatments that can help manage symptoms and potentially enhance quality of life. Persons with ALS often must make decisions about whether to use mechanical ventilation, pursue modifications to their home for changing physical needs, engage palliative care, obtain a percutaneous endoscopic gastrostomy (PEG) tube for artificial feeding and hydration, or be trained in using assistive communication devices, among others. Some of these decisions involve undertaking near-term burdens for possible future benefits. In making these kinds of "anticipatory" decisions, patients must reflect upon their guiding preferences and desires and decide not only for their current self, but for the future person they will be at each point of the illness' progression.

Many scholars have highlighted the ways that patients with ALS must confront treatment decisions and the timing considerations they pose. However, these decisions are typically framed individualistically, as being made by the patient alone, in order to respect patient autonomy. Involvement of caregivers is often limited to addressing the concerns necessary to enable them to be more effective or less "burdened" caregivers. Although these aspects are important, this framing overlooks crucial aspects of why caregiver involvement matters and how it takes shape.

Working from the relational, narrative identity account of Françoise Baylis, we highlight the ways individuals' agency emerges through negotiations with others and show how others play a more substantive, co-constitutive role in the patient's sense of self. Using excerpts from interviews we are conducting with patients with ALS on the course of their illness and the potential of emerging neurotechnologies, we elucidate the ways patients make sense of who they are and who they will be at later stages of illness through their conversations with and considerations of the others around them. Patients' partners, family members, and intimate friends serve critical roles in helping patients stay rooted in their sense of self through illness and make sense of the possible futures different interventions present.

Ultimately, we highlight two critical aspects of the patient–caregiver relationship: (1) the extent to which each may rely on the other leaves their wellbeing intimately intertwined, and (2) patients often require others to help with the imaginative task of considering possible futures for each therapeutic option. In anticipating their futures selves, then, most patients do not abide by a more individualistic notion of autonomy and instead express their decisional autonomy through intimately involving their loved ones who crucially help maintain their identities.ALS on the course of their illness and the potential of emerging neurotechnologies, we elucidate the ways patients make sense of who they are and who they will be at later stages of illness through their conversations with and considerations of the others around them. Patients' partners, family members, and intimate friends serve critical roles in helping patients stay rooted in their sense of self through illness and make sense of the possible futures different interventions present. Ultimately, we highlight two critical aspects of the patient–caregiver relationship: (1) the extent to which each may rely on the other leaves their wellbeing intimately intertwined, and (2) patients often require others to help with the imaginative task of considering possible futures for each therapeutic option. In anticipating their future selves, then, most patients do not abide by a more individualistic notion of autonomy and instead express their decisional autonomy through intimately involving their loved ones who crucially help maintain their identities.

Anticipatory Decisions: Immediate Costs for (Potential) Future Benefits

People with ALS face many difficult decisions over the course of their illness. Some of these decisions are ones that require undertaking near-term costs for possible future benefits. Current examples of these kinds of decisions are (1) whether to get a PEG tube for future artificial nutrition, (2) whether to get a tracheostomy for future invasive mechanical ventilation, and (3) whether to bank one's voice for future assistive communication. In this section, we provide a brief overview of these

decisions and how they tend to be framed in the medical literature.

Most patients with ALS face the challenging discussion of whether or not to undergo surgical placement of a PEG or other feeding tube during the course of their illness. As ALS progresses, patients often experience dysphagia, or difficulty swallowing, which prevents them from taking in adequate levels of food and fluids. Clinicians, patients, and caregivers often must discuss options surrounding artificial feeding and hydration—specifically, whether or not to have a PEG tube placed. Due to the sedation involved with PEG tube placement, it is advised that patients have a lung capacity of 50% in order to ensure the procedure is safe (Miller et al., 2009). Thus, the progressive respiratory function decline of patients with ALS may require getting a PEG tube before dysphagia necessitates its use.

The evidence regarding optimal timing for PEG tube placement is uncertain. The American Academy of Neurology (AAN) (Miller et al., 2009) and European Federation of Neurological Societies (EFNS) (EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis: et al., 2012) recommend timing PEG tube placement according to lung function, weight loss, and overall condition, but recognize that there remains insufficient evidence regarding the optimal timing of the intervention. Notably, the evidence regarding the ways PEG tubes affect survival and quality of life is inconclusive, leaving the question of the extent of the potential benefits hazy (Katzberg et al., 2011). Stavroulakis et al. interviewed 10 patients with ALS and their carers on how, and at what point, they decided to pursue a PEG tube (Stavroulakis et al., 2014). Even when clinicians proposed PEG tubes as an option in the early stages of dysphagia, no patients chose to do so until chewing and swallowing became consistently unsafe, weight loss became significant, and there was a rising risk for aspiration and chest infection.

Patients and carers often sought to adapt mealtime by liquidizing food and limiting food types before turning to getting a PEG tube (Stavroulakis et al., 2014). Others note that patients often perceive PEG tubes as a chief marker of deterioration and the decision to get one as a sign of “giving in” and succumbing to the illness, increasing the degree of psychological burden for some (Oliver & Turner, 2010). Patients must decide relatively early on whether they wish to undergo the surgery and maintenance involved in getting the tube placed in order to potentially prolong their life using this therapeutic intervention. Most patients also face the difficult decision about whether to use mechanical ventilation. For patients with ALS, respiratory muscle weakness and loss of lung volume often leads to death due to respiratory failure, the primary cause of death in this patient population. Both noninvasive and invasive ventilation via tracheostomy are methods that can prolong patients’ life expectancy. Forms of noninvasive ventilation (NIV), such as receiving air through a face or nasal mask, is part of routine care for many patients with ALS due to the lower burden it poses on the patients and the ways it can dramatically improve patients’ quality of life. NIV greatly reduces sleep fragmentation, depression, physical fatigue, and daytime drowsiness—enabling patients to remain engaged in their daily activities (EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis: et al., 2012). Both the AAN (Miller et al., 2009) and EFNS (EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis: et al., 2012) find NIV likely effective in prolonging survival, slowing lung function decline, and increasing or helping maintain quality of life, and thus recommend early use of the intervention.

However, even in its noninvasive form, one study found one third of patients decline NIV due to concerns of preserving their sense of self and freedom from being “hooked up to machines,” feeling claustrophobic or distressed in the mask, or feeling like it was forced upon them by healthcare providers (Ando et al., 2015). Once NIV is no longer sufficient, tracheostomy and invasive ventilation become an option to prolong life. Tracheostomy typically makes speech impossible, except when patients can obtain valves that preserve their ability to speak. Further, getting a tracheostomy can compromise the patient’s ability to swallow, which would then require getting a PEG tube as well. This leaves the patient having to weigh the potential costs and benefits of both interventions. The AAN suggests considering tracheostomy with invasive ventilation (TIV) due to the possible increase in the quality of life for the patient, but warns of the decreased quality of life that has been reported in studies on caregivers and is often attributed to the longer required care hours, the more severe disease state of the patient, and possible feelings of being “trapped” in a hopeless situation (Kaub-Wittemer et al., 2003; Miller et al., 2009). The EFNS guidelines recognize its potential to prolong survival, but note that there are no studies yet that document improved quality of life in patients, and warn of the high emotional and social impacts on patients and caregivers (EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis: et al., 2012). The high financial burden of TIV also makes it a more untenable option for those living in places without universal healthcare coverage, and who do not have adequate insurance coverage or other financial means

(Narayanaswami et al., 2000). Finally, for patients who do pursue TIV, they must consider if there is a point at which they would like themselves withdrawn from assisted ventilation in their advance directive, adding to the many difficult decisions patients and their families must make.

In addition to decisions about feeding and respiration, individuals with ALS make decisions about the use of assistive devices for communication. For example, the Tobii Dynavox enables users to communicate through tracking eye movements. The most recent versions enable users to either select a premade voice, or voice bank their own words or phrases before their voice becomes slowed, slurred, or distorted due to disease progression. Voice banking allows individuals to continue to be able to express themselves with their own voice after they lose the ability to speak. Although voice banking holds great promise for enhancing communication, it requires a significant number of hours to log speech and train on how to use the device—time that could be spent doing other activities the user finds meaningful and that may become prohibitive as they decline.

We have heard the complexity and frequency of these challenging treatment discussions reflected in interviews we are conducting as part of a qualitative study of persons with ALS about their illness and perspectives on emerging therapeutic technologies (Versalovic et al., 2020). In these interviews, individuals endorse a high degree of familiarity with these kinds of difficult treatment discussions. With regard to the decision whether or not to get a PEG tube, uncertainty about the likelihood of future benefit can weigh heavily. As two people noted:

> *The requirement is you have a certain respiratory function and it may not be that you have a swallowing problem. So, you have to make the decision prior to knowing directly whether or not you will ever truly need a feeding tube, so while it's unfortunate, I don't think that's unreasonable. I mean it is what it is, and*

> *you have to take that into account to make that decision. Obviously if you're a victim of the accident, you're a paraplegic and you tell me now, well, it's too late. Who could have*
>
> *anticipated and had the surgery in advance of some unfortunate, you know, life changing accident? But on a degenerative disease, it'd just be part of the conversation. We have really personal, intimate conversations all the time. You know, about what you're willing to do and under what circumstances.* (Participant 6)

> *Well, I see where with ALS, timing is critical. The neurologist suggested that I have the feeding tube and a trache put in rather soon. Well, my health's still good, I still have… I've lost a few pounds, but I think I'm holding on okay. I think it's a concern of, you know, do I want this thing in me? You know? But I see the benefits still.* (Participant 7)

Timing considerations can be delicate—too soon and one may preemptively sacrifice time at the higher level of physical independence one has now, too late and one will not be able to receive the treatment:

> *Well, I've been offered a trache, a feeding tube, and I refuse because I can still breathe, I can still eat, and now I'm beyond the point where they can give me anesthesia and do these things, which is just fine with me.* (Participant 13)

> *They want me to have a stomach insert put into me – feeding tube – to get used to it. My response to that is: that's [one] more thing to take care of. Why hurry into that when you really don't need to? I'm eating fine and maintaining weight. Moving forward, it doesn't make sense.* (Participant 1)

Knowing what one will want in the future is itself a challenge. The burden of catching up to understanding one's current condition makes it all the more difficult to decide on future wishes:

The risk versus reward again comes into play. Everybody's going to find different… I have a feeding tube, and we did it early. I can still eat, I can't use my hands to feed myself, but I can still eat solids, drink no problem, but… I did it early as a preemptive. And we use it every day at breakfast so I'm comfortable with it. So, if it got to the point where that's [all] I could do, it's there, it's done. I was… one of the concerns: your breathing rate, your lung capacity. As it gets below 50%, they start getting worried about you going into surgery. So, having that done and out of the way allowed me to not have to worry about, you know. How's my lung function doing? How am I going to recover? How is my recovery times going to be? I was a lot more healthy when I got that done. (Participant 2)

They've talked to me a lot when I go up there, like having a … what is it? A PEG, or like a feeding, you know, while you're healthy, having this stuff done, and they always ask me. It's kind of like, I don't think… I can see where having a tube, on having a … I know it's not a tube, but stuff like that. But they have talked about it. I can see where it could be complicated. Because, you know, I'm healthy right now… But I mean, I've kind of dealt with that too just with those things. It's not the… but to do it while you're healthy, it's kind of hard to sink in. Do this now. It's just like with the … I have an AVAPS [a form of noninvasive positive pressure ventilation], and I don't use the dang thing. I've had it for a couple years and I just … it's like you need to do this now, because when you do need it, trying to learn it. And so I keep saying I'm gonna do this, I'm gonna do this, but I haven't done it. (Participant 11)

The time at which I got my Tobii was very early in my ALS journey. I thought, "What's the big deal? I can talk fine, no problems," still sang in my church choir. Is there any problems I'm not seeing? … I got my Tobii. I had someone from the ALS chapter come out and work with me on storing phrases and names of people in my life. Yet, here I am again, still conversing. I've backed away from the whole automation part. I

> *am having a speech technology person come out, they'll be here a week from today, and get back on voice banking because I've got to tell you, I'm on this journey. I'm not sure it's real. I was a machinist for Boeing company for 31 years- played golf, ran, hunted, fished, you name it, and now we're here. I'm not sure it's real.* (Participant 3)

The process of accepting the diagnosis can be extremely difficult on patients. Due to its more gradual progression, it can be hard for patients to comprehend the losses they will experience over the course of the illness. They often must make decisions to take on interventions before they are necessary in order to prepare for what is to come and make the necessary plans so that they and their caregivers are prepared for ALS' later stages.

From Mere Caregivers to Co-Authors of Identity

In this section, we problematize the ways decisionmaking is often portrayed as more individualistic in nature. We review the rhetoric that often surrounds caregiver involvement in patient decisionmaking, and show the ways it often under-acknowledges the critical roles caregivers play. We then introduce work by Françoise Baylis to show the ways identity and agency are best understood relationally; we come to understand who we are through negotiation with others. It is only through seeing how others view us that we build the coherent self-understanding often required for autonomous decisionmaking.

Recent studies done on decisionmaking practices regarding these potential therapeutic interventions have highlighted carer involvement in patient decision-making. However, they often depict caregivers as primarily serving as additional sources of patient information and as providers of at-home care. In examining the ways patients make decisions for TIV, for instance, Ceriana et al. encourage discussing the interventions with patients and their families in order to prepare them for the resulting at-home care needs (Ceriana et al., 2017). Hogden et al. interviewed caregivers on their involvement in the medical decisionmaking of their loved ones with ALS (Hogden et al., 2013). They highlight three important roles the caregivers serve: promoting the patients' voices, enhancing the patients' health literacy, and providing emotional support. EFNS guidelines emphasize the importance of involving them in decisionmaking due to the important roles they serve for the patient, while warning that care teams should ensure they do not encroach on the patient's autonomy (Miller et al., 2009).

These approaches reflect Anita Ho's concern that family member involvement in medical decisionmaking is often limited to viewing them as at-home caregivers, providers of company during care, and sources of additional patient information for the clinicians (Ho, 2008). Outside of serving these roles, clinicians often become suspicious of the ways family involvement could pose undue pressure on the patient. She incorporates feminist conceptions of relational autonomy into medical decisionmaking processes to correct for the traditional, masculine portrayal of individuals as socially isolatable units, and to more adequately show the ways patients are fundamentally rooted in their social and familial relationships. We now turn to how such a relational understanding of identity is useful in thinking about anticipatory decisionmaking in ALS.

The relational, narrative identity literature shows how others co-author our identities as they help us interpret and understand ourselves. Our intimate relationships, in particular, hold us in who we are: they remind us of who we have been in the past, recall our core values that we may unintentionally act against, and ground us in our sense of self.(Lindemann, 2014) As Baier put it, persons are inherently "second persons," as personal identity emerges through the ways others care for us throughout our lives and continue holding us accountable to ourselves (Baier, 1981). Baylis works within this tradition and shows the extent to which identity is a dynamic and relational project that occurs through our ongoing negotiations with others (Baylis, 2013).

