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**Stepping into the Breach: Disability-Centered Care Ethics in
Contemporary Nurse Memoirs**

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Abstract

Stepping into the Breach: Disability-Centered Care Ethics in Contemporary Nurse Memoirs

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This project examines contemporary memoirs by professional nurses in the United States with the goal of understanding and defining feminist, anti-ableist care ethics. I analyze the care encounters nurses depict in their writing primarily through the theoretical lenses of disability studies and feminist care ethics, drawing upon theories of autobiography to guide my readings. In doing so, I ask what role professional caretakers working in clinical, institutional contexts might play to help us move toward a more equitable and caring society. The impetus for exploring what it might look like for an ethics of care to center disability is rooted in our national legacy of denying care to disabled people, a legacy which continues to shape clinical experiences today and which has been brought into stark relief during the ongoing Covid-19 pandemic. While this project centers the aims of disability justice, it proceeds from the understanding that all of us seeking healthcare, disabled or otherwise, stand to benefit from efforts to imagine and enact more equitable approaches to care. In many ways, this project constitutes an attempt to craft a

bridge between some of the texts and discourses emerging from medical institutions and the aims of disability justice. It also seeks to unsettle any easy binaries drawn between the medical-industrial complex and people seeking care. To these ends, I draw out the hierarchies of power at work within medical institutions, purposefully focusing on caretakers who are near the bottom of said hierarchy and whose work is often devalued compared to that of physicians. Ultimately, the collection of analyses I perform reveals both the promising subversive potentials of disability-centered care performed by nurses in these contexts and limitations on the types of care possible in the absence of broader cultural and institutional transformation.

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Introduction: Locating Care in Nurse Memoirs

Nurse and writer Theresa Brown remarks in one of her memoirs, “Doctors heal, or try to, but as nurses we step into the breach, figure out what needs to be done for any given patient today, on this shift, and then, with love and exasperation, do it as best we can” (*Critical Care* 11). It is this act of stepping into the breach, as Brown’s speaker so aptly puts it, that this dissertation attempts to locate and further define. The phrase calls to mind a sense of risk, of entering unknown or unfamiliar territory for the presumed benefit of another. It is characterized by thoughtfulness, “figur[ing] out what needs to be done,” and by action, “do[ing] it as best we can.” It is laden with emotions like “love and exasperation.” Stepping into the breach, in short, captures the many complex elements at play within acts of care.

Care itself has many definitions. Perhaps the most frequently cited in the realm of feminist care ethics comes from Berenice Fisher and Joan Tronto, who write,

[...] caring can be viewed as a species activity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web. (40)

Disability scholar and activist Leah Lakshmi Piepzna-Samarasinha also describes care in terms of webs—webs of resources that disabled people create and maintain with and for one another and themselves. Much like how Tronto and Fisher employ the collective “we” in their definition—and similar to Tronto’s elaboration upon care as communal instead of dyadic (103-104)—Piepzna-Samarasinha’s work emphasizes care as a collective effort within disability communities. They write about “healing justice” in much the same way

that this project aims to discuss “care”— as work that centers anti-ableism and accessibility “as a central part of how we heal, not an add-on or an afterthought” (Piepzna-Samarasinha 64). Following the lead of Piepzna-Samarasinha, I intend that any ethics of care emerging from this project be informed by and oriented toward a disability justice movement and its theoretical underpinnings. By adopting this standpoint, we can then (re)imagine ways of stepping into the breach (to return to Brown’s metaphor for nursing) that speak to acts of both care and activism—and to activism as a form of care.

The impetus for exploring what it might look like for an ethics of care to center disability is rooted in our national legacy of denying care to disabled people, a legacy which continues to shape clinical experiences today. I have written this project during the Covid-19 pandemic; meanwhile, articles continue to surface exposing failures of care for disabled people, such as denying disabled people treatment due to perceptions regarding low quality of life (Shapiro, “One Man’s Covid-19 Death”) and coercing elderly and disabled people to sign do-not-resuscitate (DNR) orders (Shapiro, “Oregon Hospitals”). Triage and “crisis standards of care” practices across several states during Covid-19 have been the topic of numerous articles (see Ne’eman) which recognize thinly-veiled discrimination within states’ measures to ration care. Meanwhile, a lack of public health governance paired with the cultural push to get back to “normal” living reveals an insidious underlying lack of care for disabled and immune-compromised people. As disability rights activist Mia Mingus so eloquently puts it:

We are currently witnessing the pandemic state-sanctioned violence of murder, eugenics, abuse and bone-chilling neglect in the face of mass suffering, illness and

death. We are the richest nation in the world and we continue to choose greed and comfort over people and life. (“You Are Not Entitled”)

Ongoing maltreatment and lack of care for people with disabilities makes it all too obvious that the project of advocating for disability justice in healthcare remains a work in progress. While this dissertation will not rewrite legislation or otherwise end such instances of systemic violence, my goal is that it will contribute to efforts to understand the specific roles professional caretakers can play to help us move toward a more equitable and caring society.

When I use the phrase “disability justice” I am drawing upon Mingus’ activist work, where she argues:

As organizers, we need to think of access with an understanding of disability justice, moving away from an equality-based model of sameness and “we are just like you” to a model of disability that embraces difference, confronts privilege and challenges what is considered “normal” on every front. We don’t want to simply join the ranks of the privileged; we want to dismantle those ranks and the systems that maintain them. (“Changing the Framework”)

Disability justice in this project has less to do with access and more to do with confronting systems of privilege that make it safe for some to pursue medical care and dangerous for others. The nurse writers who speak to the aims of disability justice are those who, beyond merely tolerating disability, demonstrate a willingness to subvert and dismantle ableist impulses and the systems that maintain them. These are the speakers who recognize that, disabled or not, all of us stand to benefit from medical care that prioritizes the values of disability justice.

The overarching goal of this dissertation is to contribute to ongoing efforts to define an ethics of care that centers disability. More specifically, I am interested in the possibilities

of disability-centered care taking place (or failing to take place) within clinical, institutional contexts. To accomplish this goal, I look to contemporary autobiographical texts by professional nurses, analyzing the care encounters they depict in their writing through the lenses of disability studies and feminist care ethics. This approach allows me to define the approaches and possible outcomes of disability-centered care in context-specific scenarios. In this regard, my approach follows that of Merel Visse and Alistair Niemeijer, who write: “[...] as care ethicists interested in autoethnography, rather than searching for a good that can be generalized and extrapolated to multiple situations, we radically emphasize the particular” (305). A deliberate premise of this project is that my observations of what qualifies as effective and ethical care are context-specific, at times transferable to other types of care encounters and at other times suspended within a unique circumstance.

By and large, the nurse writers featured in this project demonstrate a commitment to care, characterized in many cases by their approaches to advocating for care recipients and by their recognition of the ableism entrenched within the medical-industrial complex. In some cases, I observe and critique nurse narrators who portray themselves participating in these ableist practices and attitudes. In some cases, but not all, a narrator does so self-consciously to demonstrate the imperfections of care performed within an inherently ableist context. Ultimately, the collection of analyses I perform reveals both the promising subversive potentials of disability-centered care performed by nurses in these contexts and also limitations on the types of care possible in the absence of broader cultural and institutional transformation.

THEORETICAL FRAMEWORKS

To interrogate what the autobiographical work of nurses might teach us about an ethics of care that centers disability, I draw primarily from theories of autobiography, disability studies, and feminist care ethics. The work of two foundational scholars of autobiography, Sidonie Smith and Julia Watson, informs much of how I approach and discuss the primary texts I have included in this project. Smith and Watson urge readers of life writing to avoid thinking in terms of a unified “I” for autobiographical subjects. My language intends to honor the many iterations of self at work within a given autobiographical act. When describing and analyzing each nurse’s writing, I refer to the main voice within the text as the narrator or speaker. The speaker is the narrating “I,” the “persona of the historical person who wants to tell [...] a story about the self” (Smith and Watson 72). This speaker to whom I frequently refer is different from both the historical “I”—the “flesh-and-blood person located in a particular time and place”—and the narrated “I”—the “protagonist of the narrative, the version of the self that the narrating ‘I’ chooses to constitute [...] for the reader” (Smith and Watson 72-73).¹ I emphasize this distinction because my interpretation of a text is often informed by the degree of congruence an author depicts among their various selves. This comes into play in Chapter Three, where I argue

¹ Smith and Watson also discuss a fourth iteration of an autobiographical “I”: The ideological “I,” or the cultural concepts of personhood at play in a narrative. They write, “At any historical moment, there are heterogeneous identities culturally available to a narrator (identities marked through embodiment and through culture; gender, ethnicity, generation, family, sexuality, religion, among others)” (Smith and Watson 76-77). I chose not to include this fourth iteration as a component of my terminology for the sake of simplicity.

that Eddie Lueken’s autobiographical essay constructs distance between the narrating “I” and narrated “I” to craft what becomes a sort of apology to the subject of her care.

Much of my engagement with disability studies is informed by an understanding that disabled people have historically been and continue to be violated and abused by medical institutions and certain practitioners who work within them. In many ways, this project constitutes an attempt to craft a bridge between some of the texts and discourses emerging from such institutions and the aims of disability justice. It also seeks to unsettle any easy binaries drawn between the medical-industrial complex and people seeking care. To these ends, I draw out the hierarchies of power at work within medical institutions, purposefully focusing on caretakers who are near the bottom of said hierarchy and whose work is often devalued compared to that of physicians and surgeons. Looking at the care performed by nurses helps illuminate the nuances and different types of stakeholders involved in clinical encounters, so that instead of viewing medicine as a generalizable evil, we can begin to interrogate possibilities for disability allyship with some of those stakeholders. I therefore seek to interpret autobiographical narratives of nursing taking place in clinical contexts, mining them for moments of subversion and disability advocacy, and calling them out for instances of implied or explicit ableism.

The relationship between disability studies and medicine is complex, as several disability scholars have recognized. Eli Clare meditates upon this complex relationship throughout *Brilliant Imperfection: Grappling with Cure* (2017), writing that medicine “benefits some of us in significant ways— saving our lives or increasing our comfort. At the same time, it also commits damage, routinely turning body-minds into medical objects

and creating lies about *normal* and *natural*” (Clare 26). One of the primary things for which medicine and those who practice it have been critiqued by disability scholars and activists is its pathologization of disabled bodies as “absolute, inferior state[s] and a personal misfortune” (Garland Thomson, *Extraordinary Bodies* 6). While much of disability studies as a field has moved beyond critiquing the medical model, these discussions remain pertinent to the project of transforming medical institutions and assessing the potentials of disability-centered care ethics within our current institutional frameworks.

Rather than setting aside the medical model, a more productive approach is to examine it, to understand the roles of caretakers and the forms of care operating within. As Moya Bailey and Izetta Autumn Mobley argue, avoiding the medical model is a privilege of whiteness. They write: “While certainly the medical model is a problematic trope, it may signal differently to communities that have tried for many decades to receive the most elementary care only to be refused” (28). A Black disabled person may therefore seek not a rejection of medicine entirely, but instead healthcare access and a more equitable relationship to medical interventions. Such an argument resembles that of Chapter One, where medical efforts toward cure are constitutive of meaningful care for people with HIV/AIDS. This project therefore understands the medical model and medical institutions as a site for further discovery pertaining to the role of medicine in disability-centered care ethics.