Baylis' account views identity as having a narrative structure—we are a constellation of our stories; our lives have thematic threads that weave throughout our lives' plot twists and narrative arcs. Further, it is a relational, narrative account in that the stories that comprise who we are do not only come from us. They also arise from others around us. Finding who we are requires balancing the characteristics we attribute to ourselves and that others attribute to us. Baylis argues that we identify identity-constituting narratives through using an "equilibrium constraint" that "requires minimal endorsement or uptake by others of one's projected self-narrative" (Baylis, 2013). In order for one to identify what stories and accounts are truly reflective of who they are, the narratives must obtain recognition by others. They do not need affirmation in the form of others agreeing with the guiding values or decisions people choose; rather, these stories need affirmation in terms of others validating that certain things have been the case. That is, others provide a kind of "reality constraint" to the narratives one can tell (Schechtman, 2010). For example, if someone were to claim to be someone who prioritized their career above other things, others around them do not need to agree that this should have been their top priority—only that this indeed has been a guiding force in that person's life. This recognition need not come from many people; a smaller, selective community can provide the recognition the person's identifying narrative requires. This identity-supporting role is often played by patients' partners or other close family members:

> *Participant: I think that how your loved ones will relate to the different remedies is important to gather from them. And you would have to use that to weigh out your decision. My grandson worries about me. So, if I could do something to alleviate the worry, I would.*
>
> *Interviewer: So, yeah, his worry is something that sort of weighs on you?*
>
> *Participant: As well as [my wife], of course, too. But he is so young, he doesn't understand and comprehend the thing. So, it takes more work and consideration for him than [my wife] who has been with me all this time and understands me probably as well as I know myself.*
>
> *Interviewer: And so that affects the decision about whether or not to get one and can you imagine ways in which having one of these kinds of devices would be, um, good or bad for a relationship?*
>
> *Participant: Um. I would, I would say this. That if I got something that where I could jog and ride a bike that would bring joy to those around me.* (Participant 1)

Further, in her aptly-named, foundational piece, "I Am Who I Am: On the Perceived Threats to Personal Identity from Deep Brain Stimulation," Baylis argues that our identities are dynamic—they change in response to illness, treatments for illness, and so on (Baylis, 2013). She suggests that such disruptions in a life are not threats to personal identity unless they undermine the individual's capacity for agency and autonomy—the critical capacities that decisionmaking requires. Thus, for Baylis, as long as someone can meaningfully author their own life (defined as "the cyclical and iterative process of projecting, defending, and revising a self-narrative"), they continue to shape and reshape their identity (Françoise Baylis, 2011). Baylis offers the example of a neural device—an implant administering deep brain stimulation—that might shift a person's narrative, but only threatens identity when it undermines agency. She also recognizes that external forces—for example, oppressive master narratives, such as common negative stories about illness and disability—can problematically undermine this narrative building process.

People with ALS often maintain a high level of cognitive functioning through their physical decline yet often face perceptions of cognitive impairments due to their physical dependence. As two people we interviewed remarked:

> *After 16 years of adjusting to people's reaction to my appearance and disability, I have gotten used to it. Although, it still frustrates me that many people who see me in a wheelchair automatically assume I am mentally incapacitated and hard of hearing and refuse to speak directly to me.* (Participant 15)
>
> *It could be that somebody, like when Stephen Hawking talks, they might think that they're not as intelligent as somebody else, because they have to use a device like that. They're ignorant, unfortunately, but I think that's just the way some people think, perhaps. Just like a wheelchair, that kind of thing.* (Participant 16)

Strangers may project limiting narratives. They may talk down to the person in the wheelchair and not grant them the respect they would have when that person had been able to walk on their own, despite them still functioning at the same cognitive level. Many relational theorists describe this experience in terms of negative master narratives that constrain the individual's ability to contribute effectively to their self-narrative and leave individuals "forced to live within constraints set by others who have fixed ideas about who she is and who she can be" (Françoise Baylis, 2011). Intimate others often serve critical roles in helping individuals resist these restricting projected narratives. Facing these mis-identifications alone can lead to feelings of insecurity or craziness, which risk recapitulating the oppressive narrative. In the accounts above, the individuals are disregarded as lesser-than and incompetent simply for being in a wheelchair. If the individual says something to call out the other person's perception of them, they may be further disregarded as unstable—others who more accurately understand who the individual is can importantly bolster their ability to push back against these harmful interpretations of their condition. As individuals lose control over the things around them, it becomes all the more important to have others who can recognize the state they are actually in, and the ways they truly have or have not shifted in their defining characteristics.

However, it is important to note that this aspect of relational identity does not mean loved ones must accept the characteristics the individual wishes to claim. It also requires that the person be open to understanding how those they trust understand the shifts they are going through. For example, consider a father who wants to claim that he is still the same person he has always been to his daughter. When his daughter claims that in some ways his increasing dependence has made him slow down a bit and become more emotionally connected to those around him, he may have good reason to incorporate this aspect into his understanding of who he is, possibly leading him to more fully understand the person he historically has been as well. This iterative cycle of self-ascription and ascription by others enables individuals to maintain their agency amidst illness and continue participating in the dynamic process of self-understanding (Baylis, 2013).

Baylis' account helps us understand the way identity and agency take shape. However, her account focuses on comprehending past and current narratives and gives less guidance on how to understand the person who will come to be. We now turn to consider the roles others play in negotiating the way people with ALS understand what their guiding values and motivations are for choosing for or against certain interventions whose effects lie in a future made radically uncertain

by illness.

“Who Will I Be?”: Negotiating Future Narratives

Baylis’ account focuses on present identity-constituting narratives. However, patients with ALS and their families must reflect not only on where and who they are now, but what their guiding preferences will be over the course of a dramatically shifting future. Although the projected life expectancy is 2–5 years after the disease’s onset, 10%–20% live longer than 10 years.29 This variation in life expectancy and the rate at which the illness will progress present much uncertainty in themselves. Adding considerations of possible future treatments and the ways emerging assistive technologies may develop compounds what are often already overwhelming medical discussions.

Implantable brain-computer interfaces (BCI) like Braingate hold the potential for individuals with paralysis or other motor impairment, like ALS, to control prosthetic limbs or other devices using neural signals—possibly enabling them to bring a glass of water to their lips, extend a hand toward the person they love, or move their wheelchair without the assistance of others (Daly & Huggins, 2015; Spataro et al., 2017). There is also hope that implantable BCI devices could enable individuals who have lost the ability to communicate through voice or other means (e.g., eye movements) to a control communication device using neural signals alone (Chaudhary et al., 2017). However, with these devices comes long training hours to reach proficiency and, in the case of implantable BCIs, brain surgery for inserting electrodes. Patients must weigh these often very alluring potential payoffs with the expenditure of time that could be spent otherwise and surgical burden on an already strained body. As patients weigh these varying factors, family members and caregivers serve key roles in helping patients navigate the decisionmaking process.

Family involvement could help distribute the decisional burden faced with

emerging neural technologies. Consider:

> *Participant: I have two sons and most of the decisions that we've made have involved primarily my wife, but my two sons have been very actively involved. They're distant, they're not, they're not local here, but you know, thanks to our wonderful communication system ... and they're impacting us and, and they are involved in the decisionmaking process. And if I were presented with the option of what you're saying, uh, I would still involve them in the decisionmaking process. But ultimately, it's my decision. So.*
>
> *Interviewer: So why, so can you say more about why you would want them involved in the decisionmaking process?*
>
> *Participant: Because I think three or four brains are better than one. I mean they're going to look for things that, uh, I would, you know, I can still remember, you know, years ago, my, you know, every time we bought a house I had my dad walk through it. Not because I needed him to make the decision or not, but he's going to look at the house through different eyes than I look at it and he's going to see things that I don't see and he can tell me about them, you know, now what I do with that information is, you know, my decision. But at least it's input from a different, you know, you're getting a different perspective on things.* (Participant 4)

> *Participant: I think it's a big role in the family because a lot of times if you leave it up to the individual, they'll say no. Maybe you need the spouse or son or daughter to kind of encourage you and make you look at it a different way. So, family support I think is key to using some of these prosthetics.*
>
> *Interviewer: So, look at a different way you mean, think about the possible benefits of doing it?*
>
> *Participant: Right. They might see the benefits that you don't. And they can bring up and they're becoming involved in what you might be getting. They might do some research to get ideas as to what it can do, what it can't do. They're the ones that would read the manual. Me, no. Just on, off, start. I would be kind of tunneled and they would be able to open it up. I think family is a great support.* (Participant 14)

Family members often serve critical roles in helping patients understand the therapeutic options being presented to them. Patients may ultimately see decisions as being up to themselves, and yet recognize the importance of needing to get loved ones' perspectives in order to get a better sense of the full picture. In these situations, it becomes clear that the involvement of intimate others is far from problematic influences on autonomous decisionmaking; it is precisely the kind of influence that the individual desires and needs. Family members may both help the patient digest the relevant clinical information and affirm the individual's understanding of their guiding values. Even in moments of the family pushing back on some of the individual's expressed preferences, this can help them better reflect upon and ground their decisions.

In addition to helping patients think through the benefits and drawbacks of different treatments, family members' and caregivers' valuation of those benefits and drawbacks are intimately intertwined as patients often place weight on what will foreseeably lessen the burden on their loved ones. Chio et al.

interviewed patient–caregiver couples and found caregiver burden to increase with their loved one's degree of impairment (Chio et al., 2005), a finding reflected in other studies as well (Burke et al., 2017; Goldstein et al., 2006). They also found both patients and caregivers to report similar mean depression and quality of life scores, a concordance level reflected in caregiver–patient pairs in other neurologic disorders (Thommessen et al., 2002). Foley et al. interviewed people with ALS and found them to emphasize the importance of retaining a degree of reciprocality in their relationships—people with ALS not only receive care from their partners and/or other family members but also desire to reassure their family members, make medical decisions that consider their needs as well, and maintain their own caregiving roles to their spouse or children (Foley et al., 2014). They also found that patients' sentiments regarding the point at which they would no longer wish to prolong their lives were tied to their perceived parental responsibilities, and urged increasing attention to the ways patients with ALS maintain their familial roles throughout their increasing physical dependence. In our interviews, the potential benefits interventions provide for family members and caregivers were noted:

> *I feel within my family the things that I choose to do I take that into consideration. If there's something that I can do to make it easier, less of a burden on the family by doing, you know, doing something, then I will be more inclined to do it. Being, you know, a needy person, I am always evaluating what I ask for or what I…my demands, I guess … from my family to do this for me or that for me. I am evaluating that constantly. So if there's something that I can do to make their life easier, like, if I could get a robotic arm so that I could, you know, do little things, I would do it because that would allow when we're sitting watching TV and I have an itch on my head, I don't have to have her get up and come over and scratch my head. I*

> *can do it myself and let her have quality of life, instead of having to jump at every need I have.*
> (Participant 2)

The ability to soothe family members' worries, partake in activities with their loved ones, and lessen the number of things caregivers must attend to can be strong motivators to adopt particular therapeutic interventions. Thus, for patients, being able to decide whether or not to take on an intervention will partially hinge upon the ways it affects their relationships with those around them. As one person remarked:

> *My biggest concern would be how my family perceived it, or like [my wife]. Now, I know [my wife], it wouldn't bother her, but a man's wife. What's she going to feel like, if he wants to hug her, or how are his kids going to feel, especially if they're older, and they're used to Dad being the way he was, and all of a sudden, he comes in with prosthetic arms or something that he' going to want to use to pick them up or touch them?* (Participant 9)

Weighing whether or not one wants to get a certain intervention requires envisioning how one sees themselves and the way they would like the remainder of their time to play out. This facet of self-understanding is often particularly evident for patients with ALS through their physical dependence on caregivers—their ability to have their basic needs met often depends on proper reading and response from the loved ones who care for them. However, beyond this more obvious physical level, their ability to more fully envision possible future courses of treatment is often only possible alongside and through others; the project of drafting potential courses of action requires others to help them recognize what that future reality could look like, and the ways it will likely affect each person involved. It often takes place as a collaborative and iterative process of mutual imagination as they each consider the ways the intervention could shape their remaining time together.

We recognize that some will not desire this process to be as collaborative. Some may declare their preferences very clearly from the start or value making decisions more independently, making the suggestion of including others seem inappropriate, if not disrespectful. Our aims here are neither to capture the way all people make these decisions, nor to suggest that this more collaborative path is the one all should take. Our work here addresses those cases when caregivers are already a part of the process, to shed more light on what we mean when we talk of the importance of caregiver involvement. In these cases, we must recognize the ways caregiver burden and patients' psychological burdens can overlap as both of their lives are inextricably shaped by the course of the illness. Likewise, we must also consider the ways caregivers and patients may be able to better discover and appreciate life's joys by each other's side. Pleasures that they once thought would be diminished may unexpectedly be retained, or uncovered in a new form, leaving them able to appreciate all that they have overcome to reach that stage together. Giving space for people with ALS to explore these options more thoroughly with their loved ones can both better enable them to envision the preferences they both will have at later stages of illness and the burdens they are willing to take on. These close relationship dynamics scaffold patients' autonomy and often crucially enable them to better envision the future each intervention entails.

Conclusion

Relational accounts of identity offer great promise for showing the many social and structural ties that shape our agency and autonomy. Understanding the type of person one is and the values that have consistently shaped their lives requires engaging with the narratives both of others and themselves. In navigating the many difficult decisions regarding their course of care, patients with ALS must consider and weigh multiple possible narratives for how the remainder of their lives will play out. Caregivers and loved ones often play crucial roles in this process as co-creators of these future narratives. Going forward, heightened attention must be paid to the complexities of caregiver involvement and the many roles others serve in helping patients make sense of the options at hand. Attending to these relational dynamics is critical to both maximizing patient autonomy and caring for the intertwined wellbeing of the family. Beyond the physical assistance caregivers provide, they often critically help construct the patient's understanding of where they are currently and how they will navigate the uncertainty both the illness and treatments bring.

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(II)

What Are We Protecting? A Neuroethics Case Study on the Risks and Harms of De-Identification Norms in Qualitative Research

Abstract: Anonymization norms are designed to protect participants from the potential harms of identification. In removing identifiers within datasets, participants are protected from the possibility of identity disclosure. However, the threshold for anonymization within qualitative research remains uncertain. The contextual details that can be critical to the narrative a participant wishes to convey can be the very information that increases the risk of identification. The history of protectionism within medical research protections combined with the lack of clarity regarding data-anonymization thresholds for qualitative data often lead to particularly (or, as I argue, often problematically) high standards for anonymization.

I explore this issue using a case from a qualitative study in neuroethics I conducted previously wherein data anonymization standards required redacting participant testimonies in concerning ways. Here, I problematize these norms on grounds that: (1) they are not *effective* in anonymizing data in the way they intend; (2) they undermine *participant agency*; (3) they are in conflict with *justice aims* insofar as they frustrate participants' political agency; (4) these norms *inequitably impact the marginalized and oppressed*. In return, I offer a framework that shifts our focus away from questions of how we protect participants and their data and toward questions of how we respect and empower participants. Ultimately, I do not conclude that we should do away with protections for participants and their data. Instead, I argue that the

obligation to protect must be balanced with considerations of empowering participant agency through opening avenues for greater input in how these narratives are shared within medical research.

Introduction

In August 2023, the family of Henrietta Lacks settled its lawsuit against Thermo Fisher Scientific that accused the biotechnology giant of “unjust enrichment” and financially profiting off of her cells (Meredith Wadman, 2023). Over seventy years prior, a physician removed Lacks’ cells from her tumor without her knowledge or consent. These rapidly growing cells, then named “HeLa” cells, could be easily reproduced in a laboratory and soon became a heavily relied upon cell line within biomedical research. They enabled researchers to develop vaccines for polio, the coronavirus, and treatments for diseases ranging from Parkinson’s to covid-19 to the flu. Lacks herself died at age 31 and was buried in an unmarked grave. For decades, the Lacks family had no idea her cells were part of so much research. In 2013, the European Molecular Biology Laboratory published the HeLa genome without the consent of the Lacks family, revealing genetic information about her descendants who had become all the more recognizable after Rebecca Skloot’s 2010 book *The Immortal Life of Henrietta Lacks* (Oza & Lenharo, 2023). The Lacks family ultimately reached an agreement with the National Institutes of Health to gain control over how this genetic data is used.

The story of Henrietta Lacks spotlights many issues in medical research: exploitation, racism, consent, privacy. It illustrates how these issues are entangled, such that understanding one requires considering its relationship to the others. In this case, the knowledge of Lacks’ identity both led to the invasion of her family’s privacy *and* enabled them to claim the monetary compensation owed for the non-consensual exploitation of their family member. Diagnosing the problems in this case is a complex task. One thing seems clear though: more thoroughly anonymizing the ‘HeLa’ cells would not have solved the problems at hand. This lack of care regarding anonymization occurred against a backdrop of exploitation and a silencing of the Lacks' voices in the process. Through holding Thermo Fisher Scientific accountable, gaining control over data uses, and sharing their stories, the Lacks family has regained some agency in the research process.

My focus in this paper is an exploration of some of the ways data anonymization norms in qualitative research can frustrate participant agency. Qualitative methodologies collect participant narratives for a variety of reasons, including to understand the factors shaping different types of experiences, explore how systems are operating, and identify intervention points (Bourgeault et al., 2010). They often utilize interviews to provide rich, nuanced narratives, and can elicit concerns or issues, often described in some depth, that would not be apparent through standard quantitative methodologies (Grigoropoulou & Small, 2022; Renjith et al., 2021). As qualitative research studies are a form of human subjects research, they fall within the governance of human subjects protections and guidelines that developed to prevent exploitative research practices, such as those that occurred in the Lacks case.

Among these protections are assurances regarding participant confidentiality and data anonymization. Anonymization norms are designed to protect participants from the risks of identification and are rooted in non-maleficence, or reducing risks of participant harm. However, the history of protectionism within medical research protections combined with the lack of clarity regarding data-anonymization thresholds for qualitative data can lead to high thresholds for anonymization. The emphasis is centered on eliminating risks of deductive disclosure, or of people identifying participants based upon narrative context such as the references to types of experiences or manners of speech. However, upholding these data protection standards can come at the risk of central aims of both researchers and participants: researchers want to identify and highlight significant experiences, and the participants who relay those experiences want their testimony to get uptake in the research world.

I explore these issues using a case from a qualitative study in neuroethics I conducted previously. After recruiting a diverse participant pool and upon writing up findings for submission for publication, we were required to redact and remove some key participant testimonies (and social identities) out of a desire to ensure participant protection. Removing HIPAA identifiers was not enough; requirements from publishers and a pre-publication database asserted the need to protect participants by removing any contextual clues that risked betraying participants' identities. Though we removed them in order to publish the study results, I argue here that these requests ought to have been weighed against the harms and benefits of leaving participant testimony un-redacted.

In what follows, I explore what can be lost when standards require complete confidentiality for qualitative data. In section 1, I describe and contextualize data anonymization norms and their use. In section 2, I describe and analyze the aforementioned case within neuroethics. In section 3, I problematize these norms on grounds that: (1) they are not *effective* in anonymizing data in the way they intend; (2) they undermine *participant agency*, in the ways they can frustrate the kind of uptake participants may desire; (3) they are in conflict with *justice aims* insofar as they frustrate participants' political agency; (4) these norms *inequitably impact the marginalized and oppressed*. In section 4, I offer a framework that shifts our focus away from questions of how we protect participants and their data and toward questions of how we respect and empower participants. Ultimately, I do not conclude that we should do away with protections for participants and their data. Instead, I argue that the obligation to protect must be balanced with considerations of empowering participant agency through opening avenues for greater input in how these narratives are shared within medical research.

Finally, while the present investigation centers a case within the subfield of neuroethics, the implications of this investigation go far beyond qualitative work within neuroethics. As we will see, the goal of data anonymization is one of the key arms of the larger goal of constructing and implementing ethics guidance within biomedical research more widely; as such, failures of data anonymization norms in this context are likely co-extensive with failures of the same norms in adjacent subfields.

(I) The Norms at Play

Human subjects research protections emerged in response to the public outcry against egregious research harms. In response, guidance documents – including the Belmont Report and the Common Rule – were developed to protect research participants. However, in aiming towards better protections, codified language surrounding 'vulnerable groups' justified harmful exclusions from research and other forms of research protectionism. These foundational research guidelines, in addition to the Health Insurance Portability and Accountability Act of 1996 (HIPAA), guide data protection norms in research. However, there is a lack of clarity surrounding how they should be applied to qualitative data, a problem becoming increasingly relevant given the newly established NIH Data Management and Sharing Policy. Given these factors, the uncertainty surrounding best practices for qualitative data stewardship can risk defaulting towards presumptive protectionism.

In 1932, the US Public Health Service (PHS) started what is now known as the Tuskegee Syphilis Study. PHS sought out collaboration with the Tuskegee Institute (a Black university founded by Booker T. Washington) and recruited 600 Black men (Tobin, 2022). Recruitment targeted men who were sharecroppers indebted to white farmers. They were promised free meals, free physicals, and burial insurance in addition to access to medical care. Those who had syphilis were monitored. Despite penicillin being identified as a treatment option in 1943, treatment was withheld from the 400 study participants who had syphilis. 128 participants died of the disease or related complications, 40 partners were infected with the disease, and 19 children were born with congenital syphilis (Urell, 2020).

Following the history of exploitative human subjects research in the US and in Nazi Germany, the US (and the world more broadly) developed and adopted practices designed to protect research participants. In 1972, public outcry over Tuskegee led the US Surgeon General to hospitals and universities establishing review boards. As part of this movement, the senate held hearings on human experimentation that led to the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (Tobin, 2022). This commission produced the foundational Belmont Report in 1979. The Belmont Report identified three principles to guide research involving human subjects: beneficence, which requires researchers to maximize benefits of research and minimize risks; justice, which gives researchers the responsibility to share risks and benefits equally and disseminate research findings; and respect for persons or respect for autonomy, which requires researchers to ensure voluntary participant consent to research, and ensure the option to stop participation at any time (*The Belmont Report : Ethical Principles and Guidelines for the Protection of Human Subjects of Research : Appendix*, 1978). Institutional review boards (IRBs) were also developed as a result of this report.

Notably, though the Belmont Report came out of desires to protect against previous research harms, it also codified a notion of vulnerability that fueled harmful forms of protection. The report formally introduced the notion of vulnerability:

> "One special instance of injustice results from the involvement of vulnerable subjects. Certain groups, such as racial minorities, the economically disadvantaged, the very sick, and the institutionalized may continually be sought as research subjects, owing to their ready availability in settings where research is conducted. Given their dependent status and their frequently compromised capacity for free consent, they should be protected against the danger of being involved in research solely for administrative convenience, or because they are easy to manipulate as a result of their illness or socioeconomic condition."

The stated goal was to produce a preliminary, protective framework to prevent research abuses like Tuskegee from occurring again. However, the introduction of this concept without a more clear definition led to a lack of clarity that fueled the protectionism that followed. Describing vulnerability by pointing to "racial minorities, the economically disadvantaged, the very sick, and the institutionalized" and attributing "dependent status," "their frequently compromised capacity for free consent," and "easy to manipulate as a result of their illness or socioeconomic condition," resulted in a conflation of a wide range of cases. It is critical here to appreciate that from the concept's introduction within human subjects research it defined vulnerability as a *compromised capacity for free consent* and *ease to manipulation* rather than the researchers who *made* certain participants vulnerable in different ways and the systems that fueled these abuses.

This “vulnerable” designation bolstered protectionist harms in the years to come after Belmont, including the 1977 FDA exclusion of women who were “childbearing” or “of childbearing potential” from drug trials (Charo, 1993). This exclusion from Phase I and II trials remained in place until 1993, but its impact remains both in the gaps of understanding of possible treatments that emerged in this time and in current practices like recent COVID vaccine trials that included few pregnant women (Baylis & Kaposy, 2010; Graña et al., 2022). This classification of vulnerable led both to (1) lack of engagement with these groups out of fears of ‘ease of manipulation’ and ‘capacity for consent’; (2) corresponding gaps in knowledge for how to meet the needs of group deemed vulnerable. Friesen et al. identify this tension between aims to protect and the need to include marginalized groups as the *protection-inclusion dilemma* (Friesen et al., 2022). They show that the tendency towards protectionism is exacerbated amidst uncertainty regarding the kind of risks involved in the research and lack of clarity regarding standard research practices.

Qualitative research data is a form of human subjects data. As such, it falls under the purview of the Health Insurance Portability Accountability Act ((U.S. Department of Health and Human Services, Office for Civil Rights, 2013)) and the Federal Policy for the Protection of Human Subjects, or ‘Common Rule’ (Protections (OHRP), 2009), that regulates human subjects research. Both policies require some degree of data de-identification, though where that threshold lies remains unclear and underdetermined in both. Lack of clarity regarding anonymization standards has previously been identified as a barrier to qualitative data-sharing (Mozersky et al., 2020). Despite this, the NIH recently enacted its Data Management and Sharing (DMS) policy which requires all NIH-funded research to share data more broadly and relies upon the same unclear standards, furthering the urgency of clarifying the purpose the data protections should serve and how data de-identification should be understood (National Institute of Health, 2023). In response to this gap, many databases, journals, and researchers have come to rely on the "dominant model" of confidentiality, i.e., the elimination of any deductive disclosure risk (where the combination of reported traits risk disclosing the individual's identity) (Kaiser, 2009). This is a very high standard, requiring the removal of any and all potentially identifying contextual details in qualitative data shared outside the research team.

Most broadly, qualitative methods ground investigations in non-numerical data, often through some form of interview. They often allow for more open-ended responses and in this way are different in approach from questionnaires, surveys, or the collection of biometric data that produce variables that lend themselves to numerical (or *quantitative*) analysis (Bourgeault et al., 2010; Catherine Pope, 2019; Renjith et al., 2021). While a survey might collect Likert scale data (e.g., a 1 to 5 ranking of how strongly one feels about something), a qualitative interview could allow space for explaining *why* that participant feels the way they do or *how* a certain course of events came to be. In this way, qualitative data often yields rich narratives that can provide deep insights into the lived-experiences of participants and serve as a means to better understand the range of ways systems are experienced by different people (Griffith et al., 2017).

Because qualitative research collects data from a subject by an investigator, it qualifies as human subjects research under federal regulation. HIPAA was passed in 1996 with the goal of standardizing electronic health information to improve portability for insurance purposes (Nass et al., 2009). Improving the ability to share health information came with elevated privacy risks. To address these concerns, the act lists 18 identifiers that must be removed for data to be considered de-identified, including name, zip code, and account numbers (U.S. Department of Health and Human Services, Office for Civil Rights, 2013). HIPAA itself focuses on clinical care, regulating the way health information could be shared by healthcare providers and health plans. As such, it applies to any research involving information from patients' medical records. Yet it has come to apply more broadly as well, as it has become a guiding standard for many data sharing policies in human subjects research.

The Common Rule was created to protect individuals participating in research through ensuring protections regarding privacy, confidentiality, data collection, personal impacts, and financial harms. It describes what kinds of research are subject to regulation, lays out requirements for Institutional Review Board (IRB) procedures, and was heavily influenced by the Belmont Report's guiding principles of respect for persons (e.g., requiring informed consent), beneficence (e.g., conducting risk-benefit analyses), and justice (e.g., ensuring equitable subject selection) (Protections (OHRP), 2009). The Common Rule went through its most recent revision in 2018 and details the kinds of data-sharing plans IRBs should expect for identifiable private information. The Common Rule defines identifiable private information in this way: "private information for which the identity of the subject is or may readily be ascertained by the investigator or associated with the information." While this definition faces difficulties when considering forms of quantitative data as well, it is particularly unclear for qualitative results. In the case of neural imagining, for instance MRI scans, decoupling the identifiers from the images would likely drastically lessen the ability for researchers and the participants themselves to know which image is which. However, in the context of interviews, this becomes more difficult, especially if the interviews are long in length and small in number as is often the norm within qualitative research. In the interviews, participants can share detailed, contextually rich stories from their lives. The data set then includes transcripts with HIPAA identifiers (usually participant and/or family names) removed. Due to the amount of contextual details that remain even after HIPAA de-identification, the likelihood of the subject's identity being 'readily ascertained' is often much higher. Even after removing any clear identifiers, the textual details and context will likely enable the researcher to know whose transcript the data came from.

Appreciating the different aims and standards of rigor between qualitative and quantitative research is particularly important here. Quantitative research is the dominant paradigm within medical research. Most broadly, it is hypothesis driven and aims at generalizability. Qualitative research is more often exploratory and not hypothesis-driven. The aim is to capture the range of experiences; "outlier" cases become just as, if not more, important than the most often reported experiences. In these ways, quantitative research lends itself to the abstraction and separation of variables that fit in line with complete de-identification operating as the ideal. For qualitative research, the rich detail and context can be critically important to keep together for the data to do their work.

The NIH enacted a new Data Management and Sharing Policy in January 2023 that requires all NIH-funded research to share scientific data (National Institute of Health, 2023). Its "Principles and Best Practices for Protecting Participant Privacy" encourages researchers to rely on standards for identifiability as outlined in the Common Rule and HIPAA without much additional guidance. The policy does state that any data that cannot be de-identified may be subject to controlled, rather than open, access where researchers must sign additional data use agreements to be able to access the datasets. Additionally, in the case the data are found to not be de-identifiable, they leave open the possibility that such data will not be required to be shared. Thus, examining whether data de-identification is possible and what kinds of participant protections they require is both timely and necessary. The federal policies governing human subjects research and promoting data sharing are only one piece of the research norms picture. These norms are established and reinforced across the research ecosystem including journals, researchers, IRB-specific policies, and, as the case study to follow spotlights, databases.

(II) Considering a Neuroethics Case

Study Aims

In 2019, a research group interested in the prospect of developing a neural technology to help people living with substance use disorders reached out to our neuroethics group. They asked to collaborate on a project to interview people in treatment about their experience with the disorder, their perspectives on current treatment options, and their thoughts on the possibility of deep brain stimulation as a treatment option. After extensive research team discussions and approval by our institutional review board, in 2020 we began conducting interviews with people in residential treatment for substance use disorders.

A bit of background will help situate this study. Substance use disorders are a significant health issue with limited treatment options. A US national survey in 2020 estimated that 38.7 million people (14.5% of the population) had a substance use disorder (SUD) (Substance Abuse and Mental Health Services Administration, n.d.). The national trend worsened over the course of the interviews, as drug overdose deaths rose above 100,000 in 2021, a 28.5% increase from the previous year (CDC, National Center for Health Statistics, 2022). Although inpatient treatment helps people with SUDs achieve initial abstinence, the rate of relapse is high (Andersson et al., 2019). Medication options remain limited in number, have high recurrence rates, and can be difficult to access.

In working towards broadening treatment options, some researchers are considering deep brain stimulation (DBS) as a potential treatment (Rezai, 2022). DBS is a surgically invasive therapy wherein electrodes are implanted in the brain to deliver targeted stimulation. DBS is broadly thought to disrupt brain networks whose overactivity or over connection gives rise to symptoms (C. R. P. Sullivan et al., 2021). Because of its initial successes in movement disorders such as Parkinson disease and essential tremor, DBS is being explored as a treatment option for depression, posttraumatic stress disorder, and, in the case of our study, SUDs (Chang et al., 2022; Mahoney et al., 2022).

While initial case reports of experimental DBS for refractory SUDs describe notable improvements, enthusiasm has been tempered by concerns from researchers and ethicists regarding potential coercion in the study of DBS for SUDs (Pisapia et al., 2013). SUDs are particularly socially stigmatized and often criminalized, increasing the risk of pressure to pursue treatments to avoid prosecution (Association of Women's Health, Obstetric and Neonatal Nurses, 2015; Kleinman & Morris, 2021). Additionally, seeing as many people with SUDs use non-invasive methods such as a 12 step program and recognize the social factors that contribute to substance use, it is not clear whether individuals would be interested in physically invasive neurosurgical intervention.

A scientific research team based at an NIH-funded Center for Addiction Research believed that understanding the relevance of these concerns would require engaging directly with potential device end-users. They recognized that target population preferences can often differ significantly from researcher or clinician perspectives (Anderson, 2004). Approaching research questions with open-ended, semi-structured interview questions was particularly important given the sociopolitical dimensions of SUDs. Why turn to a surgically invasive, individual-level, technological intervention for a disorder broadly recognized as being intimately tied to multigenerational structural inequalities and the failings of broader social support systems? We sought data to help navigate how to balance the immediate needs of relief for people currently seeking treatment for SUDs alongside calls for increased structural and social advocacy, support, and resources for addressing SUDs.

The Methods, The Publishing, and The Pushback

We conducted 20 semistructured interviews with people in a residential treatment center for substance use disorders about the possibility of deep brain stimulation as a treatment option. However, by the 10th participant interview, it became evident that our recruitment tactics needed improvement: our cohort was nearly all white. As an important topic in these interviews was understanding the ways potential stigmas surrounding neural devices could interact with stigmas surrounding participants' personal identities and substance use disorders more broadly, this lack of racial and ethnic diversity was particularly concerning.

To address this shortcoming, we broadened recruitment to another treatment center. Though our sample remained far from representative of the US population, we achieved a more diverse spread of participants: 10 white/caucasian, 1 Hispanic/Latine, 7 Black/African American, 2 Asian/Pacific Islander, and 1 American Indian/Alaska Native. Given the long length of each interview (~2 hours) and our methodological goal of careful analysis for each narrative (conforming to broader qualitative research norms (Starks & Brown Trinidad, 2007)), we concluded recruitment with these 20 participants. Our findings included nuanced reflections on how their racial and ethnic identities affected how their disorder was perceived by others, how familial experiences with the carceral system shaped their data privacy concerns, and how cultural contexts shaped treatment options.