With all this in mind, this project also aims to contribute to the body of scholarship seeking to bring disability studies and health humanities in closer proximity to one another. In her 2005 article “Disease versus Disability: The Medical Humanities and Disability

Studies,” Diane Price Herndl locates the division of these two fields in the goals articulated by the scholars therein. Herndl writes that disability studies originated from activist efforts, whereas the medical humanities began within the institution of the medical school: “Thus, while disability studies takes as its primary goal changing policies, environments, and minds, medical humanities seeks to improve the status quo” (Herndl 595).

Yet even while demonstrating what she sees as a fundamental breach in the two areas of scholarship, Herndl argues that the two fields can still be valuable to one another. She argues that disability studies can enhance medical practices by introducing a social model that can help improve care practices, while the medical humanities “has the attention of physicians and the institutional space to make changes in medical practice” (Herndl 597). Following Herndl’s lead, this project operates from the understanding that professional nurses, sometimes seen as representatives and instruments of the medical system, actually occupy a liminal space within the medical-industrial complex where they can (and sometimes already do) exist as allies and advocates for disability justice. I hope to build on the scholarship of disability researchers and health humanists—including Diane Price Herndl, Martha Stoddard Holmes, and Rebecca Garden—to challenge the ableist foundations of Western medicine and to argue that the rights of caretakers and of people seeking care need not exist in opposition.² There is disability allyship to be found in the pages of nurse memoirs.

² The Covid-19 pandemic has brought into stark relief how the needs of caretakers are often synonymous with the rights of those seeking care. In a 2020 op-ed, Brown discusses nurses being fired for publicly advocating for safer working conditions: “They don’t want to infect their grandparents, spouses or children with the coronavirus. They don’t want to infect their non-Covid-19 patients” (“The Reason”). As she

This project also relies heavily upon the field of feminist care ethics for the theoretical underpinnings of my analyses. I take a broad understanding of what constitutes an ethics of care from Eva Feder Kittay, who writes: “An ethic of care regards the moral subject as inherently relational. It understands moral reasoning to be contextual and responsive rather than deduced from a universalizable maxim or the result of a calculus performed on utilities” (*Love’s Labor* 61). This theoretical understanding of care ethics means that I do not approach each analysis with a checklist of criteria or a preconceived idea of what constitutes care in every situation. My approach starts with the texts themselves, asking not how they fit into a box labeled “care ethics” but instead how they more complexly respond to and interact with the aims of disability justice. As Robert Stake and Merel Visse write in the introduction to *A Paradigm of Care*, “We are not so concerned about what conceptually constitutes care, to view care as an object for the mind, and, most of the time, we do not aim to dwell on definitions. What we want is to join and enlarge the chorus of caring” (Stake and Visse xiv). For the purposes of this project, enlarging the chorus of caring means reading the portrayal of lived experience through a critical lens, identifying and celebrating ethical, disability-centered care while at the same time critiquing and building upon the “imperfectibility of caring” (Fisher 123) where appropriate.

describes, nurses’ advocacy would make it safer not only for care workers, but for all of us seeking care during the pandemic. Nursing shortages mean higher nurse-to-patient ratios and rationing of care, which makes it more worrisome to note that, in recent years, nurses have been leaving the profession in search of safer and less exploitative working conditions (“Nursing Shortage” 12).

Scholars such as Kittay, Fisher, and Tronto factor into these pages as frequent sources of theoretical insight. However, just as I attend to the whiteness of nurse memoirs as a sub-genre, I am also conscious of feminist care ethics as a predominantly white field of scholarship. In a critique of the field's whiteness, Parvati Raghuram writes:

When discussing caring relationships between able-bodied people care ethics may presume a knowing subject who has a sense of care entitlements. However, looking through the lens of those who have been disadvantaged, including racialized populations disenfranchised through colonial and postcolonial violence, poses the issue of how one might entitle care givers to recognise their own care needs. (626)

This project takes seriously and hopes to build on Nicki Ward's insistence that care ethics "are not in themselves universalizing," and that what counts as "'good care' for one particular group, can actually serve to exclude, particularly in the context of intersectional identities" (61-62). One goal of this project is to unpack the theoretical frameworks of care that remain largely or exclusively informed by whiteness. Much of this work takes place in Chapter Two, where I discuss white feminist arguments toward interdependence and draw out forms of reciprocity within care relationships that rely upon privileges afforded by whiteness, class, and professional status. I therefore take my cue from scholars including Rosalie Rolon-Dow, Audrey Thompson, and other Black feminists such as Abigail Neely and Patricia Lopez, who write: "Black feminists offer an approach to care that always recognizes the influence of racial capitalism [...] For a feminist care ethics to fulfill its promise as a transformative ethos, it must center race, racism, and racial capitalism as the ground from which care and relationships emerge" (7). Among the ways I try to compensate for the theoretical oversights of white feminist care ethics is by striving to "develop more nuanced and complex accounts of power," which Olena Hankivsky argues

is essential for accomplishing a truly intersectional approach (259). Chapter Two is perhaps the most explicit in doing so since it deals with questions of dependency and power relations within care encounters.

METHODOLOGY

In addition to the engagement with disability studies that I have described above, this project is also informed by the work of Julie Minich, who argues for an approach to disability studies as a methodology. Minich writes, “The methodology of disability studies [...] involves scrutinizing not bodily or mental impairments but the social norms that define particular attributes as impairments, as well as the social conditions that concentrate stigmatized attributes in particular populations.” Rather than focusing my analyses on scenes that explicitly include or describe disabled subjects, my dissertation analyzes how nurse writers respond to and organize their narratives around specific social conditions. In other words, despite my focus on disability justice, not all the texts I analyze feature disabled people. While at times disability is made prominently visible in a scene, my main interest remains in asking whether and how a nurse writer orients her text toward representations of care compatible with the aims of disability justice.

Additionally, I have sought to create analyses of care ethics that themselves adopt/reflect a methodology of care. For me, reading with care looks much the same as how Michelle Boulous Walker defines slow reading: “We can distinguish slow reading from this kind of close reading in the following ways. Slow reading follows an anti-systematic trajectory and has questioning as its major motivation. It is an open-ended

reading that has ethics at its core—ethics here denoting an openness to the other” (29). Accordingly, each chapter begins with a series of questions. In moments when the texts under interrogation resist clear answers to those questions, I do my best to honor those complexities, instead of “smooth[ing] over ambiguities and irregularities” (Walker 29). Working with life writing means encountering speakers who are complex and, at times, contradictory— who can, for example, appear to adopt an ableist ideology and yet, in the same moment, do or say something subversive and insightful. My intention is to identify, describe, and try to draw meaning from this messiness that often characterizes our attempts to care for one another and to articulate that care, to avoid any overly neat conclusions that would ring false to a real-world scenario.

The decision to focus this study on a selection of texts authored by professional nurses was informed by the following key reasons: First, nurses often have more frequent and longer lasting encounters with care recipients than do other types of healthcare professionals, such as physicians. One caveat is that this largely varies by area of specialty—for example, I’ve found that writing by hospice nurses usually appears to be informed by a more lasting care relationship than writing by emergency room nurses. Nevertheless, since nurses “represent the largest group of health care professionals in the country” (“Nurses in the Workforce”), their perspectives on providing most of the direct care for people in clinical settings aligns with the goals of this project.

Second, nurses are valuable subjects to study because they are uniquely positioned within the hierarchy of the medical-industrial complex. Their profession entails a negotiation of varying levels of authority among doctors, administrators, and people

seeking care. Part of this hierarchy is informed by the way the nursing profession is highly gendered, with women comprising over 90% of the entire nursing workforce in 2017 (Smiley et al. S11, S46). By comparison, most active physicians (64.1% in 2018) are men (“Diversity in Medicine”). One consequence of this hierarchy is that, although nurses often invest great amounts of time in each care recipient, “their insight and knowledge about that patient can be circumvented by less engaged physicians and administrators” (Feinstein 21-22). Brown also remarks upon these gender disparities in her memoir *The Shift: One Nurse, Twelve Hours, Four Patients’ Lives* (2016): “The MD-RN relationship is historically rooted in gender differences and the condescension and imperiousness that marked men’s relationships with women a century ago. Many women have now become doctors [...] but vestiges of the history remain” (175). Thus, examining these texts is an opportunity to consider how medical hierarchy and gendered expectations affect care ethics.

Third, in keeping with this discussion of medical hierarchy, nurses are uniquely positioned in that they are contributors to the medical-industrial complex, thus bearing witness to its many achievements and flaws. They are also subjects of the medical system in what may be violent or harmful ways, and can be both complicit and resistant within the system. Thus, attending to nurse memoirs can facilitate a discussion of whether ethical, disability-centered caretaking is even possible within our existing frameworks. What types of care do the systems within a hospital, for example, encourage or allow for on the part of nurses? What do they render impossible or ineffective?

Fourth and last, examining nurse memoirs is an opportunity to recognize caretaking work that can get taken for granted in our personal lives and that is not well attended to in

academic spaces. In his introduction to a collection of nurse-authored essays entitled *I Wasn't Strong Like This When I Started Out: True Stories of Becoming a Nurse*, Lee Gutkind describes the ways in which many of us relegate nurses to the back of our consciousness, even though they are the foundation of many healthcare settings. He writes:

I saw very few doctors, but I remember quite vividly who they were and what we talked about. Doctors are deity [...] Yet they could not function in most venues without nurses. And where in my recollections are the helpful and caring nurses who were constantly in and out of rooms [...]? (Gutkind 13)

Gutkind here speaks to a broader cultural tendency to value the work of physicians—a tendency that plays out in whose narratives invite scholarly attention, whose labor earns greater compensation, and who wields authority in clinical spaces.

One limitation of focusing this project exclusively on a sub-genre of published memoirs by professional nurses is that their authors are overwhelmingly white women. According to the 2017 National Nursing Workforce Survey, approximately 71% of the licensed practical nurse (LPN) workforce and 81% of the registered nurse (RN) workforce is white (Smiley et al. S46). An effect of this discrepancy is that I am working with only a limited set of perspectives on performing care as a nurse in clinical spaces. While other populations who work in clinical spaces such as cleaning staff, administrative workers, and receptionists may be more racially diverse, published narratives of the care they offer are difficult to come by.³ For these reasons, I have sought to incorporate demographics of the clinical nursing profession into my analysis as an opportunity to interrogate the whiteness

³ One notable exception is the short documentary *Keepers of the House*, in which environmental service workers at a hospital describe their encounters with people seeking medical attention. Interviewees are overwhelmingly women and people of color (Klevansky et al.).

of the profession and how the construction of whiteness gets tied to constructions of ableism in medical institutions.

Another limitation that I have sought to curtail is the risk that centering the memoirs of nurses may entail a methodology that makes care recipient narratives more marginal to this project. Arthur Frank is one scholar who argues in favor of centering the voice of “the wounded storyteller.” In the preface to his book, he writes that he purposefully keeps healthcare workers in the background to avoid “reframing everything ill people say into a question of how some health-care worker might respond” (Frank xvi). The parameters I’ve set forth will indeed be centering nurse-authored texts, but for the purposes of understanding the degree to which nurse writers center care recipient narratives as a means of enacting literary caretaking. In other words, rather than merely celebrating a clinical perspective, I turn a critical eye toward the language of healthcare workers in a way that exposes moments of ableism or violence.

Ultimately, the methodological choices of this project resonate with Rosemarie Garland-Thomson’s argument regarding disability bioethics:

What critical disability studies can do is enlarge our shared understanding of what it means to live with disabilities and be counted as disabled. To do this, the insights and knowledge of critical disability studies need to be *applied*—to be brought into—medical science as a knowledge base and to its practitioners. (“Disability Bioethics” 325)

While I do not share Garland-Thomson’s language of disability bioethics (opting instead for language that emphasizes care and de-emphasizes medicine), this project can be considered one means of responding to her call for applied disability knowledge. By taking

nurse writers as my primary subjects, I hope to bring knowledges of disability and care ethics to bear upon care encounters as they are narrated by medical practitioners.

NOTES ON TERMINOLOGY

Throughout this project I have opted to use the language of care ethics instead of the language of medicine by substituting words such as “care recipient” in place of the word “patient.” One reason for doing so is that I intend for my analyses to approach each text as first and foremost a text about care. Rather than (re)affirm the supremacy of the medical gaze, I intend to emphasize the care relations taking place at any given moment. A second reason for this choice is that an ethical care encounter should be subversive of traditional hierarchies, and my terminology is intended to reflect this belief. As Simi Linton writes,

A patient is understood to belong to a doctor or other health care professional, or more generally to an institution [...] Disabled people, who have often spent a great deal of time as patients, discuss the ways that we have been socialized in the medical culture to be compliant, and that has often undermined our ability to challenge authority or to function autonomously. (29)

Phrases such as “the recipient of a nurse’s care” in place of “the nurse’s patient” are intended to curtail the language of ownership that remains so prevalent within medical institutions.

Additionally, this project intermittently switches between person-first language (e.g. people with disabilities) and identity-first language (e.g. disabled people). My use of both is meant to signal that both are appropriate, so long as one factors in pertinent contextual considerations. Although person-first language is still commonly thought to be

the “correct” way to talk about disability (many academic journals continue to require person-first language as part of their style guides), identity-first language “has more recently been adopted by a wider swath of the disability community, particularly those who identify as disability rights advocates” (Andrews et al.). I use both approaches nearly interchangeably in this project, except for cases where the person involved either indicates or appears to give clues as to their preference.

CHAPTER SUMMARIES

Chapter One considers how pursuits of cure can run counter to ethical care by analyzing two memoirs: *Peaceful Passages: A Hospice Nurse's stories of Dying Well* by Janet Wehr and *Taking Turns: Stories from HIV/AIDS Care Unit 371* by MK Czerwiec. Disability studies has long recognized the eugenic impulses of prioritizing cure above all else (Clare 26, Kafer 30-32, Kim 7). This chapter builds on recent scholarship in the field to continue questioning and complicating the roles of and relationship between cure and care in medical contexts. It asks how a disability-centered ethics of care should approach questions of cure, ultimately demonstrating that context is crucial for such questions. My analysis of Wehr's and Czerwiec's memoirs shows that casting cure out of the frame can allow for important caretaking to take place. I also show, however, that although cure can disrupt care in some contexts, cure can also come to represent the most meaningful care efforts in others. This chapter is therefore one space where understanding racial disparities in health outcomes and other social barriers to medical access factors into an understanding of care ethics and the role of cure in medicine. It proceeds from the understanding that, like

disability communities who have been targeted by the eugenic impulses of cure, disenfranchised groups who have been excluded from pursuits of cure also have a stake in this discussion.

Chapter Two constitutes a critical examination of the power dynamics depicted in the care encounters within three autobiographical texts: “Becoming a Nurse” by Laura Devaney, *Beautiful Unbroken: One Nurse’s Life* by Mary Jane Nealon, and *Critical Care: A New Nurse Faces Death, Life, and Everything In Between* by Theresa Brown. While key figures in feminist care ethics argue that we must embrace models of interdependence to escape the myth of independence and pursue disability-centered care, this chapter asks how nurse writers conceptualize interdependence in their clinical, institutional contexts. The ambivalence with which the nurse narrators included in this chapter approach concepts of interdependence ultimately helps us to understand the institutional and cultural hurdles to enacting interdependent care frameworks that we have yet to overcome. Such hurdles require an approach guided by anti-racism and anti-ableism, without which the hegemonic, white clinical spaces that comprise much of the U.S. healthcare system stand little chance of enacting the theoretical principles of interdependence.

Lastly, Chapter Three asks how we might think about caretaker memoirs as examples of what Katrien De Moor calls “literary care.” I interrogate the ethics of life writing as they play out in four primary texts: *Beautiful Unbroken: One Nurse’s Life* by Mary Jane Nealon, *Intensive Care: The Story of a Nurse* by Echo Heron, *Critical Care: A New Nurse Faces Death, Life, and Everything In Between* by Theresa Brown, and “Hitting the Bone” by Eddie Lueken. I offer three topics—authority, appropriation, and spectacle—

as an organizing principle and loose set of concepts around which to compose an analysis of literary care ethics. This chapter ultimately aims to reframe memoir as a possible form of care and as an opportunity to consider the politics of representation in our efforts to identify disability-centered care ethics.

Chapter 1: Cure's Place in Disability-Centered Care

In Mary Jane Nealon's memoir *Beautiful Unbroken* (2011), the nurse narrator sees a woman in the supermarket who reminds her of her mother and wonders, "What is our responsibility when we stand alongside each other?" Two pages later, she describes sitting with her friend Donna at the clinic, where the doctor tells them Donna needs surgery to identify her cancer, then promptly calls a surgeon colleague with "the flourish of a rich and powerful man who was about to use his power for good." She then writes,

This is what we owe each other, I thought, to see the body alongside us and to try and save it from loneliness or from tumors that begin in the lung and end up in the liver [...] In the darkroom where the surgeon held a portrait of Donna over a tray filled with chemicals. Would her image reappear? Would it fade? (Nealon 49-52)

Throughout her chapter the question repeats: "What do we *owe* each other?" It applies not only to the narrator's childhood friend but to the stranger in the supermarket. "What do we *owe* each other?" presumes that there is, indeed, something that is owed from those around us, especially those who possess the wealth, power, and resources of Donna's doctor. Her question also presumes we owe something to those around us in return. The conclusion that this narrator draws can yield alternate readings, one highly medicalized and the other less so. In the medical version, the care rendered might involve seeing the body via diagnosis and saving it "from tumors" through cure. In a more socially oriented interpretation, the caretaker sees the body both in and beyond its materiality and saves it "from loneliness." Of course, we could also read both possibilities at once, not as mutually exclusive outcomes but as equal contributors toward answering that resounding question: "What do we *owe* each other?"

The answer to this question is important because it yields different outcomes depending upon perspective: A physician might, for example, apply the Hippocratic Oath by attempting to cure through any means necessary. A disabled person, on the other hand, might argue that what she is owed is not cure but instead the recognition that her disability is not a problem that needs to be solved. My goal in giving these two examples is not to pit two groups against one another but to demonstrate that interpretations related to the value of “cure” sometimes run counter to considerations of “care.” As I will show, recent efforts in disability studies speak to the tension of recognizing the simultaneous life-saving capabilities and eugenic impulses of cure. Disability advocates and scholars direct us to question, complicate and consider if/how we might begin to reconcile the roles of cure and care in medical encounters.

In this chapter, I will explore the fraught status of cure and care as standalone concepts and discuss the relationship between the two. I will draw from two memoirs about nursing in the United States: *Peaceful Passages: A Hospice Nurse's Stories of Dying Well* by Janet Wehr and *Taking Turns: Stories from HIV/AIDS Care Unit 371* by MK Czerwicz. In my analysis of these texts, I will ask how each of them interacts with the notion of cure: When is cure the goal of care? Considering the absence of cure as a possibility in each speaker's unique context, how do the texts position care in relation to cure? How do they narrate their performances of medical care given cure's impossibility?

Mining nurse memoirs for answers to these questions is valuable for three main reasons: First, nurses are uniquely positioned within the hierarchy of the medical-industrial complex, frequently negotiating among doctors, administrators, care recipients, and

families. Given their positions, they perform care and bear witness to the role of cure without necessarily holding authority over whether curative interventions are pursued and to what extent. Second, the frequency with which nurses perceive themselves to be advocates of care recipients can be leveraged when considering the relationship between cure and care. More specifically, the nurse-as-advocate motif provides a promising perspective in terms of what nurses make of the relationship between cure and care, and what that relationship means for the well-being of the people seeking care.

Lastly, nurses are the most frequent members of medical teams to challenge pursuits of cure that they perceive to be harmful, and they also tend to be less invested in the idea of cure as the primary objective of their caretaking roles. In a 2021 study, researchers Mary Ann Meeker and Diane White interviewed nurses about their experience providing end-of-life care. In their introduction, they write:

Overly aggressive cure-focused care pursued for too long in the illness trajectory comprises a failure of timely transition to comfort-focused care and a default to ongoing curative care past the time when it can promote meaningful improvement for the patient and/or when the patient finds the burden of care worthwhile. (Meeker and White 530)

Among their findings, Meeker and White found that nurses “were more likely than others on the healthcare team, especially physicians, to acknowledge that recovery was becoming less likely” (536). In addition to being the catalyst in shifting toward less cure-centric practices, nurses also reported that it was rare to experience caring for “a patient receiving comfort care that [the nurse] believed should be continuing curative care instead.” By contrast, “The reverse of that—a patient the nurse believed would be best served by a

comfort-focused approach, but who was continuing active disease-targeted treatment—was universal in the nurses’ narratives” (Meeker and White 536).

A similar study from 2015 analyzing interviews with acute care nurses showed that “A central capacity these nurses demonstrated was the ability to redirect the hopes of patients and families away from cure and technology to other future possibilities, such as appreciating small improvements, spending time with family or leaving a legacy” (Peter et al. 750). The results of each of these studies helps demonstrate not only how pervasive the ideology of cure continues to be in healthcare settings, but also how destructive an insistence upon cure can be. They also help illuminate the complexities of a nurse’s position within the hierarchy of medicine as a sort of liaison between the different medical and social possibilities that Nealon’s narrator considers when she asks what we owe one another. Ultimately, my hope in approaching these questions about cure and its relationship to caretaking from the perspectives of nurses is that it will help prompt us toward imagining further consolidation of the goals of disability activists with the roles of medical providers.