We structured our findings thematically and included interview excerpts through data tables and in-line text to most accurately reflect participants' perspectives in their own voices. These data were valuable in opening critical conversations regarding justice issues, as much research regarding novel neural devices is predominantly white and often avoids engaging in conversations on ways racism shapes neural device development and implementation (Shen, 2020).

We anonymized our data by removing HIPAA identifiers, and presented all demographic data in aggregate form in tables. However, discussions regarding how to handle participant testimonies that disclosed individual characteristics remained fraught. Given the low number of non-whites represented in the cohort, how could we protect them from potentially being identified by clinicians, staff and other residents at the treatment center? Further, upon its acceptance to a journal, the editors required that we submit the paper to a widely used pre-publication database that directed us to: "remove all information that would *allow the patient / study participant* or their family, friends or neighbors *to identify them*" (email correspondence, emphasis added).

In attempts to meet these standards and prioritize protecting participants from identifiability, what were once richly informative testimonies became:

(1) **Participant 1**.[3] "I feel like I get stereotyped as that typical drunk [ethnicity] guy, at the store buying alcohol first thing in the morning, getting drunk, sitting out all day, just drinking and lazy [ethnicity] stereotype… That actually bugs me because I typically, at least at a minimum put in about a 70-hour work week."

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[3] Participants will be referred back to using these numbers (and bolding) throughout the paper.

(2) **Participant 2**. “I'm one of [religious group]. Okay? And so it's international, so there's English congregations that meet at the same place that we do, and they don't have that same stigma that the [ethnicity] people do. It's more of a [ethnicity] community thing, the stigma.”[4]

Others had to be removed entirely on grounds of providing potentially identifiable details, including:

(3) **Participant 3**. “I have several [family members] doing life sentences.”

(4) **Participant 4**. “And we never had a funeral. We never had a celebration of life, his ashes are still in my closet. [additional content redacted for purposes here]”

Presenting these quotes in a generalized format (e.g., “One participant described…”) would not resolve the issue either, as the small sample size (inherent to qualitative research) would have still risked betraying attribution of claims to specific participants. The redactions in the resulting paper (Versalovic et al., 2023) lessened the ability for the findings to more robustly capture the ways that social stigma against SUDs, racial bias, and interactions with the carceral system operated for those we interviewed. Additionally, though quotes referencing particular ethnicities were deemed problematic and shifted to the problematic label “ethnicity guy”, it seems questionable whether these slightly edited quotes—or any quotes included in the paper—were actually rendered unidentifiable by the participants who shared them.

(III) Identifying Harms

Here, I outline four areas of concern for how these norms operate in qualitative research. I problematize these norms on the grounds that: (1) they are not *effective*, or they often fall short of anonymizing data in

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[4] This quotation was ultimately removed from the final version of the paper.

the ways we attend; (2) they undermine *participant agency*, in that they can frustrate the kind of uptake or recognition participants may desire; (3) they are in conflict with *justice aims* insofar as they frustrate participants' political agency to push back against harmful practices in the field; and (4) they *inequitably impact the marginalized and oppressed,* insofar as the narratives of those from marginalized groups are more likely to be redacted in virtue of having been marginalized.

(I) *Effectiveness.*

On a pragmatic level, there is reason to be skeptical that these norms achieve anonymization in the first place. Taking example 1, it is unlikely that removing the reference to the participants' particular ethnicity meets the threshold of making the excerpt un-identifiable to the participant, or to a person who knows the participant well. Unless another participant has a similar experience — of dealing with a racial stereotype, of rebuking it appropriately — and conveys that experience in similar ways, the participant's narrative will still be distinct enough to be re-identified by the participant. Removing references to the ethnicity of the participant from the excerpt only *appears* to achieve the goal of anonymization. Similarly, example 4's reference to never having a celebration of life for a particular person due to stigma against substance use leaves, at minimum, the excerpt likely identifiable by the person who shared it. The remaining context left after certain words or content are removed still leaves this possibility of re-identification open. Further, non-content-related factors can also leave room for identifiability. The use of particular syntax or expressions will help participants, or those who know them well, re-identify the speaker as well. Diversifying participant pools across generational, cultural, or regional lines will likely increase the risk for the ways manners of speech can lead to increased identifiability risk. Removing references to ethnicity would not lower this risk.

In phenomenological interviewing in particular, the investigator's aim is to capture the range of experiences across participants rather than aim for prediction and generalizability in the way quantitative methods often do (Starks & Brown Trinidad, 2007). Phenomenological interview methods, as used in our study, take 'outlier' and more uncommon experiences and narratives as valuable areas of focus and exploration. Successful phenomenological interview projects often identify the dimensions of participant experience that may be under-appreciated or misunderstood, which can often lead to interviews with small cohorts of people with unique perspectives, or even case studies of specific people. Here, then, increased identifiability is a risk inherent to the methodology. Participant narratives are intended to speak to unique experiences, and in doing so, render participants at higher risk for being re-identified.

That is not to say any attempts to anonymize are necessarily futile, or that researchers should not take measures to prevent and mitigate different degrees of disclosure risk. Redactions will likely still provide protections to readers who are less familiar with the study participants. For example, those who are very familiar with Participant 1 may recognize the excerpt as theirs, but a more distant clinic member may not. The participant then could be protected against the need to 'answer to' any questions or concerns that these more distant other researchers or clinic members may have about naming the existence of harmful social biases.

Ideally, then, these redaction practices could operate as a *shibboleth* of sorts — those who have already have knowledge of the participants' experiences, or have had similar experiences, are able to 'read between the lines' enough to understand but participants are protected from repercussions that come from those who have not previously had access. In this case, though, the threshold for anonymization is better conceived in terms of how the participant is able to communicate what they desire to with different audiences — a threshold the participant themselves is more likely to understand than the researcher. How is the researcher to know whether the participant has only shared their experiences with the way addiction shaped their particular familial experiences with entrusted loved ones and researchers versus when they may take pride in owning this story and conveying it openly? This consideration then becomes one of participant *agency* in determining what the effective thresholds should be.

(II) *Participant Agency*.

Amidst the US medical system wherein patients often experience being unheard and constrained, centering participant agency in medical research is particularly important. Collecting and sharing participant narratives can be one (albeit small) way to promote individual agency. Participants can be motivated to join a qualitative research study out of this desire to share their story—to, in our case, to impact biomedical research. It is important to consider ways that minimizing redactions to participant narratives can be a way of respecting participants' contributions and agency.

Keep in mind that participants shared their perspectives here as part of this specific phenomenological interview study. They understood that the interviewer was part of a team wanting to better understand the ethical and social issues surrounding the possibility of deep brain stimulation as a treatment for substance use disorders. Participants chose to share what they did knowing they were speaking within the study space. They chose what details to include, and how they wished to communicate their experiences to the interviewer.

The interviewer plays a role as well. In phenomenological interviewing, the aim is to capture participant experience (Bevan, 2014). Rather than prompting participants to share their preferences (—e.g.

“Did you find the care you received satisfactory?”) or beliefs (—e.g., “Why do you think you received the care you did?”), phenomenological interviews prompt participants to describe their lived-experiences at the level of their physical sensations (—e.g., “How did it feel entering the clinic?”). The interview, analysis, and sharing process for this kind of data entails many *hermeneutics*, or interpretive steps: the participant interprets their own experiences in order to describe them, the research team interprets the participant’s testimony using theoretical resources, the reader interprets the write-up (Padilla, 2003; Wiklund et al., 2002). Misinterpretations can occur at each hermeneutic step, distorting not only the phenomena under investigation but also the intentions of the participant in sharing their stories in their own voice. Maintaining the narrative’s fidelity as it was shared by the participant can be one way of minimizing hermeneutical distortions and respecting participant agency as expressed through the sharing of their story.

One of the goals of research participants may be to have their voices heard and their knowledge included in the making of medical knowledge. For instance, in a different qualitative study we conducted with participants in a robotic arm trial for spinal cord injuries, we asked participants what they felt was owed in trial participation. One participant responded:

> “Recognition. We're going through a lot with our bodies. We are subjecting ourselves to dangerous procedures... They're building their careers off of us, off of test subjects. So I think that we should be recognized for our participation in any type of articles, write ups.”

This participant expressed concern over the ways they felt somewhat exploited due to inequities in the types of benefits gained by the researchers as opposed to the trial participants. The users’ participation in the trial helped the researchers gain professional clout and contributed to their careers. By contrast, participants' compensation often fell short of covering the costs of the carer and transportation support required for trial participation. This participant requested some kind of greater recognition in return.

Precisely what form of recognition the participant desired is not clear. However, this account does flag the need to take seriously the disparities between researchers' and trial participants' benefits. In both studies, participants described volunteering for research against a backdrop of a loss of agency: for those with spinal cord injury, the change in mobility and ableism of US society had led to a high degree of physical dependence and social isolation; for those with substance use disorders, shame surrounding substance use had led to social isolation. Some participants described doing these interviews as a reclaiming of purpose and agency through the ways they were being consulted for their expertise related to such difficult experiences. Participants were often proud of their participation. These considerations do not mean participant testimony should not be redacted or anonymized, but they do show the need to not presume that complete anonymization is participants' priority or preference.

Finally, the low compensation levels in these studies heightens the need to consider what other kinds of benefits can come from participation in interview-based studies. In our SUD study, participants were offered a $25 gift card in return for participating in the 1.5 to 2 hour interview.[5] People used their limited time in a treatment center to participate. Each day at a treatment center often comes with a high financial burden due to the range of care services provided (*e.g.* clinicians, therapists, nutritionists, life-skills support) and the often inadequate insurance coverage. Further, each day comes with added

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[5] Issues regarding participant protectionism also impact how compensation is often approached in these projects with the presumption that compensation should not be at amounts that could unduly impact someone's decision to participate in a research project. However, given the relatively low risks to participation in interview-based studies like this, there are good reasons for pushing back on these low compensation norms as well. Shifting towards more participatory and participant-empowering approaches to research could also show the importance of more appropriately compensating participants for the expertise they provide.

burdens to family members who may be going without the support that person cannot provide while in treatment. Researchers have a responsibility not to take this usage of time lightly and to take seriously participants' expectations and hopes for how the narratives they share will be used.

Considering participant agency requires appreciating the backdrop the research is operating within, and the constraints operating within the medical system. Questions surrounding participant agency are not as simple as whether they have it or not. We must consider the kind of agency participants wish to express through study participation.

(III) *Justice Aims.*

Researchers have a responsibility to consider the *political* agency of both individual participants and the researchers' projects as a whole to push back against unjust practices within neuroscience in particular. As the BRAIN Initiative invests significant funding into the development of neural technologies, questions of equitable access (Lázaro-Muñoz et al., 2018; Yuste et al., 2017), just design (Choy et al., 2022; Danielle Nadin, 2020; Louis et al., 2022), entrenched ableism (Stramondo, 2019; L. S. Sullivan et al., 2018), and user care are increasingly pressing.

Scientific racism has operated – and still operates – within neuroscience in ways that make it a setting in which it is especially important to prioritize research approaches that facilitate identifying the roles and effects of racial marginalization and discrimination. Reckoning with neuroscience's (and neuroethics') racist histories is increasingly important. In 2020, Francis X. Shen wrote of the shortcomings of the BRAIN Neuroethics Roadmap's avoidance of naming racial injustice as an issue in need of prioritizing (Shen, 2020). Addressing issues of racial injustice must go beyond diversification of those within the field, to "critically reexamining research priorities and methods." Minimally, neuroethics needs to recognize racism as an issue worthy of the field's attention. Shen points out that even in 2020, the prominent neuroethics journal, *American Journal of Bioethics: Neuroscience*, enables a keyword option for "gender," but there is none for race or racism.

Similarly, other scholarship flags the ways that "demographically narrow," (predominantly male, white, able-bodied) researchers have reinforced exclusionary and harmful notions of 'normal' vs 'aberrant' (often: 'violent') brains and what kinds of traits should be preserved. For instance, Winston Chiong points to the history of defining 'normality' in ways that have led to harms including the targeted use of ablative psychosurgery in women and Black people, and the classification of homosexuality as a psychiatric disorder. The lack of diversity amongst researchers has impacted neuroethics as well as neuroscience — as neuroethics has often stopped short of engaging with the *social dimensions* of neuroscience and neurotechnology (Chiong, 2020).

Further, Oliver Rollins sounded the call for an antiracist neuroscience that must engage with "the dynamic and often embedded ways in which the sociohistorical investment in and present-day realities of systemic racial inequality are realized and lived, through quotidian societal activities and relationships" (Rollins, 2021b). He chronicles the many ways racism shaped neuroscientific notions of "normal" and "aberrant" (e.g., *violent*) psychologies, and how these paradigms have been weaponized against racialized (especially Black and indigenous) bodies. He maps out the turn from explicitly racist reasonings to any discussion of race becoming a "taboo" and the subsuming of a colorblind stance within the field of neuroscience. He pinpoints this turn in the late 1970s, when outcries against researchers using IQ scores to justify racist, genetic-determinist approaches to white/black racial differences and attributing "urban riots” to “brain dysfunction” (with the implication of psychosurgery as a means for treatment/control) led to colorblind defenses by physicians and researchers and discussions of race becoming a taboo altogether (Rollins, 2021a). Through tracing the residue of racist histories that arise in current practices, Rollins argues “Published research on the brain and violence is not as much totally devoid of race as it is sanitized of meaningful discussions about the impact of race” (109). This over-correction to a field-protective stance against talking about racial categories (instead often using presumed proxy categories of socioeconomic status or cultural background) has led to an inability to investigate what measures and claims in the field lead to differential harms to racialized bodies. While he warns we must take care in how race is discussed to protect against problematic reification of these categories, he advocates for deeper engagement in the ways racism is perpetuated in current neuroscience work. Simply relying on the racial categories as used on demographic surveys will fall far short of understanding the way these identities are experienced.

Elucidating these social dimensions, however, requires that we cultivate the ability to name denigrative, disenfranchising, and oppressive forces. It is crucial that our language be specific, so as to open the path to ameliorating the harm these forces cause. Vague references to ‘experiences of racism’ can help acknowledge these harms in a broad sense — and acknowledgment of harm on its own can be ameliorative. However, this language is ambiguous, and cannot give us a clear picture of the mechanics of racism as they appear in experiences of it.. Participant 1 reveals that there is some form of ethnic prejudice they encounter that intensifies their experience of substance use related stigma. However, the redaction of the particular reference to the identity they chose to invoke in the interview lessens the strength of their testimony. A person reading that passage will likely project whatever groups they may already presume to fit the stereotype. At best, the quote will affirm that there is some cultural variation across how people experience SUD stigma. At worst, it risks reifying the stereotypes they already hold.

Similarly, for Participant 2, they articulate the way certain religious and ethnic intersections affect access to treatment options and experiences of stigma. However, given the way these intersecting social identities would almost certainly betray the participants' name amongst this group, both references were redacted. Here again, readers of the redacted data are left understanding that religious spaces can counter cultural stigma, but unsure in what contexts. The participant also loses the ability to take pride through expressing the way their particular religious community has helped empower them (a narrative that can helpfully counter presumptions that religious spaces might only exacerbate stigma). The data lose the ability to help identify how these different dimensions are operating. In the process, they lose at least some of the ability to speak to potential intervention points.

Culturally dominant identities (e.g., whiteness, able-bodied, male) are also less likely to be named because they are considered the default, the norm, or the standard. In Iris Marion Young's account of oppression, she captures this aspect of oppression in terms of cultural imperialism (Young, 2020). For Young, oppressed groups "suffer some inhibition of their ability to develop and exercise their capacities and express their needs, thoughts, and feelings" (42) due to the everyday practices, norms, and institutional rules of economic, political, and cultural institutions. Forms of structural oppression include — but are not limited to — racism, anti-semistism, queerphobia, sexism, classism, and ableism. Due to the irreducibility of the way each form of oppression operates, she articulates five 'faces' of oppression that capture the ways oppression can operate: exploitation, marginalization, powerlessness, cultural imperialism, and violence.