In addition to being written by nurses, the memoirs under consideration in this chapter are alike in that they both take place in contexts where cure is not a possibility. Wehr’s memoir *Peaceful Passages* follows its narrator’s experiences as a hospice nurse, whereas Czerwicz’s graphic memoir *Taking Turns* takes place circa 1994, during the height of the HIV/AIDS epidemic in the United States and prior to the development of antiretroviral treatments. The context of each memoir is such that their narrators are precluded from the pursuit of cure, and the texts thereby provide an opportunity for considering the types of care ethics that can emerge when providers are not pressured by

cultural and medical drives toward cure. Care-based interactions in both texts help illuminate the possibilities of care that become available when cure is not. These unique contexts also leave space for us to make meaning of cure's absence: What can care become without cure? What are its limitations when cure is off the table? And, importantly, when does the pursuit of cure in itself constitute an act of care?

Considering the contexts of hospice and HIV/AIDS together also constitutes an attempt to probe the tension between disability studies and health humanities and to contribute to ongoing attempts at negotiating between the two. As will become clear in my analysis of each memoir, past rejections of the medical model within disability studies do not translate well to contexts involving the pursuit of medical coverage for marginalized communities—for example, the communities most impacted by HIV/AIDS. The specific material and historical contexts of care encounters become essential to unpacking the role of cure in contemporary medicine more broadly—a task for which an approach guided exclusively by disability studies or health humanities alone would be inadequate.

While both memoirs under consideration in this chapter share a common unmooring from the ideology of cure, they differ in their interpretations as far as what the absence of cure means for their caretaker narrators and the people for whom they care. Wehr's narrator depicts the absence of cure as opening space for the dying to confront their mortality and accept meaningful, comfort-focused care. By contrast, Czerwicz's graphic memoir positions the absence of cure as a foundational conflict within the narrative. My analysis of these texts will account for this essential distinction in each narrator's relationship to the ideology of cure.

Despite this important difference, I will argue that the nurse narrators in these texts emphasize that both caretaking and healing persist in the absence of cure. Additionally, while neither text suggests that cure is antithetical to care, Wehr's memoir proposes that relentless pursuits of cure can become harmful to a care recipient's wellbeing and can even interrupt important caretaking interventions. By contrast, Czerwiec's text positions the broader national failure to pursue cure as a breach of care ethics altogether. Ultimately, both texts illuminate the important functions and outcomes of caretaking that can and should take place independent of cure.

RECKONING WITH THE IDEOLOGY OF CURE

The question of how cure functions in nurse memoirs is one that speaks to ongoing debates within disability studies about the nature of cure. Among disability scholars and activists, the concept of cure remains a site of contestation. Cure itself—of illness, of impairment—is a phenomenon that usually takes place via medical intervention; because most disability activists have come to see disability as a largely social and political issue rather than merely a medical one, many have directed their attention toward resisting the medicalization of disability altogether, and for good reasons. As Simi Linton writes in *Claiming Disability*, although some medical treatments have proven beneficial to many disabled people, “the medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and, significantly, as an individual burden and personal tragedy” (11). Linton goes on to write that an emphasis upon medical intervention means that we “‘treat’ the condition and the person with the condition rather

than ‘treating’ the social processes and policies that constrict disabled people’s lives” (11). Linton is drawing a distinction between the medical and social models of disability, the latter of which emphasizes “curing” social and political barriers to access rather than individual bodies.

While there are some within the disability studies arena who reject “cure” and the medicalization of disability entirely in favor of an exclusively social model, there are many who suggest that we would benefit from reckoning with cure without rejecting it entirely. Such scholars recognize both the value and inadequacies of a purely social model of disability, pushing not for an all-out acceptance of pathologization or of cure, but instead for a nuancing of how cure can be simultaneously beneficial and violent. Eli Clare gets to the heart of this tension in *Brilliant Imperfection*, writing: “Many lives, including my own, depend upon or have been made possible by cure and its technologies [...] But cure arrives in many different guises, connected to elimination and erasure in a variety of configurations” (26). Clare’s reckoning with cure is such that, even as he acknowledges that medical technology made his life with cerebral palsy possible, that same medical technology would, if given the chance, eradicate cerebral palsy from existence.

Furthermore, Eunjung Kim, Leah Lakshmi Piepzna-Samarasinha, and Alison Kafer are additional examples of scholars/activists who, like Clare, acknowledge cure’s violence and advocate for a more nuanced understanding of its possibilities. Kim coins the term “curative violence” to articulate two levels of violence provoked by cure: one where cure seeks to erase disability altogether and another where the pursuit of cure entails material violence toward disabled people. The resistance to cure that Kim articulates invokes and

extends beyond objectives related to disability pride: she reminds us that the ideology of cure is rooted in a history of violence and eugenics. One of the most violent of cure's "configurations" (Clare 26), then, is its eugenic impulse and its threat of disability erasure. Piepzna-Samarasinha also articulates a variety of dangers provoked by cure and advocates for a crip model of healing. They write,

The healing may be acupuncture and herbs, not pills and surgery, but assumptions in both places abound that disabled and sick folks are sad people longing to be 'normal,' that cure is always the goal, and that disabled people are objects who have no knowledge of our bodies. (Piepzna-Samarasinha 63)

Piepzna-Samarasinha's argument orients us away from the assumption that cure or any type of traditional "healing" need factor into our discussion of what constitutes wellness and justice for disabled people. Additionally, Kafer proposes an alternative to either the medical or social model of disability, introducing a political/relational model that "recognizes the possibility of simultaneously desiring to be cured of chronic pain and to be identified and allied with disabled people" (6). Kafer's approach is, like Clare's, a resistance to the rendering of medical intervention as either violent or wholeheartedly beneficial. It reminds us that creating strict lines between impairment and disability—or between disability allyship and pursuit of medical intervention—can constitute an exclusionary and reductive practice.

Some scholars also bring such insights from disability studies to bear upon questions of illness. The distinctions among illness, impairment, and disability are complex, but most disability scholars have come to accept chronic illness as a form of disability. In her essay "Unhealthy Disabled," Susan Wendell writes specifically about the

notion of cure as it relates to chronic illness. Although Wendell describes chronic illness as “a kind of disability,” she writes that efforts to assert chronic illness as “a valuable difference” have not come as far as those related to disability pride (30). She writes:

Is illness by definition an evil, or have we made less progress in recognizing chronic illnesses as potentially valuable differences than we have in relation to other disabilities? Certainly it is difficult to say that one is glad to have been ill and be believed, despite the fact that many people who are or have been ill testify that it has changed them for the better. [...] although I would joyfully accept a cure if it were offered me, I do not need a cure and I do not regret having become ill. (Wendell 30)

Wendell’s article testifies to the porous boundaries between the categories of illness and disability and prevents us from drawing any definitive conclusion related to cure as either a necessary pursuit or even as a desirable outcome of caretaking endeavors.

The critiques and theorizations of cure by disability activists and scholars have yet to fully take hold in the expansive health humanities realm, but there are some relevant examples of scholars publishing in traditional medical spaces who question the implications of continuously emphasizing cure as the fundamental goal of healthcare. For example, Lisa Rosenbaum asks: “Is there some inevitable trade-off between the capacity to care and the capacity to cure?” (4) She tells a story of a cardiologist who had no medical treatments to offer the care recipient and instead “offered himself,” providing comfort until the individual died. She writes, “Now, of course, science has given us countless tools for preventing and treating disease. But somehow, in our efforts to systematize all we know (and make it profitable), the centrality of the doctor-patient relationship got lost” (Rosenbaum 3-4). The narrative Rosenbaum includes in her article suggests that Western medicine, in maximizing its potential to cure, has minimized its commitment to care. Her

article implicitly suggests that a commitment to care involves “the centrality of the doctor-patient relationship,” a phrase belonging to traditional medical contexts that disability studies scholars might contest. Nevertheless, her narrative of the cardiologist is noteworthy precisely because it is a narrative that rarely (if ever) takes place in today’s culture, where anything other than cure is often considered a failure and where the physician, a heroic purveyor of cure in our cultural imagination, hardly has time to help people die.

This “obsession” with cure is further described by Arthur Frank, whose work is frequently read in health humanities contexts. In his book *The Wounded Storyteller*, Frank defines the remission society as people who, like him, “accept some level of illness as the permanent background and intermittent foreground of their lives” (82). Belonging to the remission society is a means of rejecting the restitution narrative that healthcare providers frequently pursue, the central facet of which is cure. He writes that an obsession with cure means that medicine cannot place people seeking care in narratives other than that of restitution: “Medicine’s hope of restitution crowds out any other stories” (Frank 83). Rosenbaum’s article seems to agree that this monopoly of the restitution narrative has cancelled out other possibilities for the care that is rendered within medical institutions.

We can also find some critical analysis of cure within texts more specifically related to the field of bioethics. Many of these critiques are situated in an analysis of cure as a means of pandering to a neoliberal framework of labor and production. For example, in the introduction to the book *The Ethics of Care*, Alan Blum writes that “we can resist care because of its impersonal standardization, or [...] for its attempt to rehabilitate us to be productive in a capitalist machine in order to get us back to work” (11). Although Blum

formulates this statement as a critique of care, it is fair to read it as a critique of cure instead—or, at the very least, a critique of care performed only for the sake of cure. Blum’s introduction invites us to be suspicious of care that is primarily rehabilitative in nature or that adheres to the “restitution narrative” (Frank 94-95).

Most of the scholarship engaged in critiques of cure from varying disciplinary perspectives seeks to unsettle any easy acceptance or embrace of cure that we might otherwise take for granted. In particular, recent disability studies perspectives, far from disavowing medicine altogether, orient us toward a more nuanced understanding of medicine’s emphasis upon cure and how such an emphasis can impact recipients of medical attention. In what follows, I will demonstrate that similar critiques of cure can be found in autobiographical texts written by nurses. By doing so, I hope to continue building upon these conversations about cure, offering personal narratives by nurses as one means of conceptualizing how a theoretical critique of cure might be brought to bear upon clinical encounters.

CURE IN WEHR’S *PEACEFUL PASSAGES*

In considering what a disability-centered ethics of care might look like, I am following the lead of the above disability activists and scholars who suggest that recognizing disability justice in healthcare entails complicating the notion of cure as the primary goal of caretaking. Along these lines, the narrator of Janet Wehr’s memoir *Peaceful Passages: A Hospice Nurse’s Stories of Dying Well* (2015) suggests a desire to complicate what Frank calls the “restitution narrative” that takes cure as the objective of

competent caretaking. Through my analysis of Wehr's text, I will demonstrate where and how the speaker asks the reader to complicate their assumptions about cure, showing that, while the memoir does not completely reject cure as a worthy pursuit, it does suggest that pursuing cure without limitation can constitute a harmful interruption of caretaking, a stance that we can read as a challenge to the unyielding restitution narrative. In short, I argue that care is positioned in this text as a necessary departure from pursuits of cure. By doing so, I hope to advance scholarly discussions toward a more concrete understanding of what a complication of cure can yield in medical caretaking contexts, and how certain ethics from hospice settings can translate into other medical spaces.

Wehr writes *Peaceful Passages* as a collection of stories from seventeen years of hospice nursing. The memoir's departure from cure occurs early in the introduction, where the speaker explains the exigency of the text as an attempt at teaching its reader about the process of dying. On the first page of the introduction, Wehr writes,

In most areas of healthcare, saving a life is the focus, and death is often viewed as a failure. Historically, there has not been a great deal of understanding as to why people would choose to concentrate their efforts where a medical success is not likely. Believe me when I say that it required a monumental shift in thinking for me to shift gears from the type of nursing I had previously done, which had everything to do with fixing, saving, and curing. I had to find out for myself that what we do in hospice is every bit as important, except that it's for people who no longer have those treatment options. (Wehr xiii)

Wehr's speaker introduces herself via this passage as a healthcare worker who started in a more traditional clinical space, where she states that "fixing, saving, and curing" were the main priority—language that resonates with Nealon's answer to the question "What do we owe each other?" in *Beautiful Unbroken*. The narrator's acknowledgement that abandoning

cure and instead pursuing hospice required a “monumental shift in thinking” is a rhetorical gesture that positions the speaker in alliance with the reader. The implied second person address in the phrase “believe me” explicitly asks the reader to suspend their commitment to those efforts toward “fixing, saving, and curing” and to instead open themselves to the shift in thinking that Wehr’s speaker describes. By acknowledging that most people view death as a failure, the speaker begins the memoir by leveling with the reader’s preconceived notions of caretaking. We are thus poised from this passage to consider what we might learn if we challenge the mindset of death and disability as failures, a dominant mindset that persists in clinical spaces and that disability scholars and activists rally against.

However, the text does not reject ideologies of cure altogether. As we can see from the above passage, Wehr’s speaker acknowledges that the people for whom she cares in the context of hospice services are “people who no longer have those treatment options”—treatment options that might lead to the aforementioned “fixing, saving, and curing.” This speaker wishes the reader to acknowledge that valuable caretaking is possible and necessary in the absence of cure, but the book does not complicate notions of cure in cases when it remains viable. This text functions as a site that we can mine for potential ideologies of caretaking that do not include cure—but it’s important to read it as a text in which cure has already been cast out of frame. The text therefore leaves readers to presume that this speaker does not intend to trouble cure as the default objective in such contexts where cure is possible. In a later section of this chapter, I will draw from supplemental memoirs whose narrators challenge cure even in contexts where it remains a possibility to

demonstrate that the ethics of care articulated by Wehr's text need not remain confined to a hospice setting.

To assess how Wehr's memoir positions care as separate from (or in some ways, outside of) the ideology of cure, I now turn to a moment when the speaker articulates her understanding of the difference between "giving in" and "giving up." I argue that Wehr's memoir articulates death as, at times, an important and valuable conclusion to the caretaking process, rather than a failure of care. However, I also argue that the text's insights about death must be unpacked carefully: Wehr's text employs language resembling harmful "better off dead" ideologies, leaving too much space for ableist interpretations. Despite this, the context of hospice care and the narrator's assertion that hospice affirms life rather than accelerating death helps dismantle the common perception that quality of life is contingent upon cure.

One way of reading the memoir's distinction between "giving in" and "giving up" is as a means of further subverting the notion of death as a failure of care. At one point, the narrator says,

'Giving in' and 'giving up' are two very different concepts. The giving in usually occurs well after the fight—the treatments and surgeries designed to extend life, or, in some cases, cure an illness—have been put aside. This is usually a time when patients realize that they would rather be gone than to accept the limited life their disease offers. Most often, they comment on the realization that there is somewhere better to be than sick in bed. (Wehr 49)

In this excerpt, the narrator expands upon her argument in the introduction: that, despite what many practitioners of Western medicine might believe, death is not a failure. She emphasizes the phrase "giving in" as a positive, beneficial decision to accept one's

prognosis and live accordingly—to stop resisting the inevitable process of dying. As I have suggested, this excerpt can be read as a means of articulating the absence of cure—and, for that matter, the normative ways of living that cure propels us toward—as something other than a failure. Acceptance of death is, in this articulation, a valuable means of caring for oneself and, by extension, helping others accept death is a means by which the narrating hospice nurse performs care.

However, this passage comes dangerously close to invoking the “better off dead” mentality with which people with severe chronic illnesses and disabilities are all too familiar. This mentality is part of what Wendell gestures toward when she acknowledges the history of eugenics embedded in the medical model of disability (31). Mel Y. Chen, too, locates a connection between euthanasia and eugenics discourses (125), and Paul Longmore speaks about euthanasia discourses extensively in his interrogation of stereotypes in on-screen depictions of disability. Of movies in which disabled characters resort to suicide, Longmore writes:

[...] these dramas present death as the only logical and humane solution. But instead of eliminating the disabled person who is a violent threat, it relieves both the individual viewer and society of the impossible emotional, moral, and financial burden of severe disability. The disabled characters choose death themselves, beg for it as release from their insupportable existence. The nondisabled characters resist this decision, but then reluctantly bow to it as necessary and merciful. (Longmore 137)

While Wehr’s memoir helps articulate an ethics of care that emphasizes caretaking beyond (and in absence) of cure, it incorporates brief moments such as this that invoke quality of life arguments that have historically proven dangerous to the wellbeing and very existence of disabled people. In ableist, medicalizing logics, death is sometimes understood as a kind

of cure. Wehr's text evokes this "better off dead" ideology when her narrator affirms that "there is somewhere better to be than sick in bed" (49). In this example, the disabled, sick-in-bed individual that the narrator imagines represents the "emotional, moral, and financial burden" of Longmore's description.

Regardless of whether we chalk the above example up to a poor choice of words or to a more insidious (perhaps even subconscious) bias, instances such as the above remind us that valuable insights we might glean from the text warrant careful assessment. After all, in contrast to the above example, the text takes care in other ways to explicitly dismantle common perceptions about the role of hospice as a mere waiting room before death. Early on, the speaker asserts, "'Hospice doesn't help you die. Hospice helps you *live* until you die,' because hospice is all about bringing quality to life, not hastening death" (Wehr 29). In this passage, the speaker asserts that the turn away from cure does not necessarily entail immediate death or misery, and that there is instead a rich landscape of caring opportunities to explore once we suspend our commitment to cure. Upon first glance, use of the phrase "bringing quality to life" gives me pause—after all, such phrases are often used to justify re/turning disabled bodies to normative ways of being, much like how "better off dead" arguments come into play when cure proves unsuccessful. However, Wehr's narrator uses this phrase in a context absent of cure-focused treatment; this context enables a reading of this passage as a possible example of disability-centered caretaking, where "quality of life" remains ambiguous but escapes the potential to mean cure-oriented and potentially harmful medical attention.

Beyond beginning with the suggestion that caretaking without possibilities of cure is an important and valuable endeavor, Wehr's memoir also makes clear that pursuing cure relentlessly constitutes a harmful and even violent interruption of care. It also makes clear that such a cure-centric stance is all too popular in traditional medical contexts. This critique of cure takes place primarily in a scene with Madeline: upon the narrator's arrival at Madeline's home, she notices that her breathing has characteristics of the "death rattle" and says that Madeline is near to dying. In the scene, Madeline's granddaughter tells the narrating nurse that she and Madeline had a conversation days ago about how, after a full life, she was ready to rest. However, Madeline's peaceful transition into death, each stage of which the nurse carefully explains to the family, is abruptly interrupted by Madeline's grandson. The rest of the scene is narrated as follows:

Unexpectedly, a man I did not recognize then burst through the door into the apartment [...] He was introduced as Christine's brother, Robert, who was a prominent surgeon at our hospital. Robert stormed past us and went into the room where Madeline lay so close to dying. He visually assessed her for no more than a few seconds, then moved briskly to the phone and dialed 911. When he had ordered an ambulance, he turned to me and yelled, "What do you think you're doing? My grandmother is dying! She needs emergency treatment NOW!" [...] I prayed that the emergency room personnel would not intubate her or perform CPR. I wanted what Jack and Christine wanted, which was for her to be in her own bed, in her own home, with people who loved her and understood her desire to leave. I packed up my nursing bag and left Madeline's home, feeling as if I had failed her. (Wehr 5-7)

Wehr's speaker goes on to write that the emergency room staff sent Madeline back home, ending the chapter by writing, "Madeline held on until she was back under her fluffy down comforter, in her little pink bedroom, and quietly slipped away" (7). This scene makes explicit in several ways that curing Madeline is no longer a possibility: The nurse speaker recognizes the signs of death and explains them to Madeline's family, and the emergency

room staff sends Madeline home to pass away peacefully in the absence of further treatment options. In other words, the need for caring treatment rather than cure-oriented treatment is made explicitly apparent and, according to Madeline's granddaughter, focusing on comfort is what Madeline truly wants.

Furthermore, the scene implicitly critiques traditional medical contexts, symbolized by Robert, for immediately defaulting to a cure-oriented response. Because cure is made such a distinct impossibility for Madeline, the text portrays Robert's interruption as all the more violent: "burst[ing] through the door," "storm[ing] past," and later, yelling at the hospice nurse. In this moment, cure—the ideology for which Robert stands—is formulated as the antithesis to the nurse's more meaningful practice of care. By emphasizing that Robert is a prominent surgeon at the hospital, the speaker underscores not only the violent costs that can be imposed by positioning cure as the quintessential goal of healthcare, but also how pronounced such a stance tends to be in traditional medical contexts—contexts which Robert comes to represent. Besides Robert, the other traditional medical providers in the scene are the emergency room staff, who evade the narrator's criticism by sending Madeline home. Even so, Wehr's narrator seems to have little faith in the emergency room to make what she sees as the right choice—to pursue care instead of cure—because she prays for Madeline not be intubated and ultimately anticipates the worst: "I packed up my nursing bag and left Madeline's home, feeling as if I had failed her" (7). This extensive scene implies that the relentless pursuit of cure, which we have culturally come to expect from traditional medical providers, can function as a breach of care in some circumstances.

At this point I want to note that the violent depiction of cure found in Wehr's memoir can carry over to texts where cure remains possible. For example, Theresa Brown's memoir *Critical Care* (2010) includes a scene from the oncology ward, describing Bill and the complicated relationship to cure that Bill's case inspired: "We had saved him, but in a way I felt we had failed him, because the process of saving him had made him so miserable, had made him hate the life he was living" (179-180). The process of saving Bill included painful chemotherapy treatments, often administered by the protagonist. After giving the above context, Brown's narrator details of one of her last interactions with Bill: "I was just leaving, saying my good nights, when Bill spoke. 'Thanks, Treese,' he said, because he's given me his own nickname. 'I needed a dose of you tonight'" (*Critical Care* 180). If read in a hospice context, the above encounter neglects the possibilities of comfort-oriented care and disrupts a peaceful dying process. This scene from Brown's narration corresponds with the care ethics we might derive from Wehr's text insofar as it challenges the ideology of cure as the primary goal of caretaking: we are asked to wonder with Brown's narrator whether such extensive curative interventions are in Bill's best interest. After all, Bill's dialogue indicates that it is not necessarily the cancer treatment that he needs, but instead "a dose of you," a metaphor in which the nurse's care and presence are his medication.