Through cultural imperialism, the dominant group's experience and cultural expressions "become the normal, or the universal, and thereby the unremarkable" whereas the difference of the oppressed groups are constructed "as lack and negation… marked as Other" (59). Oppressed group members are simultaneously rendered increasingly visible through operant stereotypes (e.g., women as nurturing and maternal, gay men as promiscuous, Black men as hypersexual) that mark them as *deviant* and yet simultaneously *invisible* from the perspective of their individual, lived-experiences. As she describes: "White males, on the other hand, insofar as they escape group marking, can be individuals" (59). Cultural imperialism operates through the homogenization of narratives: dominant groups become universalized norms; oppressed group members become conflated through harmful stereotypes that stifle the ability to be seen as individuals and on their own terms.

Young's portrayal of cultural imperialism parallels George Yancy's helpful descriptions of whiteness. Yancy points out the ways whiteness is often starkly visible to those 'Othered' by it and invisible to those who inhabit it. Whites are able to operate as individuals, while non-white bodies are simultaneously hyper-visible and invisible (Yancy, 2012).Black bodies become "seen invisible" as, through whiteness, they become racialized animations of the White imaginary. In the process, they lose both their community and individual subjecthood. Whiteness operates as the unseen or unmarked norm all 'Others' are measured against. Whiteness benefits from the ways it goes unnamed. It is difficult, even if not impossible, to fight oppressions that operate through forces that few people will acknowledge exist. For Yancy, pushing back against oppression "is about turning our bodies (and our attention) in the direction of white discourse and white social performances that attempt to pass themselves off as racially neutral, and it is about finding the courage to say, 'Look, a white!'" (11). Subverting racism requires enabling ways for racialized people to assert their own individual narratives and for White people to be called out on their complicity with and within these systems.

In a similar vein of troubling the presumed norm of whiteness, Shameka Poetry Thomas speaks to the importance of de-centering whiteness within women's reproductive research in particular by spotlighting, or *centering*, Black women's narratives (Thomas, 2022). Thomas describes the ways that all too often medical research and bioethics center White groups as the standard reference group and homogenize the experiences of all people, as though they were like those of White populations. Failing to center Black experiences perpetuates this harmful homogenization. Centering, for Thomas, is not making Black perspectives the dominant discourse. For her, to center these perspectives is to enable multiplicity: "Centering, in my perspective, is rather a process of discourse expansion that enables multiple locations of knowledge and lived experience to co-exist."

Oppression benefits from the homogenization of narratives — both through the ways dominant groups (e.g., white, able-bodied, straight, male) become invisibilized (to the oppressors at least) norms and marginalized groups are subsumed within prejudicial narratives. Identifying the ways racism, and other forms of oppression, are operating within neuroscience requires not only representing diverse perspectives in research, but making sure those voices are *heard*. Redaction practices that perpetuate the homogenization of experiences as in the accounts of Participant 1 and 2 can run counter to this aim. Given the ways dominant narratives operate, enabling testimonies to be shared in the ways participants chose to socially situate themselves can be particularly important.

Harms of disclosure must also be considered. Participants who share their stories and are then re-identified may find themselves facing additional stigma, discrimination or retaliation. Attending to these risks is especially important when studies are being conducted in clinical settings where care providers or research trial facilitators may be the ones deducing the participant's identity. These harms might not just be individual either. Collective harms could follow from re-identification. They may invoke a group identity inappropriately (e.g., someone wanting to speak for all women) or risk perpetuating particular harmful stereotypes. But, these harms must be considered against the backdrop of harms and stereotypes already operating within the system. Participants may be participating to call out discriminatory behaviors or systems they are already running up against (*i.e.*, differential treatment based upon their identity is already operating). Countering oppression within neuroscience requires empowering the political agency of participants and researchers wanting to act toward these ends. Enabling subversive agency may outweigh the value of protecting participants from recognizability.

(IV) *Inequitable Impacts.*

In addition to the ways these norms may frustrate attempts to identify how oppressive structures are operating in these research spaces, they are also at risk of directing their adverse effects inequitably upon members of marginalized groups. The systemic exclusions that render certain participants marginalized in the first place are the conditions that lead to increased identifiability. Additionally, members of marginalized groups have increased risk for hermeneutical distortions that occur through the ways testimony may be redacted or reworded when found at risk for re-identifiability. Researchers must consider the ways these anonymization norms inequitably impact those who the medical system has often harmed most.

Medical research systems were built for those with dominant group membership (think: EEG electrodes made for lighter hair and skin (Ricard et al., 2023)); increased recognition of heart attack symptoms in men). In qualitative research, dominant group members are less likely to invoke specific identity descriptors due to the ways they often disappear against the background of norms shaped for them. Oppression is hard to see for those afforded the recognition they desire. Participants constantly reminded of their 'Otherness' often become more fully aware of the ways their social identities shape their experiences.

Demarcating particular characteristics, then, can be more common for those who are marginalized. What is taken to be presumed is often less likely to be said. If I am a white person in a predominantly white space, I am both less likely to have it pointed out to me and to become aware of it myself. The way someone who is one of the few people of color in a predominantly white space may be signaled as 'Other' makes it harder to ignore the ways they are racialized by those around them. In explaining how they experienced the space, one could imagine the white person would be less likely to invoke their racial identity because that is the presumed identity of those there. For those reminded of their 'Otherness' in that space, invoking their racial identity could be particularly important to explaining why they experienced the space in the way they did.

Dominant groups' experiences are often universalized and invisibilized in ways that make them less likely to be named in ways that would render their testimonies likely to be redacted in the first place. Though redacting may still help protect marginalized individuals and groups, the increased likelihood to have testimony redacted or re-worded by researchers is an area for concern. Redaction (e.g., removing descriptors of how participants refer to their own experiences) and abstraction (e.g., higher level descriptions of participant views) of participant testimonies increases the likelihood for hermeneutical missteps. These misinterpretations become increasingly likely when researchers and audiences do not share the social identities of participants.

Personal testimony can be a particularly important and powerful tool for those who are oppressed. Keisha Ray advocates for the use of experiential race testimonies (ERT) as a way of centering Black voices in medical education praxis (Ray, 2021). First-person testimonies from Black patients in discussions of Black health help center the patients themselves (rather than the illness or provider), situate their health care experiences within the context of racism, and amoralizes Black people's health. Her approach "makes Black individuals the center of their experiences of illness and care using their own testimonies, their own words, leaving little room for learners to impose their interpretations of what an individual is experiencing." Protecting space for Black people to be represented *in their own words* and *as they want to be represented* in often harmful and predominantly white spaces is critically important.

For Ray, testimonies do not need to be long narratives with a fully formed plot. As she describes: "Testimonies afford and allow patients to claim their own experiences, thoughts, or feelings. Testimonies are personal, and when they are shared with others, tellers invite a listener, in this case the health professionals learner, into their world as an observer" (Ray, 2021). Naming Black experiences as named by Black people is critical given the differential experience of race and racism within the healthcare system. Giving people space to name these experiences is particularly important for those who have all too often not been trusted to be narrators of their own stories or had their voices removed from those stories.

Given all these risks of how research anonymization norms may be questionably effective, frustrate participant agency, limit work towards justice aims, and fall inequitably across participants, we must consider what models and methods of approach can help bring researcher and participant aims in better alignment. While discussion so far has centered aims to protect participants, the final section refocuses around participant empowerment. It is critical to consider what it means to respect participant agency within our research practices.

(IV) Towards Participant Empowerment

It is important that we consider research benefits, alongside consideration of harms, and that we do not presume that protection from those harms necessarily overrides the benefits that can come from it, both at the individual and collective level. At the least, we must not presume (I) the degree and kind of anonymity of value to participants; and (II) how they weigh the importance of confidentiality relative to other research values, like recognition for contributions within the field and utility of their testimony to serve as subversive counter-narrative within research. Undergirding both these considerations is the need to remain vigilant of the impacts of participant *protections* and more critically examine the kinds of harms we are attempting to protect participants from and the types of potential harms that may come about in their application.

Clarifying Thresholds & Centering Agency

Firstly, I suggest researchers better involve participants in determining the type of anonymization that is of value to them. We can consider a wide range of where these thresholds could lie: anonymization from those outside the project (e.g., more distant journal article readers); providers (especially in the context of a trial in a clinical setting like ours); family members; themselves (to ensure that no one else could come close to attributing the data to them). The case here represented the most thorough threshold with the editors requesting we *remove all information that would allow the participant or their family, friends, or neighbors to identify them*. While their justification seemed based upon the blind application of their quantitative data standards, there were other important considerations in how we handled the data.

Members on our research team had flagged the concern that due to the lack of demographic diversity in the treatment center we collaborated with, retaining a particular non-white racial identifier would significantly heighten the risk of them being identified by clinicians or other patients at this treatment center. Further, due to the ways participants tended to speak honestly about difficult family dynamics, there is good reason to think that many of them would have wanted to ensure particular family members would not have traced it back to them, should they have come across the resulting publication. To be sure, there are many strong reasons participants may have for wanting to prevent the possibility of deductive disclosure with different people. However, given that many studies enter the informed consent process promising complete confidentiality up front, there is rarely space for participants to more actively determine what thresholds are of value to them, if at all.

Here, my (and collaborators') work considering the ways privacy operates within agency may lend itself useful. Rather than taking a separation-based approach to privacy that identifies complete privacy as a state of being entirely unaccessed, we define a robust sense of privacy to be the ability for individuals to negotiate and shape their boundaries with others (Schönau et al., 2021). Viewing privacy in this way prevents taking complete isolation as the ideal and emphasizes the importance of ensuring the ability for participants to determine the aspects of privacy that are most important to them (Versalovic et al., 2022). In approaching it in this way, discussions of privacy can better center participant agency, rather than presuming the benefits of a separation-based approach to participant protection. Taking this approach in the context of qualitative data confidentiality protections, I advocate for taking a confidentiality practice that centers participant agency rather than protection, and opens more space for participants to shape those boundaries.

Towards this end, there have been initial gestures towards more nuanced informed-consent post-interview tools. Kaiser, for instance, recommends that the use of a form that enables participants to determine whether they (a) prefer information is shared with full transparency; (b) prefer all information is shared but with a pseudonym; (c) would like to specify which types of information must be redacted– and to leave their information for future contact should researchers have questions about these data sharing thresholds (Kaiser, 2009). Kaiser anticipates the "dominant approach" to prioritizing anonymity as a barrier to ethical review board acceptance of this "alternative approach" to participant confidentiality but helpfully points out the ways this approach is consistent with the foundational Belmont Report's emphasis on beneficence and respect for persons. Though I find Kaiser's proposed framework a helpful step towards re-envisioning these processes, her main proposal is an additional consent form at the interview's end. As it is likely that shared discussion between the interviewer and interviewee will be critical to helping participants consider the ways different kinds of information could be misused and the ways deductive disclosure may operate, I advocate for building in space *within* interview guides themselves to engage more critically in these questions with participants. How these conversations could look leads to the second consideration– how other research values may be weighed against participant protection.

Benjamin Baez's work shows the tradeoffs that can come with confidentiality practices in qualitative research. In protecting participants from attribution, they risk leaving structures operating as they have by limiting the possibility for 'call outs' of problematic behaviors (Baez, 2002). This tradeoff is particularly concerning in thinking about how they can leave harmful power imbalances undisturbed. Working towards research practices that enable more 'critical agency,' requires adjustments at many levels, from the ways we determine research aims to how we carry out participant recruitment to the ways we ask questions in interviews to the reflexivity practices we utilize to understand how researcher presumptions and biases shape the final written products of the project.

Given the history of protectionist harms of "vulnerable groups" in medical research, it is critical to remain vigilant regarding the kinds of presumptions that are made in respect to who can appreciate the kinds of risks that may come with different research decisions. Histories of protectionism have resulted in care gaps for groups that have been designated as 'vulnerable' under the Common Rule and other research guidelines including women, 'racial minorities,' and disabled bodies. Blanket presumptions for complete confidentiality may perpetuate the lack of information regarding people who lie within these categories. Increasing avenues for participant input on how they wish to have their data handled and represented can be one small step towards rectifying these harms.

In considering ways forward, remember that HIPAA's Safe Harbor methods identifiers and the Common Rule underdetermine these anonymization norms and leave open the possibility of retaining the contextual details the database requested we remove (Mozersky et al., 2020). This does not mean that approaching these confidentiality issues will be easy; in our experience, these norms are entrenched in a number of journals, databases, and researcher norms. It does however mean that legal policy changes are not required to explore and employ new approaches.

These investigations have led me to consider different methodological approaches going forward. In future work, I plan to open explicit conversation with participants within the interviews around the ways data will be used and handled. Informed consent will be less as a passing formality with inherited research protection language, and instead as a more participatory practice– one that begins at an interview's start and is revisited at its close, reflectively engages with what was shared, and opens the possibility for changes in preferences. How these practices will be best carried out remains an open question and will be a focus of future work. In addition to opening avenues for feedback during the interview, practices that enable participants to reflect upon how their narratives are being analyzed and shared will also be important to consider. These practices could include forms of member checking wherein researchers elicit participant feedback on the ways their interviews are transcribed, interpreted, and analyzed at various stages of the research process (Birt et al., 2016). Continued consideration will be required to determine how to best balance project progression with participant input and how to best arbitrate potential disputes as they arise.

Using qualitative methods as a tool for naming racial injustice, promoting critical agency, and subverting current research practices will require critically reexamining the ways we structure research and carry out our methods. At base, we must not presume the research norms around protection necessarily operate towards that end. We must look towards better engaging with participants as research partners rather than passive subjects guarded under our protection.

Considering Objections

Restructuring research norms requires considering a number of ways these too could go awry. I close by considering three possible objections: (1) Why not just increase participant numbers to lower identification risk?; (2) Won't enabling participants greater control over data after data-collection risk the quality of analysis?; (3) How will participants adequately appreciate the risks of identification? I will take them in turn.

First, lower sample sizes are inherent to many qualitative methodologies. In the case presented here, we conducted 20 1.5 to 2 hour interviews for a resulting 4,000 word-limit paper.[6] Analyzing that much data is incredibly time intensive. Working with the 20 interviews we conducted (which is high by many qualitative data standards, particularly for phenomenological approaches (Starks & Brown Trinidad, 2007)) required many tradeoffs for deciding which very limited sliver of data was represented. Concerns surrounding responsibly representing the range of experiences described would likely only increase with increased numbers. Even if increasing numbers was pragmatically possible and methodologically justified, it is unclear how much the risk for having identifiable content in the interviews would diminish. Unique participant experiences would still arise regardless of how many participants' data collected.

Second, it is important to consider how increased participant control over data sharing by letting them change whether they are comfortable with certain kinds of information being disclosed could interfere with analysis. Once data is analyzed, removing or amending the data in these ways can be disruptive and risks losing data that could be critical to the study. For instance, what if a participant shares a powerful story of frustration with a care team, and then decides later – after transcription and initial analysis – that they would prefer not to have that story shared. Here, it is important to remember

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[6] The word limits of many research journals is another norm that works much more in favor of quantitative research.

how control over determining privacy thresholds can impact participants' trust in the research process itself. Participants' evaluation of research trustworthiness can impact their ability to trust other aspects of the healthcare system. While allowing for data amendments or removal after the fact will likely slow the analysis process – and may change what is available for that analysis – respecting participant choices about their input can be a critical way of recognizing their contributions to the project. Building avenues for increased agency for participants is particularly important given the histories of exclusion and protectionism. There is a wide range of ways this involvement could take shape, from leaving contact information with participants should they have concerns after the fact, to member checking (where participants are able to review findings and give feedback on whether their views were adequately represented).

Finally, how do we protect against cases when participants may not understand the ramifications of identification? This concern falls on both the individual and more collective level. On the individual level, someone may not anticipate how information in the study could be used against them (e.g., risking disclosing a diagnosis, or retaliation for sharing negative experiences of clinicians or care staff). In addition, information disclosure does not only impact the individual choosing to share it[7]– my sharing of a family story impacts the others intertwined in that story who may not be ready to share. Further, my claiming I experienced something due to membership in an identity category could further exacerbate certain entrenched biases against that group.

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[7] This kind of concern is equally, if not more, relevant for quantitative data as well. As Pyrrho et al. point out, the ways each of our data is aggregated impacts the amount of control those who buy, sell, and trade that information then have in the broader public space: "out ability to negotiate the boundaries of what is intimate is reduced" (Pyrrho et al., 2022).

On the individual level, researchers have responsibilities to more carefully consider possible identification risks. This process cannot be another checkbox form but will require more careful conversation to help participants consider and weigh disclosure risks. For many qualitative studies, there may be little risk of harm that could come with identification risk. For others, such as studies discussing gender-affirming care or reproductive health, the stakes may be much higher. On the more collective level, researchers will need to carefully consider how they are presenting potentially stigmatizing data. This is where Baez' focus on qualitative methods being used as a way of opening "possibilities for resistance from the margins of power" (36) may be helpful. Which groups are at risk of what kinds of harm from disclosing that data? And, crucially, what benefits might come from sharing the participant's testimony as it was shared? Practicing in reflexivity, or examining pre-existing biases and data analysis through self-reflection and, most importantly, through discussion with a broader project team will be particularly important here.

Conclusion

Research protections play a vital role in safeguarding participants against the harms our medical and research systems have recapitulated again and again. But, just because the notion of participant protection is invoked and used to justify certain research norms does not mean there are actually harms those practices are protecting participants from. What I am calling for here is not a doing-away-with but rather a critically-engaging-with. In a field where there have been such limited voices amongst the researchers and participants, we must not underestimate the power that sharing participant testimony can hold in empowering participants to both have their story heard and work towards more equitable and just practices.

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(III)

Summoning Love, Letting Go, and Touching Shores:

A Self Study on Identity Holding After Death

Abstract: The relational identity literature shows that who we are emerges through the stories both we tell of ourselves and others of us. In times of increased dependency, when it can become increasingly difficult to maintain these identity-holding stories for ourselves, this identity-holding work can be increasingly practiced by others. The holding work extends beyond death, even, as loved ones work to keep alive memories of the deceased, using "preservative love" for the sake of the deceased but also for themselves. What does it mean to continue to love those who are no longer with us? Six years ago, my grandfathers passed away. I clutched onto my stories of them– worried that their fading would mean losing my ability to continue caring for them. In this self-study in identity holding, I argue that while preserving stories of loved ones who have passed is important, continued love and holding goes far beyond the accuracy of the stories we tell. Taking María Lugones' notion of playful world-traveling as a guide, I warn of the ways static narratives can run counter to love. In the place of "preservative love", I offer the alternative of "summoning love" that emphasizes embodied modes of holding the dead, through an open 'playfulness' that can enable us to reanimate our relationships with them.

“What occurred–is still occurring–was a resounding, a playful bouncing off, on and with each other, where there was a collusion, a rebounding, a sounding of the two voices, both distinct, and yet never quite apart, resonating, reverberating without any attempt to be first–even though there was no choice but to be the one that is speaking, writing, for him, in his absence, in his memory, for his memory.”

- *Writing Death* (Fernando, 2011)

“In death we surrender our embodied life on earth. Love is the only force that allows us to hold one another close beyond the grave. That is why knowing how to love each other is also a way of knowing how to die.”

- *All About Love* (hooks, 2001)

my sister mothers love me
when the world shudders
they get solid as a wall
around my girlchild self

my goddess mamas love me
whisper to each other
pointing towards the path
with the deepest breath on it

i know of so many mother ghosts

my prayers seek their palms

my tongue chants their

original names

- an excerpt from my mother loves (for jane brown) (adrienne maree brown, n.d.)

Introduction

My grandfathers both passed away six years ago, six months apart. Watching the reverberations of each of their passings through each side of my family made me wonder: how could I stay connected to their love that helped hold me for so long? How could I hold their identities, keeping them close to me and part of who I am and would become? This desire came both from the want to continue feeding that love and the draw towards continuing to understand myself. This paper traces some of the turns across six years of this grief and my attempts to learn how to keep practicing the relational care we held between us.

I approach these questions through a relational and narrative approach to identity. This paper proceeds in two parts. The first section considers the question of how we can approach lovingly holding others in their identities while alive. I use the work of Françoise Baylis and Hilde Lindemann to illustrate the ways identity care and negotiation practices operate. I show how taking these stories as *relational* means taking seriously the ways we construct ourselves in tandem with how we hold the identities of those around us. I use the work of María Lugones to show how engaging in these practices *lovingly* requires an openness to playful world-traveling.

In the second section, I consider how to approach these shared identity practices when those we are caring for have passed away. I take Hilde Lindemann’s notion of ‘preservative love’ as a starting model for how these post-mortem practices have been conceptualized. Actions of preservative love seek to reinforce and perpetuate that person’s identity narratives. Here, continued identity-holding is grounded in the obligation to prevent the person who has passed from the harm of being forgotten. We are instructed to archive stories and objects to prevent them from disappearing from memory. It is a question of them remaining here, or fading away entirely.

However, approaching holding in this way can fall short in the ways: (1) it portrays identity-holding as unidirectional (the living do it *for the dead*); (2) it often overlooks the hermeneutic gaps we may have in respect to who that person was. As an alternative, I suggest an approach based on ‘summoning love.’ Rather than presuming that to care for that relation is to preserve those stories as they were when that person was alive, summoning love calls us to towards a stance of open curiosity regarding that person’s stories, to consider what kinds of worlds we shared with that person, and which of those relational stories we wish to re-animate. In taking seriously embodied practices and an openly curious (‘playful’) stance, I entertain the ways we can lovingly awaken or feed the web of relations we shared with that person. Through these practices, we may, at least partially, return to the worlds we shared with that person, re-animating those identity-stories of us both in the process.

I: Relational Identity Holding

Relational approaches to identity and autonomy capture the ways in which who we are arises from our relationships with others (Stoljar & Mackenzie, 2000). In this way, they contrast with liberal philosophical approaches that take the autonomous, self-interested individual as their starting point. Instead of presuming the fully formed, rational, more physically independent actor as the starting point for moral theory, relational theorists center the social fabric we are dependent upon when we enter this world, when we depart from it, and the many levels of dependency that arise in between. Hilde Lindemann's account of relational identity centers the ways identity formation occurs through the social practices of holding and letting go of, what she terms, identity-holding stories (Lindemann, 2008, 2014). These narratives of identity both help us interpret the actions of those around us and the ways that we should act in respect to them.

These identity-holding practices are an integral part of human life, but they become even more evident when individuals are less able to contribute to their own stories. Lindemann begins her explorations with her sister, Carla, who was born with hydrocephaly. When she was born, she could not lift her head, turn over, speak, or grasp objects. She could not swallow and needed to be fed through a nasogastric tube. Carla died when she was 18 months old and, as Lindemann lovingly shows, Carla died very much a person with a very particular identity. Those who loved her held her within her own personal identity-constituting stories:

> "They are the stories of Carla's birth and her repeated hospitalizations, of the day my sister bathed her under close maternal supervision, of the time when my father took her outside to show her our tree fort, and of the afternoon I just recounted, when I carried her down the stairs… To the extent that our narratives reflected faithfully who she was within our family, even we children,

> who were not yet full moral agents, were taking part in the creation and maintenance of something morally valuable. We were holding her in personhood.[8]" (5-10)

Due to the severity of Carla's disabilities, Lindemann is skeptical that she was able to form a self-conception, or at the very least one she could express to those around her. Due to the extent of this dependence, Carla's first-person contributions to her identity were very limited. Those who loved her "gave her all the identity she had" (8). Lindemann makes clear these stories could have 'misfired': her brother could have imposed unrealistic expectations on the kind of play Carla would be able to engage with; Lindemann could not have claimed Carla to have been her older sister; her parents needed to learn to love her as she was.

Lindemann defines identities as "consist[ing] of tissues of stories and fragments of stories, generated from both first- and third-person perspectives, that cluster around what we take to be our own and others' most important acts, experiences, characteristics, roles, relationships and commitments" (4) (Lindemann, 2014). In this way, her view of relational identity is answering what Marya Shechtman termed the *characterization* question, regarding how to understand what values, interests, and traits comprise the identity of who one is (i.e., "Who am I?") (Schechtman, 2014). Crucially, identity having narrative structure does not mean that it is a singular, linear narrative. While earlier authors like Schechtman emphasized the importance of identity-narrative coherence within the individual (i.e., that

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[8] For Lindemann, personal identity is part of what personhood entails. For example, her elements of personhood are: "(1) a human being has sufficient mental activity to constitute a personality, (2) aspects of this personality are expressed bodily, (3) other persons recognize it as the expression of a personality, and (4) they respond to what they see" (ix). She takes these recognition and response practices as often being shaped according to who we take someone to be and in this way are tied to their personal identity. In her words: "This narrative tissue constitutes our personal identities, which play a crucial role in the practice of personhood" (ix).

person being able to explain some semblance of causal linkages and continuity over time), Lindemann builds a more expansive account to capture the ways these identity story-telling practices can be taken up by others.

For Lindemann, we care for people through the ways we work to provide extra scaffolding when they need and release binding threads when they no longer serve what they need. These identity negotiating practices are critically important moral practices:

> "The rules that govern the expression and uptake of an identity are not just social but also moral: in the same way that stage actors are meant to cover for each other when one of them drops a line or in some other way stumbles in the performance, so in ordinary social interchanges the participants are expected to help each other preserve the definition of the scene they have collaborated in establishing. They do this by responding appropriately to the personae being projected, and in that way they hold the others in their identities." (102) (Lindemann, 2014)

On this view, we are always participating in these identity-negotiating practices; when we fail to adequately hold or let go of certain stories, it is a moral shortcoming. The everyday nature of these practices does not make them insignificant. Holding well is difficult moral work. We exhibit care (or the lack thereof) through the ways we participate in these identity support and recognition practices. We *hold* each other in our identities. This view resonates with my experience of my grandfather's final days.

Grandpa's Final Days

When my grandfather's prostate cancer returned and progressed to the point of no return, my grandparents' study transitioned into a hospice room. The warmth of the faded sofa and the well-worn office chair from his time as a Notre Dame professor were interrupted by the harsh metal of the hospital bed wedged between them. We always congregated at my grandparents' house during Christmas time and that season was no exception. There is much to tell from this time, but there are three moments in particular for you to hold in your mind:

(1) The first big complication arose when my grandpa became too weak to walk to the bathroom. Carrying him was difficult and my grandpa became very embarrassed having those he'd raised now being the ones waiting on him to relieve himself. Seeing the frustration, the hospice nurse suggested a "Sara Stedy"—a device that he could step into and that could be easily pushed from room to room, imagine a walker on a supportive skateboard. The first few times were difficult getting his feet into the right place, but once we adjusted, an activity that had averted gazes became celebrated. My grandpa would stand with arms holding the two grips and give a royal wave as his chariot progressed towards the bathroom. The feeble Cancer patient was restored to the dignified elder.

(2) A few days before Christmas, my grandpa whispered a secret mission into my aunt's ear. She promised to make it so. On Christmas Eve, we moved our traditions from around the tree to the office-turned-hospice room and squished inside, encircling the bed. We passed around a tray of Christmas cookies as we took turns opening presents. Another aunt begrudgingly passed my grandpa his whisky glass and narrowed her eyes as my grandpa petitioned why the two-finger-pour he requested was only a quarter of one. He could barely take two sips anyhow, but this nightly scotch tradition was never foregone. When my grandma's turn came, she eyed my grandpa as she saw the gift tag. As she folded back

the paper, a silken negligee unfurled and she let out her familiar “Now Neal!”, the corners of her lips betraying her glee. My grandpa smiled through lips chapped from the oxygen’s flow and side eyed my aunts as my grandma asked him who else was to blame. His eyes brightened in their sunken sockets and revealed his satisfaction with still being able to embarrass my grandma with his doting affection.

(3) My grandpa died three days after Christmas. All ten of us grandkids and all six of his children had slept in the house that night; what was usually an unceasing backdrop of family bickering had been hushed by my grandpa’s labored breathing. The ones that had been on watch when his breath stopped awoke the others. We burrowed between each other in the study and surrounded him, feeling reassured by each other’s warmth as we draped over one another. My grandma held him and kept repeating “He’s gone” in a quaking voice I did not recognize as hers. Her hands gripped closer and closer to his heart and then behind his body, capturing all the remaining heat she could before it left him. When the hospice service came to retrieve him, my grandma’s grief stilled into focused resolve. As they wrapped his body, she collected the photo of the plane that held the joy he’d found in flying in his older years and the blanket his mother had sent him to college with, and tucked them in beside him. As they wheeled him out, our silence was broken by a storm of playing cards flying around us—my uncle had taken my grandpa’s bridge deck and released them in salute. The cards, blanket, and photo were all cremated with him so that he could hold them close wherever he went next.

Shifts in Shared Storytelling

The difficult circumstances of illness often reveal how much we depend on the support of others. In these times of physical faltering, those around us often play critical roles in holding and supporting us. My family’s work as holiday elves enabled my grandpa to maintain his role as my grandma’s suitor. The photo of the plane my grandma placed on the wall across from my grandpa's bed reminded both him and us of the strong pilot he was. The hospice nurse's creativity helped him retain dignity as he lost bodily control. Of course, these supports were not wholly new to my grandfather's life. That Christmas Eve was far from the first time my grandpa had conscripted family members to help him express his affection for our grandmother. And, my grandpa had always placed that photo prominently in the house as a way to remind people, himself included, of his past. These identity-scaffolding dynamics are always present but their structure often becomes most apparent when we rely upon them most. In the ways they hold us within our particular identities, they guide both what we owe to others and they to us.

Françoise Baylis's scholarship on relational identity dynamics is also instructive for understanding how these practices function when one person becomes increasingly and significantly more dependent upon the other (Baylis, 2017). For her mother, progressive memory loss came with losing her ability to find her way home, forgetting the ingredients of her traditional Christmas recipes, not remembering which family members had already passed away, and, eventually, losing ambulatory and verbal skills. Baylis challenges the presumption that the loss of memory that comes with Alzheimer's necessarily comes with the loss of belonging and recognition, and thus identity. She defends that whether these additional losses come is up to all of us.[9] As her mother progressively lost her ability to remember and participate as the person she was for so much of her life, Baylis describes:

> "Yes it is true my mother's personality has changed dramatically, and her capacities are extremely limited, but I have not "lost my mother." Her life story is not over. In the throws of her illness, my mothers has struggled to be my mother, and I chose to honor that. I do so by instantiating her identity–by keeping her in my web of interconnections… When the protagonist in the life story has dementia, she contributes less and less to the coauthoring of her identity-constituting narrative. That is, she engages less meaningfully (and perhaps eventually not at all) in the cyclical and iterative process of identity formation that typically occurs through a series of actions, interactions, reactions, and transactions." (221-222) (Baylis, 2017)

For Baylis, as her mother became progressively disoriented, she became less able to meaningfully engage in these identity formation practices. While her personality may have changed, who her mother was did not. The role of holding these identity-constituting narratives increasingly fell to those around her: "And, as they lose the ability to hold on to themselves, it is increasingly the responsibility of others to cradle them by actively contributing to their ongoing life narratives as they shift from autobiography to

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[9] Here, it is important to point out that this experience was that of Baylis. I do not have personal experience caring for those with dementia and am not claiming this to be prescriptive of how these relationships ought to operate. While dementia is never easy, it can run a much more difficult course for some than others. In many cases, even preserving some degree of social recognition can become extraordinarily difficult. Further, in this case, Baylis desired continuing a loving relationship with her mother in these ways. She shared her experience mainly to push back against presumed, dominant narratives surrounding people with dementia necessarily "being gone" long before they have died. Here, I am focused on how these loving relationships can operate with increasingly difficult circumstances when we choose them as something we wish to engage within. As the work of Leah Lakshmi Piepzna-Samarasinha's work on care labor emphasizes, engaging in these care practices must always be a choice to help guard against disproportionate care burdens, respect individual agency, and protect the space needed for self-care practices.12

biography" (223) (Baylis, 2017). Baylis hinges this identity-holding practices within patterns of recognition and belonging. In her case, her mother's identity as a partner was maintained by the visits of her father, as a grandmother by visits of her grandchildren, receiving birthday cards, attending church, and carrying out nightly prayers. Her mother progressively lost her ability to recognize those doing this caring work, but it did not make those relational bonds less clear for her family.