Both Bill's scene in Brown's memoir and Madeline's scene in Wehr's depict cure as a source of violence; yet while Wehr's text indicates that such violence constitutes a breach of care, it becomes permissible in Bill's case. Brown's narrator does not have a comfortable relationship to cure, yet ultimately supports curative interventions for Bill: "It's good to know that all this suffering can actually keep our patients alive" (*Critical*

Care 181). Both narrators level critiques at curative interventions for the suffering they cause, and neither situates the pursuit of cure as a particularly caring gesture: Wehr's narrator prays the ER doctors do not subject Madeline to further suffering, and Brown's acknowledges how Bill's cancer treatments "had made him hate the life he was living." Since both texts position cure as a site of such violence, they work together to illuminate an important question: If an act necessitates some harm (as acts of cure do in these scenes) can it be considered care?

As I have suggested, the answer Wehr's narrator indicates is that curative interventions function as a breach of care in hospice contexts. However, Brown's text positions the violence of cure within the purview of ethical caretaking on a hospital oncology ward. While both Bill and Madeline are harmed by cure-centric interventions, the scenes differ in a crucial way: Madeline's life would not have been saved by attempts at cure, but Bill's was. This comparison suggests that, while the care ethics articulated by both texts is similar, with both narrators representing curative intervention as a site of violence, it can yield different outcomes depending upon the unique context of each caretaking encounter.

Although Wehr's and Brown's narrators arrive at different conclusions regarding the permissibility of harmful curative interventions, they both articulate an ethics of care that corresponds with how feminist care ethicists Sara Ruddick and Virginia Held describe the function of violence in care scenarios. Ruddick defines a violent act as one that causes damage without compensatory benefit, by which she means "some good that the damaged person may expect from her injuries, as, for example, a patient hopes to benefit from

assaultive chemotherapy” (Ruddick 164). In this reframing, the cancer treatment Bill endures is painful but not necessarily violent, since it promises long-term “compensatory benefits” for the price of short-term pain. With this reformulation, one can recognize how a painful treatment like Bill’s is justifiable in the name of care.⁴ By the same token, the narration of Madeline’s case exposes the lack of compensatory benefits for her had the ER staff attempted resuscitation. Without compensatory benefits, curative intervention in this scenario is not a justifiable violence, and Wehr’s narrator maintains that cure-centric practices would instead constitute a breach of care.

In a slightly different approach to violence in care encounters, Virginia Held theorizes that some acts of “necessary” harm may constitute care in certain scenarios. Held writes that “violence may occasionally be called for” and uses an example of yanking a child from the path of oncoming traffic, dislocating the child’s arm in the process. In this case, Held makes the important distinction that the point of using violence “will be to further the aims of care” (121). In this view, even if we considered Bill’s cancer treatment to be a form of violence, we can still justify it as a necessary act that furthers the long-term goal of keeping Bill alive. When Brown’s narrator says, “It’s good to know that all this suffering can actually keep our patients alive” (*Critical Care* 181), she acknowledges the

⁴ To add one final element of nuance to this question—Can harmful curative interventions be considered care?—I want to consider arguments that chemotherapy treatments like Bill’s might be within the realm of care for individual nurses, but that it is not a form of care on a larger, research-oriented scale. Azra Raza’s book *The Last Cell* argues that researching cancer prevention—not cure—is the more ethical way of addressing cancer. She writes, “How good are the solutions we offer if we constantly have to ask ourselves whether the cancer or the treatment we prescribe will kill the patient? [...] Using chemotherapy, immune therapy, and stem cell transplant to cure cancer, as someone has aptly observed, is like beating the dog with a baseball to get rid of its fleas. Why is this the best we can offer?” (Raza 13).

harm Bill endures—harm in which the narrator participates by continuing to administer chemotherapy—yet ultimately understands this harm as a necessary element of caring for Bill. Similarly, Wehr’s narrator understands Madeline’s surgeon grandson as causing harm that does not “further the aims of care”: because Madeline has expressed a desire to rest peacefully (Wehr 5), her grandson’s cure-centric actions interrupt the narrator’s efforts to help her do so. Ultimately, the hospice context of Wehr’s memoir helps articulate versions of care that persist in lieu of cure, and supplementing an analysis of *Peaceful Passages* with this excerpt from *Critical Care* demonstrates that the ethics of care articulated by Wehr’s narrator is not a rejection of cure altogether, but instead one that can be deployed in other contexts in favor of cure.

In discussions of violence during care scenarios, it’s especially important to center experiences of people of color since they often endure both undue violence and inadequate treatment for pain. Neither Madeline’s nor Bill’s race are explicitly accounted for; in turn, the latent whiteness of both scenes means that readers are not asked to critically engage with questions of race and how intersectional approaches to care ethics might respond to questions of violent caretaking. Research shows that Hispanic and Black people are less likely than white people to receive medication for their pain (Brummer et al. 14), and that Black people are more likely than white people to be subject to less desirable treatments, such as limb amputations (Stettner et al. 138). Overall, “African-Americans and Hispanics tend to receive a lower quality of care across a range of disease areas, including cancer, cardiovascular disease, HIV/AIDS, diabetes, mental health and other chronic and infectious diseases” (Stettner et al. 138). Therefore, applying disability-centered care ethics

in clinical spaces and determining the use of violence to “further the aims of care” (Held 121) requires a necessary examination of racial and other biases informing which treatments providers offer to those seeking care. When reading passages such as the above, we should be aware that actors within the healthcare system tend to justify violence more readily toward racial and ethnic minorities, complicating any conclusions we might draw regarding the role of violence in care scenarios.

It would also be valid to argue that failing to treat Bill’s cancer with curative interventions would constitute a neglectful breach of care ethics, despite the harm the chemotherapy causes him. Despite how past disability theorists have turned away from cure, there are plenty of cases in which the pursuit of cure can itself constitute ethical caretaking, and where neglecting the possibilities of cure comprises a violent injustice. Such an understanding of cure takes place in M.K. Czerwiec’s graphic memoir *Taking Turns*, which I turn to next.

CURE IN CZERWIEC’S *TAKING TURNS*

Much like in Wehr’s memoir, the graphic memoir *Taking Turns: Stories from HIV/AIDS Care Unit 371* (2017) by MK Czerwiec also suggests that the absence of cure facilitates meaningful caretaking encounters that might otherwise not exist. However, in contrast to the more optimistic interpretations that we can read in Wehr’s text, *Taking Turns* positions the absence of cure as a source of conflict. Czerwiec’s memoir is therefore an example of what care can look like *despite* the absence of cure—but not necessarily as a rejection of cure. While a common disability studies perspective reads cure as a harmful

imposition upon disabled bodies, *Taking Turns* helps complicate this perspective by reminding us that medical treatments for HIV/AIDS were stymied by the degree to which governments and the public disregarded the stigmatized populations most impacted by the virus. Finally, I argue that by resisting a fully celebratory conclusion, *Taking Turns* complicates the assumption that achieving effective treatments constitutes a resolution to the process of care.

Cure is absent in Czerwiec's graphic memoir, which takes place right before the peak of HIV/AIDS deaths in Chicago (Czerwiec 64). In the book, Czerwiec's narrator introduces the very existence of Unit 371 as necessitated by the HIV/AIDS crisis. In one

series of illustrations, Czerwiec depicts herself on a first tour of the unit (see fig. 1). Karen shows her around the unit and gestures to a series of yellow doors with framed paintings in between, saying, "You may have noticed that Unit 371 doesn't look like a normal hospital unit." The subsequent illustration is a

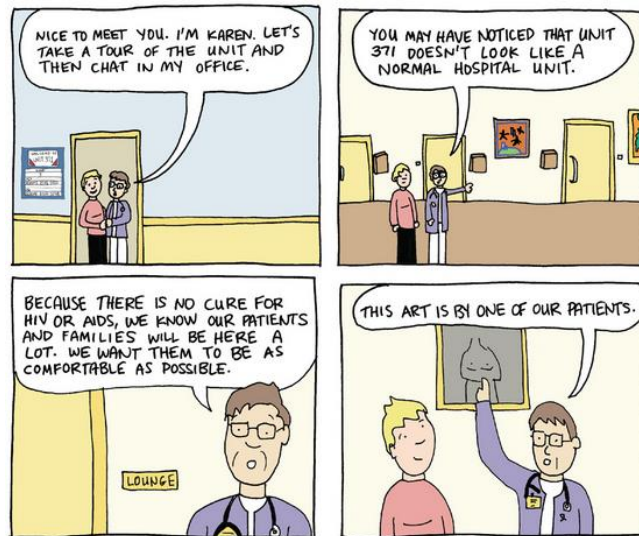


Fig. 1. Karen's tour of Unit 371 from MK Czerwiec; *Taking Turns: Stories from HIV/AIDS Care Unit 371*; Penn. State UP, 2017, pp. 19.

close-up of Karen wearing a purple jacket with a stethoscope around her neck, standing in front of a door labeled "lounge." She continues: "Because there is no cure for HIV or AIDS, we know our patients and families will be here a lot. We want them to be as comfortable as possible." The drawings and paired dialogue demonstrate that the features of Unit 371

that contrast with a “normal hospital unit” are precisely those meant to add comfort to visitors’ lives, including the lounge, with its yellow, welcoming door and array of paintings. According to Czerwiec’s narration, it is the very absence of cure that prompts the design of Unit 371 as a comfortable, welcoming space.

The text also demonstrates that the absence of cure enables creative interpretations of the caretaker role, redefining medical care via interactions that might not take place in other contexts. Early in the text, Czerwiec’s narrator says: “I would learn from AIDS what I needed to know to be a good nurse: That sometimes there’s little we can do to help, but we should always try, and often the things that help people are not what we might expect.”

In the first of two drawings, Czerwiec depicts herself in dialogue with a person in a black shirt carrying luggage (see fig. 2). Czerwiec’s character says “Are you sure we can’t

convince you to stay?

You’re very, very sick” to

which the person replies,

“No way. I’m off to the

riverboat to try my luck. I

die either way.” The



Fig. 2. The nurse caring for those who stay and those who leave from MK Czerwiec; *Taking Turns: Stories from HIV/AIDS Care Unit 371*; Penn. State UP, 2017, pp. 7.

illustration is almost entirely white, but what little color there is draws the eye toward the characters: Czerwiec in her usual dark green shirt and departing visitor wearing black and brown. The darker colors donned by this character suggest a less successful attempt at helping him: although the nurse does try to help, he decides to leave for the sake of dying somewhere meaningful to him.

The narration continues into the next illustration, which shows Czerwiec's character peering out from beneath an occupied bed. The person in bed says "Hey! My cable TV just went back on! What'd you do down there?" Czerwiec's character responds, "I'm not sure. But glad it worked!" In contrast to the first illustration, the colors here appear to be somewhat lighter: orange hair, pink clothing, and a light blue background on the TV, all of which code this interaction as more optimistic toward the type of care possible despite the absence of cure. Just as the above example suggests the material space of Unit 371 has been designed to provide comfort, this pair of illustrations represents caretaking beyond the "normal" scope of clinical practice. This second of the two scenes suggests that, because there is "little we can do to help," which I read as a gesture to the absence of HIV/AIDS treatments, the caretaker pays more attention to smaller details that add meaning to a caretaking interaction, such as getting the TV to work. Again, the narrative indicates that the very absence of cure prompts the nurse character to seek other modes of caretaking.