In holding these stories, Baylis' family members did not only hold her mother. Through continuing to participate in these practices, they continued to hold themselves within these shared identity stories as well. In continuing to recognize her mother as her mother, Baylis affirmed her own role as a daughter. Through the family's shared activities, they continued to hold themselves within that relational, narrative web. Similarly, the ways my family acted as extended agents for my grandfather anchored us within our own relations. These identity support practices are multi-directional. One cannot hold without some force being placed back on them in return. Considering these practices requires taking the deeply relational nature of these stories seriously. It requires critically examining what kinds of spaces we build through these narrative webs.

Shared Worlds & Loving Perception

In reconsidering my story of my grandpa's final days, I have found myself wondering about my telling of it. What might I be missing in it? Also, why am I relaying this story, rather than that of my other grandfather, who was no less important to me? One significant worry with the power given to others, on relational identity theories, is that our holding stories can be too partial, limited, or based on "arrogant perception." Here, I use the work of María Lugones to consider the role arrogant perceptions can play in distorting the ways we are able to understand the identities of others. And, correspondingly, I consider the loving, playful world-traveling she proposes as an antidote.

It is important to consider the ways our perceptions of others – perceptions that inform our identity-holding stories of others – can be, in María Lugones' use of Marilyn Frye's term, 'arrogant perceptions' that may be inaccurate or partial (Frye, 1983; Lugones, 1987). Lugones speaks of the ways she was taught to *perceive arrogantly* regarding how she was taught by the society around her to view her mother as in servitude to her and the others around her. Lugones is focused on wanting to understand her mother outside of who she was made to be in the patriarchal milieu she grew up within. She now sees that she may have mistook what she thought was loving her mother, but was actually abusing her mother, through: "using, taking for granted, and demanding her services in a far reaching way that, since four other people engaged in the same grafting of her substance onto themselves, left little of herself to herself" (5) (Lugones, 1987). In failing to see herself in her mother, Lugones suggests that she failed both in truly loving her mother and left herself open to being *grafted* in similar ways. To learn to love her mother, she needed to learn to travel to her mother's world. But, as Lugones shows, there are many 'worlds' we exist within,[10] with varying degrees of comfort or health, and the norms of each of these co-existing yet distinct worlds shape who we are able to be in each. We may choose to enter these worlds, but more often we are constructed within them in ways we do not understand, or that we understand but

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[10] These worlds exist simultaneously and can be constructed through a range of meaning-making practices: "A 'world' in my sense may be an actual society given its dominant culture's description and construction of life, including a construction of the relationships of production, of gender, race, etc. But a "world" can also be such a society given a non-dominant construction, or it can be such a society or *a* society given an idiosyncratic construction. As we will see it is problematic to say that these are all constructions of the same society. But they are different 'worlds'" (10) (Lugones, 1987).

do not hold ourselves in. Even if we do not welcome participation within these worlds of sense-making, they can animate us all the same.

This means that how we hold others can involve problematic ('unhealthy' in Lugones' language) constructions (Lugones, 1987). For instance, Lugones considers the ways she considers herself to be a playful person. For those who knew her well, they immediately recognized this playfulness. For others, they identified her as a very serious person (notably, a trait she remarks is often associated with the perceptions she found White/Anglo people to have of 'Hispanics'). She is afraid of being constructed as 'serious' in the same ways the world had mis-constructed her mother. She wants to understand what it means to say that she is playful, and this playfulness becomes the key to seeking out the world in which she is at *ease* and in which the dominating and stifling world scripts do not reign. She proposes a form of non-agonistic play that enables this world traveling. In agonistic play, players have a "fixed conception of him or herself" (16), abide by established rules, aim to win, and endeavor on conquering the other. In its stead, Lugones calls for *loving playfulness*, which she describes in approach this way:

> "We are by the river bank. The river is very, very low. Almost dry. Bits of water here and there. Little pools with a few trout hiding under the rocks. But mostly is wet stones, grey on the outside. We walk on the stones for awhile. You pick up the stone and crash it onto the others. As it breaks, it is quite wet inside and it is very colorful, very pretty. I pick up a stone and break it and run toward the pieces to see the colors. They are beautiful. I laugh and bring the pieces back to you and you are doing the same with your pieces. We keep crashing stones for hours, anxious to see the beautiful new colors… *the attitude that carries us through the activity, a playful attitude, turns the activity into play*. Our activity has no rules, though it is certainly an intentional activity and we

> both understand what we are doing. The playfulness that gives meaning to our activity includes uncertainty, but in this case the uncertainty is *an openness to surprise*… we are not fixed in particular construction of ourselves, which is part of saying that we are *open to self-construction*." (10) (Lugones, 1987)

Lugones seeks to learn how to better see her mother as a means for both learning how to love her mother and how to love herself. Learning how to travel to her mother's world meant a shift in attitude, an openness to re-making, and a receptivity to self-construction through these shared rock breaking and color admiring endeavors. World-traveling can correct her arrogant perceptions, and the constraining stories she tells of her mother. For Lugones, learning to love her mother is a collectively liberatory practice: "We are fully dependent on each other for the possibility of being understood and without this understanding we are not fully intelligible, we do not make sense… traveling to each other's 'worlds' would enable us to *be* through *loving* each other" (8) (Lugones, 1987).

In considering these theorists, I am concerned about the way I came to know my grandfathers, and the role of arrogant perception. Our holding may always be partial and fragmented, but my holding of one of them was undoubtedly filtered through one of these particularly dominant, identity-constructing worlds. My other grandfather – Dodo – lived with socially imposed scripts upon who he was that obscured my ability to better understand him and hold him well. While he did not face the harms of patriarchy in the ways Lugones' mother did, he too was constructed by a society that stamped him as "Hispanic" (or, sometimes, 'Mexican'-- this was not his heritage but those using it cared little about accuracy). As I only knew him in this US life, my learning of the operation of this particular ethnic category as I grew up was intertwined with the way I came to know him. In many of the ways I knew him, the impact of that constructing-world felt dormant: the version of him patiently stirring scrambled eggs in the kitchen and carefully watering the plants on hot summer days. Few people knew this side of him that I knew. For many others, he was a man of few words, quite serious and difficult, and quick to temper. His accent and ability to interact with the broader world constantly animated this othering-Hispanic construction and prevented him from moving through his US life with ease. As a child, my knowing of him was tied to my embarrassment of these parts of him and of my inability to understand his lack of patience.

When people ask me who he was, it is a particularly difficult question to answer. Really, the answer is that he was many different things in many different settings, depending upon who he was *able to be* amidst the constructions placed against him. If we are each multiple – as Lugones suggests – then he isn't just one or the other of these identities; he is constituted by the many different identities he takes on and is given. Certainly moral harms can be done in not recognizing first-person authority of people to claim their own identities; much more work could and should be done to understand how best to conceptualize our holding duties, and how they can be supported or derailed. In the next section, though, I turn to a holding concern related to the stories that animate this paper: my grandfathers and their passing. I ask, what might be required to continue caring for these shared worlds when those we built them with have passed away.

Part II: Holding and being held after death

What does holding a loved one, and being held by them, look like once the loved one has passed? The ways that people have shaped us do not end when they are gone, and we still have obligations to them as well. We are left with wills and last wishes. The voicemail of my grandpa Dodo remains on my phone– calling me home each time I listen to it; his voice reminding me most of all that I am loved and that one part of the web I am held within is being his granddaughter. I still feel loved by him. We can reciprocate this love in return.[11]

In this section, I consider Lindemann's model for holding after death: what she terms, 'preservative love.' However, in focusing these identity-holding practices on preserving stories as we had them when they were alive, we risk losing the dynamic relationality inherent to these relational identity practices and overlooking the hermeneutic gaps of how we were able to know them. I propose an alternative method of approach through a *summoning love* that calls us towards a stance of open curiosity regarding that person's stories. Through pursuing the traces they leave behind with an open, 'playful' stance, we can lovingly animate the worlds we shared with those we love and who have passed away.

Lindemann's Model of Preservative Love

Hilde Lindemann gestures towards the ways that holding practices occur between the living and the dead, describing these acts as (repurposing Sarah Ruddick's term) *preservative love*: "Because the stories that once constituted the deceased person's identity did not die when she did, those who mourn her can employ those stories in many different practices of preservative love" (198) (Lindemann, 2014). Most broadly Lindemann uses the notion of preservative love to refer to "the love that preserves people from harm—including the harm of being excluded from or cast out of personhood, or the wrong of being altogether forgotten after we die" (206). Through preserving the stories of those who have passed away, we protect them from the harm of being forgotten.

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[11] It is important to point out that here that I am working to show the ways we *can* perform that work and the ways it may operate. I am not saying that we need to do this work. There are many instances when needing to care for oneself could lead to needing to release and let go of performing these roles. Familial dynamics can be as much a site for cruelty and harm as they can be for love and care.

Preservative love, then, is one way the living continue to hold the dead. These preservative actions include the way we honor their wishes in terms of the handling of their body and the kind of funeral they receive. Beyond these mourning practices, preservative love is rooted in archiving who that person was as it occurs through the ways we may “Hand down the recipe for Great-Aunt Bessie’s pound cake to our children, store blankets in Grandma Florence’s hope chest” and the ways “stories of who the person was are taught in school or handed down” (199) (Lindemann, 2014). Lindemann’s notion of preservative love is rooted in the ways we continue to name what was *theirs*. We write down biographies, acknowledge their writings, or place their name on a park bench. In this approach, respecting people’s legacies lies in the chronicling, archiving, and preserving the deceased’s objects and stories.

We participated in a number of acts of this preservative love in the ways we honored my grandfathers. Dodo had his funeral in the Catholic church he and Noni attended for 35 years, presided over by the priest he knew well. Grandpa was buried in the military veterans’ cemetery. Grandpa’s name ‘Neil Schilmoeller’ was, in fact, inscribed on a bench in the park by his and my grandma’s home. My uncle worked to get our family name on a small brick in a Houston park to honor Dodo. We held onto a few t-shirts and sweaters they had each cherished. Now and again we practice telling stories of who they were to one another. My grandma kept Grandpa’s candle molds. You can still find old business cards with Dodo’s name on it from his pipe and valve company. This continued archive protects them from what Lindemann names as the harm of being rendered insignificant. We prevent them from being forgotten. These actions are important, to be sure, in helping to remind us of who they were.

But this sets up the problem for this section: how do we hold well those we loved who have died, and just as importantly, how do we keep their influence alive in defining who we are? In the wake of my grandfathers' passing, I became acutely aware of all their life 'archives' that I could not access or decipher. I held onto what I could. I remembered all the questions I failed to ask. I gathered the rememberings up close, feeling the weight of needing to clutch them tight.

But, in trying to clutch onto memories and preserve an archive, I embalmed them in what I had. They became stagnant, and I felt my ability to pull on who I was in their eyes atrophy. I was losing some of what it was to care for them, along with access to the parts of me they animated.

I focused my continued care efforts upon preserving the stories of my grandfathers as they stood when they passed away. I remember my grandfather as the affable former Iowa farm boy, the retired Notre Dame professor, the nuclear physicist. I remember Dodo as an often quiet, furrow-browed figure– a facade that melted away in the evenings before bed when he committed to an animated telling of that evening's bedtime story. But those memories were inevitably fragmentary and frozen in particular moments of time. Remembering them felt *preservative* – to use Lindemann's term – but also inadequate. While clutching at the stories that I did have of them, I realized that my memories of my grandfathers stopped when I was 23 – meaning they were so very limited. I only came to know them in their later years (they were my grandpas after all), so I missed out on much of who they were, but also, the lens I interpreted those moments through was that of a 23 year old. To be sure, our understandings of others are always fragmented, but figuring out how to handle these fragmented pieces when we cannot check with the person they are meant to capture is particularly difficult.

I am ever grateful for the ways I was a recipient of their love. But, that is exactly the crux of my worry – I knew them *in terms of* the ways they cared for me. There were so many more parts of them that I did not have access to, whether because they chose not to share those sides with me or because I self-selected what parts of them I drew attention to. Was I getting them right? Could I keep ahold of them? What if they started slipping away? Who would I be without them? In focusing questions upon preserving them and embalming them as they were, I lost much of the dynamism that defined our shared identity-holding and world-building practices.

Further, the differential access I had to each of them concerned me. For Grandpa, continuing to care for him through preserving an archive was more simple – he had six children, ten grandkids, and a large neighborhood community. His personality and the kind of recognition the world afforded him as a white man who was more easily granted a sense of belonging made knowing him more straightforward. I could more easily trust the ways he continued through how his presence was chronicled, archived, and preserved across different social webs. There are so many people who continue telling stories of who he was, and in ways that resonate with who he was: kind, smart, charming, helpful, doting. Objects of significance were quite literally stamped with his name – anyone who found his old Notre Dame chair in his office would see his name plaque, anyone walking the park would find his bench, those walking the adorned military cemetery would find the stone with his name there.

For Dodo, it is more difficult to rely on acts of preservation. He had two children, two grandchildren, and an extremely small social community. Having left his family decades prior, most of those who had known him had also passed away. He lived a much quieter life. Each day up until his final weeks, he would wake up, do his exercises beside his bed, eat fruit and porridge with Noni, grab his briefcase, and walk fifteen minutes in Texas heat to a non-descript storage unit-converted-to-workspace to work with my uncle to sell pipe valve parts. Many of those who did meet him did not know what to make of him. He often kept to himself, spoke little in public due to shame around his accent, and had little patience for the misunderstandings he often encountered. There is no public stone with his name. Instead, there is a place only my sister, Dad, Noni, Tio, and I know, under a bush directly behind his and Noni's church's tabernacle. It is under that hedge that, to Noni's request, we transferred him from a plastic produce bag from Noni's purse to the Earth using an old trowel and with a decade of the rosary to seal the deal. Preserving him through continued storytelling is more complicated too. My point is not that Dodo's life was any less significant, but that it was quieter, smaller, and with additional layers of complication in terms of what and how to preserve.

This differential ability to rely on the archiving practices that define much of Lindemann's notion of preservative love heightens the need for modes of continued engagement and learning of who they were and who they are to me now. For Dodo especially, I cannot leave the continuation of his memory to those practices. I need alternative modes of engagement and additional avenues for continuing to hold the world we shared. I seek ways to kindle the embers of memory I have of each of them and to re-awaken aspects of the warmth and love they each provided me.

Seeking An Alternative Approach

Approaching identity relationally shows the ways our fragmented stories are often held by a much wider social web. Piecing these fragments together can be a collaborative project. Here, the negotiation can be understood as the push and pull between each of the recollections of those who knew him well. After-death rituals often involve shared story-telling, which allows for richer appreciation of the whole person, as they were in their many 'worlds.' Yet, while working to remember together can be a key way we continue honoring those who have passed, I remain curious about the ways we can continue *loving* those who have passed away beyond these collective piecing-together efforts, and how that loving can reanimate their roles in our own identities. Even when I am able to correct a certain memory through talking with my family, this *understanding* can still feel empty. My knowing can still feel lonely. It leaves me in search of more ways I can call in these loving relations for my own narrative. This aspect of holding after death may be as much about how the dead can still hold us, as how we hold them.

I still take attending to careful storytelling of those who have passed away as a critically important way of caring for their legacy. However, focusing on this particular *storytelling* aspect of care risks freezing them within our fragmented, limited, and often-distorted perceptions of who they were. Instead, I think the real value of careful chronicling lies in the ways it can guide our ability to decipher which caring *practices* to engage with them within. That is, I want to focus less on getting the stories complete or remembered accurately, and more on caring practices that embody their ongoing contributions to my relational identities.

Using Lugones' frame, I advocate for a mode of engagement with the dead that may initially seem inimical to grief: *play*. I call attention to the ways we can continue animating the cares that those we loved held together. Rather than centering the practice of 'preservative love' through more static memory, I'm interested instead in *embodied* and playful practices – quotidian, perhaps ritual exercises of agency – that call the loved one into our very much alive selves. This might mean seeking out the worlds where they and I find ourselves at *ease,* in Lugones's words. By openly attending to care practices we once shared, we can practice what I call "*summoning love*." Here, storytelling practices can still be important guides but they are not the main mode of holding care.