This pair of scenes demonstrates possible modes of care that are distinct yet equally meaningful: care by improving the experience of the person who decides to stay on Unit 371, and care by honoring the decision to leave. We can read the latter as a form of care that cedes authority⁵ to the departing man: Czerwiec's character does not force more direct care or judgement upon him. While the choice of colors implies a different tone in either scenario (the first more somber, the second more optimistic), both recipients of care are

⁵ A nurse's gesture to cede authority need not and should not only exist in the absence of cure. I discuss this point more thoroughly in Chapter Two.

smiling. Their smiles are a subtle acknowledgement that, although there is sometimes nothing more the nurse can do, this does not translate into a judgement upon the recipient of care. By the same token, the fact that the narrator isn't smiling in either scenario might indicate the intense physical and emotional work involved in caring for people who may soon die despite those efforts. Even bearing this in mind, we do not encounter the departing man as a failure, despondent and "giving up" (to invoke Wehr's phrasing). Instead, the narrator depicts the interaction in such a way that respects his decision and acknowledges that care might look different in each case: caring by way of intervention and caring by being present without being coercive or forceful. Just as Linda S. Raphael and Madden Rowell suggest that Czerwiec's stylistic decision to make characters look similar suggests "the complexity of the relationship" between caretaker and care recipient (182), so too am I suggesting that their smiles ask us to read the difference in outcomes as a complex phenomenon: in the absence of cure, every small attempt at rendering care, however successful, becomes meaningful and worthwhile.

This is not to say that Czerwiec's graphic memoir appears to be against cure as an ideology. Instead, a major conflict of this narrative is the lack of treatment options at the time for people with HIV/AIDS, not to mention the violent social implications of an HIV/AIDS diagnosis, all of which comprise the backdrop of this text. In one of the final illustrations of the memoir, Czerwiec depicts a physician who used to work on Unit 371 (see fig. 3). In the illustration, the man is mostly bald, wearing rectangular glasses and a

navy shirt. What appears to be a bright red chair frames him from behind. He says, “I think that was an extraordinary time. Something happened. A community formed, a community of compassion. I hope we never need a place like Unit 371 again, but I’m glad and grateful it was there when we did.” The doctor’s sentiment speaks to the

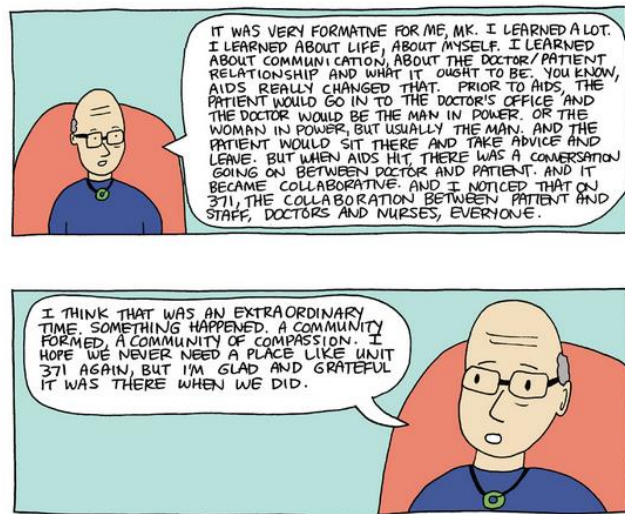


Fig. 3. Physician reminiscing about Unit 371 from MK Czerwicz; *Taking Turns: Stories from HIV/AIDS Care Unit 371*; Penn. State UP, 2017, pp. 173.

trauma inherent in taking care of people with little chance of surviving the virus. It shows that caretaking in the absence of cure can be devastating. However, the physician also indicates that the care that emerged *because of* the absence of cure was also meaningful, and that the community necessitated by the HIV/AIDS crisis was one of compassion and collaboration between the people performing care and those receiving it.

The graphic memoir helps complicate the ideology of cure and the degree to which cure is a desirable outcome by introducing somewhat of a paradox: In a common disability studies perspective, authorities call upon cure when they deem the disabled body worthless and in need of “fixing.” And yet, the mechanism of cure as it relates to HIV/AIDS makes clear that those in power only pursue cure for groups deemed worthy. Because the HIV/AIDS crisis in the U.S. was compounded by stigmatization rooted in homophobia, bias against intravenous drug users, and xenophobia toward Haitian immigrants, we see a complication of the degree to which cure was dismissed from the purview of medical and

political priority. The text invokes a history of marginalization and discrimination against people with HIV/AIDS, and the physician's hope that "we never need a place like Unit 371 again" is one of them.

By gesturing toward the violent social and political responses to HIV/AIDS, *Taking Turns* evokes an ethics of care that recognizes care recipients' needs beyond the merely biological. Yet it also asks us to consider that the pursuit of cure can itself function as a form of care in some circumstances, troubling any easy distinction between the medical and the social. This distinction is further complicated when one considers the extensive history of discriminatory treatment (or lack of treatment) for people with HIV/AIDS. In the early days of the epidemic in the U.S., the virus was associated primarily with gay men, drug users, and Haitians, groups stigmatized such that hostility toward them "made dismissing people with AIDS's demand for treatment easier" (Wallis 625). The federal administration under Reagan did not address the spreading virus until the late 1980s, after the epidemic had already been raging for years. By then, although it was not legally sanctioned, "Stories of AIDS patients being put under impromptu isolation, being ostracized, or being neglected in hospitals appeared regularly in the first years of the epidemic" (Wallis 625-626). Treatment for people with HIV/AIDS was insubstantial on both a micro level, with many healthcare practitioners questioning their duty to care for people with HIV/AIDS, and on a larger scale via the oppressive silence of political and public health representatives. As Paula Treichler writes:

So long as AIDS was seen as a battle for the body of the gay male [...] the biomedical establishment was not tremendously interested in it [...] But with the discovery that the agent associated with AIDS appeared to be a virus—indeed, a

novel retrovirus—what had seemed predominantly a public health phenomenon (clinical and service oriented) suddenly could be rewritten in terms of high theory and high science. (34)

The lingering and seemingly irresolvable conflict of *Taking Turns* is such that, not only did cure for HIV/AIDS not exist, but the possibility for viable treatments also only developed once those with resources were persuaded to care about those stigmatized populations.

In the memoir, Unit 371 is positioned as a space of care for people with HIV/AIDS until a time when advocates could achieve more mainstream care about those populations. Like the “community of compassion” described by the interviewed physician, Victoria

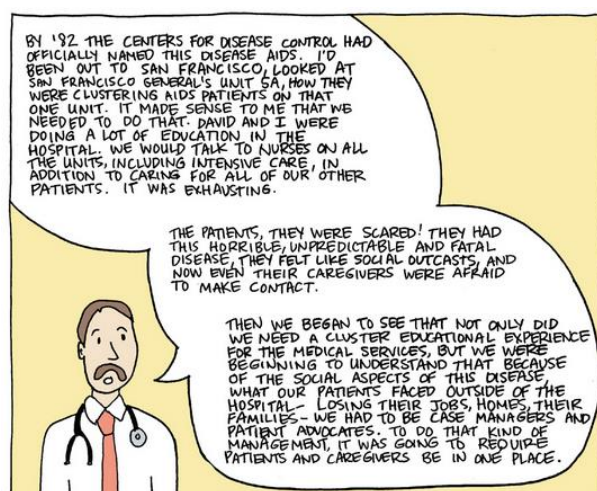


Fig. 4. Doctor describing the origins of the clinic from MK Czerwicz; *Taking Turns: Stories from HIV/AIDS Care Unit 371*; Penn. State UP, 2017, pp. 28.

Lupascu's analysis of *Taking Turns* reads Unit 371 as “a dedicated space for the AIDS patients in Chicago [...] where stigma and biased care could not interfere with treatment and valorization of every human life” (160). An integral part of the care ethics that emerges from this memoir involves imagining and enacting meaningful care practices in the

absence of cure and, importantly, asserting care in the absence of more widespread political and social empathy for people with HIV/AIDS. Czerwicz's narrator illustrates one of the founding doctors of Unit 371 chronicling its origin (see fig. 4): “[...] we were beginning to understand that because of the social aspects of this disease, what our patients faced outside of the hospital—losing their jobs, homes, their families—we had to be case

managers and patient advocates.” The other founding doctor also acknowledges that other clinics often refused to treat people with HIV/AIDS, remarking that they found themselves “taking care of our own people, our community that desperately needed care” (Czerwiec 26). The origin story of Unit 371 corresponds with Douglas Crimp’s testimony of the HIV/AIDS epidemic: “Every public agency whose job it is to combat the epidemic has been slow to act, failed entirely, or been deliberately counterproductive. We have therefore had to provide our own centers for support, care, and education and even to fund and conduct our own treatment research” (146). Far from subverting the ideology of cure, Czerwiec’s work reminds us that advocating for cure can itself constitute a caretaking endeavor. While in some cases pursuing cure can symbolize a devaluation of a stigmatized group (for example, people with autism or severe cognitive disabilities), in other cases pursuing cure for a stigmatized group represents a step toward equitable medical treatment. Cure in the context of the HIV/AIDS crisis indicates larger cultural assumptions about whose lives are worth saving.

Czerwiec’s graphic memoir goes on to complicate the assumption that the arrival of effective HIV/AIDS treatments constituted a resolution to the epidemic. In this sense, although the text’s gradual conclusion acknowledges medical progress, it successfully evades what Frank calls the “restitution narrative” and leaves space for more nuanced readings of cure. The narrator says, “And then hope arrived,” going on to portray a doctor describing Highly Active Anti-Retroviral Therapy (H.A.A.R.T.) and colorful illustrations

of individuals' improved health (Czerwiec 146-149). These are quickly followed, however, by the closing of Unit 371 (Czerwiec 164), the sense of feeling “miserable and ashamed for

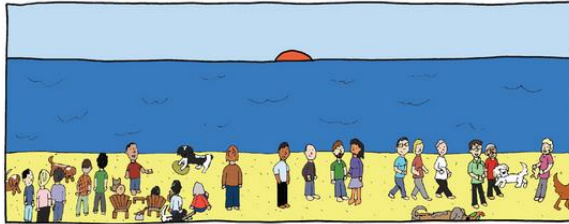


Fig. 5. Daytime celebration on the beach from MK Czerwiec; *Taking Turns: Stories from HIV/AIDS Care Unit 371*; Penn. State UP, 2017, pp. 201.