Recall again how Lugones describes the playfulness of smashing rocks. There aren't rules, so much as playful engagements. What matters is less how it is done, and more that we do it together, in a spirit of connected exploration and openness to what we might discover. What if we aim to hold each other that way? Consider how Janelle Taylor describes the ways in which she cares for her mother, whose advancing dementia has made typical behavioral patterns out of reach. Continuing to hold her mother required adjustment but was still possible– long conversations become a head resting on a shoulder, direction-giving becomes a hand holding you as you walk. Taylor too invokes this imagery of *play*:

> "Our conversations go nowhere, but it hardly matters what we say, really, or whether we said it before, or whether it is accurate or interesting or even comprehensible. The exchange itself is the point. Mom and I are playing cards with expressions, including touches, smiles, and gestures as well as words, lobbing them back and forth to each other in slow easy underhand arcs. That she drops the ball more and more often doesn't stop the game from being enjoyable. It is a way of being together." (327) (Taylor, 2008)

In this play, like in Lugones', adherence to any particular rules are released. There is an entering into a place of clumsily, yet caringly, playing catch with (i.e., holding) each other. Being together in these distilled-down ways enables them to be at ease with one another and reflect back the care that holds them each in place. Taylor wishes that, just once, instead of asking others asking "Does she recognize you?", people asked "Janelle, are you keeping the cares together?"

For both Lugones and Taylor, entrenchment within particular narratives frustrates the potential for love. For Lugones, there must be a release of particular rules of how -things-ought-to-be-understood or ought-to-be-done in order to find each other in these shared, ease-ful worlds. While Lindemann still acknowledges ways the dead continue to hold the living, her frame remains focused on the value of these post mortem holding practices in how they preserve that person as they were and prevent the harm of forgetting. Here, with Lugones and Taylor, I aim to open up mutual holding practices between those who are living and those who have passed away, ones that can continue to shape and reshape our identities. Through continuing these relations through embodied *practices*, we might return some of the dynamism inherent to these practices when both are alive.

A Summoning Love

Instead of centering preservative forms of love, I propose “summoning love” as a way of approaching holding and behind held by the dead. Here, the fragments of memory left behind are still key. But instead of being the central archive, they become the traces we follow. Rather than center questions of “Who were they?” acts of summoning love focus on “What did they care for? How can we continue engaging in those (to use Taylor’s language) ‘cares’?” I view these practices as expansive and without clear bounds. But, most generally, acts of summoning love pursue traces, the things-left-behind, and picking up where they left off. Through engaging in modes of care they shared when alive, we can encounter and ‘play’ with pieces of who they were. When operating well, these acts can reinforce the relational threads that person provided when alive and that we can continue maintaining in their absence.

Here, an image of finding and kindling an ember may be helpful. Sometimes the flame will be more clear and more easy to feed; other times, it will be like fiercely protecting a small spark from the winds that can all too easily make it disappear again. We may seek these traces in physical objects or spaces: we sit in their chair, wear an old shirt of theirs, hold the glasses that rested across their face. We may seek them through speaking to them: we talk back to an old voicemail; we seek advice through sharing a story and listening at a gravesite. We can also summon through picking up acts we knew them through. It can take place in the ways we attend to loving them through continuing the nurture and care for the things they, too, valued.

I view summoning as occurring to different degrees. The kind of presence and agency and animacy of those relations varies. We can try, yet fail to summon well. Or we can summon, but only partially. There are very few times I take myself to have fully summoned in the ways I aspire. This was one:

Every Sunday Dodo would make scrambled eggs for Noni. Noni did all of the food preparation, except for the Sunday eggs. When I was over for breakfast, it was always the part of breakfast I cherished most. We would eat our fruit and porridge in anticipation of Dodo setting the plate of eggs on the table. They were perfectly soft, just-cooked, with a balanced sweet-saltiness. We all loved Dodo's eggs. Noni did not cry much immediately after he died. But, she tells of when the first Sunday with no eggs came. She laid her head on that table and cried and cried.

One day when I was over, I saw the well-worn nonstick pan. I turned it on low. I placed the butter. I cracked the eggs. I opened the fridge and tested out my best guess at the unknown 'secret ingredient.' They were fine but not his. I repeated this ritual every time I was over, slowly deciphering how he may have made them as they were. In that practice, there was an openness, receptivity, and curiosity of what I would find there. The curiosity went beyond the quest for the secret ingredient. It was a curiosity for how engaging in this practice could help me better understand who he was and see where further traces of him may lie. In taking that role, there was a resounding somberness; I felt his lack of presence. And simultaneously, there was a playfulness. It was a hide-and-seek of the pieces of who he was and who he raised me to be. There was one day when I tried them and smiled. I brought them to the table and Noni squealed with excitement. To be clear, they were not the same, or even as good, nor will they likely ever be. But, they were so close we could both feel him at that table.

In the process, I saw deeper into Dodo's methods and creativity. I felt his patience in my arms as I stirred and stirred on low heat. I saw the way he had been able to look at us seated at the table in anticipation. I felt the excitement and satisfaction of being able to do something well. I *saw* these parts of him, and felt those threads within me. These threads were not only ones tied to my own self-understanding, but ones that pulled me towards re-animating a form of care Dodo gave to Noni, and those around that table.

I take one difference between preserving and summoning love to be one of proximity. Continuing to love and be loved by my grandfather was not found in simply recalling the way he used to make the eggs or keeping his egg pan as an heirloom in a cabinet. Though these stories and objects provide the access points, I do not take them *to be* the acts of continued care and love themselves. Through working to embody and engage with the parts of my grandfathers I miss most, I gain access to a sense of shared agency bestowed upon me through my connections to them.

Through embodied practices such as these, I believe we can seek to animate the worlds we built with those we loved. Taking this approach requires critical engagement with which identity threads we wish to re-string and nurture. The guiding question is not "Who were they?" in terms of locating them within an archive. Rather, it is a practice guided by "How can we continue loving them?" and "How can we continue loving the things they loved?" Rather than remembering being defined through the ways we clutch onto remnants, remembering in these ways seeks Lugones' loving, playful, open, and curious stance towards acts that may enable us to encounter them. Rather than defined by an attitude of dictating a certain identity narrative, it is one of engaging curiously through embodied practices of care.

Reflecting on my own mortality has drawn me closer towards approaching remembering and continued loving after death in these ways. I care that people remember different aspects of who I am, will be, and was. But, I find the idea of people equating having those memory archives with what it is to continue honoring and loving me unsatisfying. I want it to be a question of using those stories to guide summoning practices. The worlds we created together will still be there, but for them to remain animated they will need to be kindled and fed through continued acts of care. There, you will find those parts of me.

By summoning, I intentionally highlight the ways that the living can call the dead into the present, to enable them to actively shape the identities of those who still live. This is a mode of centering care practices that enable us to continue being shaped by, and in a metaphorical sense, reanimating the dead in our identities. This focus on attending to these shared cares does not mean loving the dead comes with an obligation to continue all of the caring practices. Summoning the love of my grandfathers is not to be confused with wanting to reflect back all parts of them. Part of me learning how to summon their love is a journey of learning how to understand them and which parts of our shared worlds I wish to continue playing within. There are many things I do not wish to summon. Turning our attention towards these holding practices enables us to *practice* which things we would like to continue forward. As Lugones shows that she is able to *be* through the ways she is able to *love*, participating in these practices comes with our own agency in deciding what ways we wish to travel to these worlds, what things we want to leave behind, and which aspects we wish to usher in before us.

A little bit ago I lost my sense of play in holding my grandpas' stories. I wanted to clutch them in close. I took loving them to be a need to preserve them as I knew them, to embalm them in the ways I took them to be. Clutching them there in my palm and within my heart, I thought I could keep them close. In reality, in many ways I let go of the care practices we shared. I obsessed over a carefully crafted post. I stared at photos. I would passingly think of the wishes they had for me, let them momentarily tug at my guilt, and stuff them back under. I jotted down rememberings when I could, but did not protect the time to sit with them. The feelings of care for them have not faltered, but in many ways I let them go unfed and unnurtured. The calls towards care and holding of the dead, in my context here in particular, calls me towards playful,[12] loving practices.

In trying to guard over my rememberings, I let some of our shared cares go unnurtured. Over the course of writing this dissertation, I bought two African Violets. Grandpa loved African Violets. He propagated them, meticulously re-potted, and knew the right light they needed. It has been a long time since those violets bloomed. It turns out trying to force water into their roots when you find them long-since dry can only do so much. Today, I crimped off the dead petals. I cupped the plant in my hands and I said I am sorry, in words equally directed towards the objects of my attention and the shared world my grandpa andI inhabited that has become increasingly overgrown. I left water underneath just long enough for them to saturate and then gave them relief. I felt the bristle of the leaves. I shifted its position in the light. In the process, I felt like I was summoning him closer than I had in a long while.

An Objection: Too Minimal and Unbounded

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[12] Here it is important to remember that in Lugones and Taylor's notions of playfulness, playfulness is not to be confused with unimportant. Play as conceived here is serious in terms of its importance, but playful in disposition.

One could protest that reaching for these quotidian practices is too, well, mundane. Surely caring for the robust, multi-dimensional people they were goes beyond caring for a plant. Further, how are these small acts to do the work of maintaining relational webs and animating shared worlds?

Caring for my grandfathers' legacies will go far beyond caring for a plant. But, for too long I centered questions around honoring legacies and remembering those who have passed around calcifying my understanding of them. I interpreted carrying them forward as a preparedness to repeat those stories back to those I decided needed to hear. I still take these story-saving and holding practices as important ways I honor them. However, I hold these stories with a curiosity and openness to new understandings. I see them as signposts to continue exploring and upturning the many complexities of who they were, and who I am in the process.

I know now that, for me, there are many practices that go beyond holding these stories close, in order to both care for them and summon them back to me.

IV. Conclusion

Holding my grandpa through his dying process showed me not only how much we hold others in their identities, particularly in difficult times, but also how they hold us. Through that difficult but beautiful time, it was not just us holding our grandpa within who he was; he held us in return. Resting my hand on his arm was a way I called him into his role as my grandfather and in turn that he held me as Neil Schilmoeller's granddaughter. I knew the time we had together was lessening. I asked him for stories of growing up in Iowa. I asked him, ever reasonably, for his thoughts on the meaning of life. His wavering energy made answering the first slow and fragmented, the second nearly impossible. I tried to write down what I could. But, caregiving and grieving are both exhausting processes and there was so much I left unchronicled. But, there, leaning against him within the study filled with his things, he held me as his granddaughter and anchored me to *this* family. And then, he died. In the days, weeks, months, and years that have followed, everything's gotten scrambled. It left me wondering: how can I protect my grandpa from 'the forgetting' if there is so little I can remember?

Ultimately, where this paper lands is a familiar place: that we honor our loved ones who have gone before us not just through stories, but through our actions. It is my hope that in tracing these experiences, and considering how we contribute to each other's relational identities, we can draw attention to times our rememberings may come apart from care practices and open doors for continued engagement with those who have passed away. This paper is by no means exhaustive of the ways we may conceive of our care practices for those who have passed away. Nonetheless, I hope it provides the roughest roadmap for those who feel fearful about losing their hold on loved ones, losing how they themselves are held, and who wish to keep loving those who have passed away. Taking ourselves relationally means taking seriously the ways we co-constitute one another.

My grandpas grounded me within aspects of myself. In choosing modes of continued care, I call those threads back to me. In attending to the violets, in sitting with colored pencils, in pouring candles, I call grandpa to my side. In practicing the bedtime stories Dodo once told me, in the slow stirring of the scrambled eggs he always made for us, in the appreciation of the stillness in a good meal, I call Dodo back to me. And, in the process, I call myself back, I uphold and renew the ways they have helped to define me. In these spaces, the line between caring for myself and for them blur as I animate us both.

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Closing Remarks

The papers above trace the bioethical dimensions of storytelling practices. The ways we engage in these social storytelling practices hold epistemic, ethical, and ontological significance. They shape how we come to understand ourselves and others, our abilities to understand our responsibilities to those around us, and constitute the tools we use to construct and make meaning within the worlds we inhabit. Though they hold great power, they often operate through the mundane, everyday exchanges that surround us, that we take for granted. This project, then, takes seriously the robust power and implications seemingly everyday story building and exchanging practices have on how we make sense of and operate within the worlds around us.

These practices operate within our daily exchanges through the ways we thread together who those around us have been, who they are now, and who they may be in the future. This threading goes beyond the narrative fibers coalescing around each person. They thread between those who participate in and help build those shared narrative stories. Thread by thread these relational webs hold us within our sense of who we are and what we are able to do. When these relations are not reinforced, they risk atrophying– in ways not only of danger to the person at their center, but all those who share those narrative strings. A serious diagnosis stresses a patients' understanding of themselves and the kind of futures they can access. The same diagnosis ripples across family members' understanding of their own medical risks and the ways they can participate in shared endeavors with their loved one. A loved one passing away threatens the relations they anchored and the worlds they helped animate.

The relational nature of these storytelling practices means that we are, to varying degrees, at the mercy of those around us. Acknowledging the relational also reveals opportunities for others to step in to reinforce those meaning-making webs. A loved one

to hold someone with ALS in the identities they held before; they continue to recognize them as their helping partner and ensure they can still participate in the communities that have been a source of pride (albeit in modified, re-negotiated ways). Someone steps up in the wake of a friend's passing and maintains their shared gardening rituals in a way that reanimates the world they built together. Through continuing to engage in these care practices, they summon back that part of who that person was and revive those relational threads in the process. The roles we play in facilitating or frustrating these storytelling practices shape the kind of agency we, and those around us, have.

These dimensions become all the more important to attend to when they operate within our medical systems. The power wielded within medical spaces heightens the stakes for who is able to participate in epistemic practices and who receive proper recognition to have their needs met. As shown in the first paper, enabling shared storytelling practices becomes intertwined with empowering patients' medical decision-making. In the second, differential uptake and agency across research participant testimonies shapes which kinds of experiences are represented and thus accounted for within the medical research ecosystem. These storytelling practices shape the kind of agency people have when operating within medical spaces.

To be clear, facilitating more robust narrative sharing within medical spaces will not be the remedy to the harms and inequities within our medical system. Addressing oppression will require robust reform: healthcare must be financially accessible; racist metrics must be recalibrated or done away with;

disorders must be recognizable across body types and skin shades. However, I do take these storytelling practices as sites for resistance, understanding, and empowerment. When operating towards these ends, they can be helpful tools in mobilizing the systemic reforms required to re-calibrate and re-imagine more just and caring medical systems.

Most broadly, across the pages here, I advocated for some of the ways these shared storytelling endeavors can be instruments of care. In *Holding and Letting Go*, Hilde Lindemann describes her account of identity holding as “the roughest sketch of an underexplored moral terrain” (126). It is my hope that these papers map a few more dimensions of this terrain, opening more avenues for future investigations in the process. The everyday nature of these practices provides assurance that we will have opportunities to perform these storyteller roles adeptly, clumsily, lovingly, arrogantly, respectfully… again and again and again. In tracing, rehashing, and reflecting on these practices, we work towards more care-filled practices in each turn.

Y Colorín Colorado

My grandfather, Dodo, told me stories before I went to sleep. They would swap between English and Spanish depending on the day and the mood. There was sleeping beauty, cinderella, the three little pigs, the runaway pancake. I would close my eyes and hear his words through his warm, gravelly voice. Each story, in whichever language it was told, ended the same way: *Y colorín colorado, este cuenta se ha acabado.*

Translations vary, but it's a version of *and they lived happily ever after*– another way of saying *and that's the story*. But as a kid, I knew it was an expression without finality. It was a closing punctuation, a direction, and a promise. It marked the end of that story for that evening. It told me to go to sleep. It nodded to there being another to follow the next time he tucked me into bed.

Of course, there was a day he told a final story to me and honestly, I couldn't tell you how long before he passed it was. But, I know that that promise of more stories got buried deep inside of me. And that some part of that desire found a way to breathe throughout my work here in these papers and in this demarcating project.

This work punctuates my doctoral training and is my parting token for my PhD. And, it is a promise for all the projects to come. For now, it's time for this chica to go to bed and sleep a long long while. And with that,

Y colorín colorado, este cuenta se ha acabado.