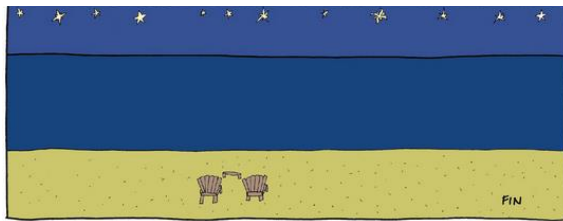


Fig. 6. Stargazing on the beach from MK Czerwiec; *Taking Turns: Stories from HIV/AIDS Care Unit 371*; Penn. State UP, 2017, pp. 202.

feeling miserable” (Czerwiec 165), and, finally, a colorful daytime celebration on the beach followed by a star-filled sky at night (see figs. 5 and 6). The stars represent each of the lives lost to HIV/AIDS and the narrator’s process of grieving their losses through art. The emerging HIV/AIDS treatments of the late ‘90s did not “cure” the virus, and the juxtaposed images of hope and grief that comprise the final pages of

Taking Turns unsettle any impulse to consider the epidemic truly over. The text has taught the reader at this point to understand cure as more than a medical phenomenon, such that the arrival of medical treatment alone does not itself constitute a cure for the epidemic.

By resisting a fully celebratory conclusion, I argue that, *Taking Turns* also troubles any assumption that achieving cure concludes the care process. Mary Jane Nealon evokes this sense in her memoir *Beautiful Unbroken* (2011) when she narrates suspicion surrounding HIV/AIDS medications. She writes, “These were the sons and grandsons of the Tuskegee experiment, in which black men were purposely untreated for syphilis so clinicians could watch what happened as the disease attacked their brains and nervous systems (Nealon 163). Just as Czerwiec’s graphic memoir works to articulate the broader

national failure to care that necessitated the emergence of Unit 371, so too does Nealon's text reference a particularly poignant failure of medical intervention to demonstrate the long-lasting effects of such breaches of care, effects which extend far beyond medicine's capacity to cure a given disease or virus.

Even today, 44% of all new HIV cases are Black people and 21% are Hispanic people. Meanwhile, Black people with HIV are less likely to receive antiretroviral therapy, and Hispanic people are twice as likely to die while hospitalized for HIV-related illnesses than white people (Brummer et al. 13). While Czerwiec's conclusion celebrates emerging treatments for HIV/AIDS, it also leaves space to honor the ongoing work we need to do to achieve equity of care for those most impacted by the virus. Crimp argues that we must grieve the lives lost to HIV/AIDS, manage ongoing homophobic hatred, and acknowledge the "simple and horrible fact, rarely given voice, that all of us will almost certainly live with AIDS for the remainder of our lives, however long that may be" (267). The possibilities rendered by Czerwiec's nuanced depiction of cure extend beyond the pages of the book itself, asking us to recognize cure, including medicine's lack of curative efforts, as a social phenomenon warranting ongoing attention.

CONCLUSION: HONORING THE COMPLEXITIES OF CURE

Perhaps I am taking a page from Czerwiec's book, then, by resisting a conclusion to this conversation about the nature of cure and its relationship to care. After all, the texts included in this discussion resist providing straightforward answers as to how the ideology of cure should factor into considerations of care ethics. If anything, each of the texts asks

us in different ways to continue asking questions, working to unsettle both generalizations about the nature of care and beliefs about the sovereignty of cure which remain deeply entrenched in Western medical cultures.

Of the conclusions one can draw by comparing the above nursing memoirs, perhaps the most prominent is that we would do well to recognize that care interventions taking place in absence of cure are valid and valuable forms of caring labor, often demanding creativity and flexibility from caregivers. We should recognize, too, that a failure to cure can constitute a breach of care—but so, too, can an unmooring from cure represent a step toward meaningful relationships, as Wehr’s memoir reminds us.

Ultimately, *Taking Turns* and *Peaceful Passages* work together to suggest that an ethics of care that centers disability should recognize the complexities of cure and the many forms of uneasy relationships one might have with it. They also make clear that care informed by disability studies and feminist care ethics should redefine cure not as the exclusive or even most valuable objective of medical caretaking, but instead as one variable that can be brought to bear upon care encounters as appropriate.

As both *Taking Turns* and *Peaceful Passages* make clear, questions about cure are intricately tied to notions of value and worth: In some ways, the pursuit of cure can depend upon which groups are deemed worthy of saving. In another sense, ideologies of cure can also mark some bodies as deviant or in need of normalizing. This theme of value will carry over substantially into the next chapter, which focuses on ideas of dependence and reciprocity in caretaking encounters. I will continue my assessment of disability-centered care ethics in additional nurse memoirs, primarily *Critical Care* by Theresa Brown and

Beautiful Unbroken by Mary Jane Nealon. Chapter Two will ask: How do these memoirs conceptualize and evaluate the inevitability of dependence within caretaking relationships? To what degree do their narrators portray themselves as proponents of independence? What role, if any, does reciprocity play in each memoir's theorization of care? As with Chapter One, I will continue drawing heavily from scholars of disability and feminist care ethics, using insights from both fields to consider how we should pursue the discourse of dependency in an ethics of care oriented toward disability justice.

Chapter Two: Interdependence and Reciprocity in Clinical Spaces

In the final chapter of the book *Disability and Difference in Global Contexts* (2011), Nirmala Erevelles demonstrates that people with disabilities are prevented from claiming full citizenship status in part because of “their perceived lack of autonomy on account of their dependence on their caregivers (paid and/or unpaid) for the social reproduction of their lives” (173). She goes on to suggest that it is not a disabled person’s relationship to dependence that must change but instead our cultural insistence that independence is an inherently superior state of being. Erevelles arrives at a question that informs the impetus of this chapter: “Does the caring relationship always have to produce inequality?” (175).

This chapter explores the above question posed by Erevelles, mining a selection of nurse memoirs for evidence of the narrators’ engagement with ideologies of dependence in the care encounters they depict. The primary autobiographical texts I will consider include Laura DeVaney’s “Becoming A Nurse,” Mary Jane Nealon’s *Beautiful Unbroken: One Nurse’s Life* and Theresa Brown’s *Critical Care: A New Nurse Faces Death, Life, and Everything in Between*. My analysis will address the following questions: How do these texts respond to the inevitability of dependence within a caretaking relationship? What role, if any, does reciprocity play in each nurse writer’s theorization of care? Ultimately, I will show that these texts do not fully embrace interdependence; instead, their ambivalence about it allows us to understand the practical barriers to enacting interdependence frameworks in clinical spaces.

One such barrier to embracing interdependence is both practical and largely unspoken: ideologies of whiteness, around which our national healthcare system, including

the nursing profession, was constructed.⁶ As I noted in the Introduction, the sub-genre of published nurse memoirs is populated mostly by white women. Each of the memoirs in this chapter illustrates an ambivalent relationship with interdependence, such that an analysis of these texts can bring us to understand an investment in the institution of whiteness itself as a barrier to valuing interdependence. As Ismalia De Sousa and Colleen Varcoe write,

Individualistic and egalitarian values that favor self-improvement also protect whiteness [...] and trust that every humxn is equipped with the same tools for success. Consequently, failing to succeed is wrongfully attributed to individual inadequacy [...] rather than society's sociopolitical structures. (4)

This chapter therefore understands independence and whiteness as entangled—conceptually, historically, and practically—and playing out in the structures and cultural beliefs that De Sousa and Varcoe describe. This understanding means that a subject's investment in independence can be read as buying in to a culture dominated by white ideologies—and vice-versa. To clarify, this is not to say that ideologies of whiteness and independence are synonymous with one another; instead, I wish to recognize each of them as social inventions that (a) have real-world and often deleterious consequences, and (b) inform one another in meaningful ways.

The term “whiteness” in this context is intended to evoke what Micah Del Rosario describes as “the more indirect, inconspicuous ways in which white people enact their racial identities” (712). The memoirs under analysis in this chapter do not incorporate a

⁶ Patricia D'Antonio historicizes the nursing profession as it arose in the United States, specifically attending to the racial segregation of nursing education and practice as the profession developed in the American South. In 1961, the Georgia State Nurses Association became the last state association to desegregate, after threats of expulsion from the American Nurses Association (D'Antonio 130).

noticeable degree of self-consciousness pertaining to forms of privilege at work in their pages. Yet an understanding of how interdependence functions in clinical nursing contexts demands a layer of interrogation pertaining to racial identity and white privilege. In Carole Schroeder and Robin DiAngelo's definition of whiteness, they write,

Whiteness is both "empty," in that it is normalized and thus typically unmarked, and content laden or "full," in that it generates norms and reference points, ways of conceptualizing the world [...] This definition counters the dominant representation of racism [...] as discreet incidents that some individuals may or may not "do," and goes beyond naming specific privileges. (245)

Therefore, while the white identities of our nurse narrators may frequently be left "unmarked" in the texts themselves, my analyses will attempt to draw out the privileges and racial positions informing their relationship to interdependence—including markers of class and professional status, which are themselves impossible to disentangle from race.

This attempt to incorporate an examination of race within my analysis of disability and care ethics is a response to the fact that both areas of scholarship remain largely centered around white experiences. As Sami Schalk and Jina B. Kim argue, "integrating race into feminist disability studies [should be] generative and broadening, [...] not limit our sites of analysis to disabled women of color nor preclude substantive engagement with sexuality, class, or other vectors of power" (37). This chapter continues to theorize the emergence of a disability-centered ethics of care with particular attention to pertinent "vectors of power" informing care encounters. By considering the often violent and precarious experiences informing the relationships that many disabled people have with healthcare institutions, we can more responsibly interrogate the promises and pitfalls of interdependence frameworks forwarded by mainstream feminist care ethicists. In the

following section, I will introduce feminist care ethicists whose work informs my analysis of the nurse memoirs in this chapter. I will also lay the foundation for one aspiration of this chapter, which is to respond to and employ the theories of feminist care ethics in a way that simultaneously centers disability and examines whiteness.

DEPENDENCE AND RECIPROCITY IN FEMINIST CARE ETHICS

The feminist care ethicists included in this section seek to unsettle the presumed value of independence, but it's worth foregrounding their work with an understanding that the myth of independence as it exists in the United States is informed by white, Western ideologies. Audrey Thompson critiques the field of feminist care ethics for centering a "liberal White feminist perspective" (526) and failing to account for "the cultural specificity of what counts as caring" (527). As an example of this, she explains that although white feminists seek to unsettle the myth of independence, "[...] the work of caring in the Black community has never been solely the job of the family; it has been shared by the Black church, by extended and fictive kin, and by the Black community at large" (Thompson 532). Thompson's critique helps to identify the elements of white feminist theories of care that lack cultural specificity, thereby limiting their impact.

Given that my primary materials are written by white nurses, I find it useful to continue with an overview of how white feminist care ethics seeks to unsettle the myth of independence as a means of understanding these memoirs' ambivalent relationships to interdependence. I am including scholars in this section with an eye toward Thompson's critique: I understand these scholars to be both subverting the ideology of independence

and, as Thompson argues, failing to acknowledge or explicitly locate the racial dimensions of the independence myth. In turn, this oversight means that white feminist care ethicists neglect to identify some of the practical constraints created by the continued domination of such an ideology in clinical spaces.

Feminist care ethics urges us to recognize that human independence is a myth; these scholars recognize that dependence is an integral, inescapable element of our shared humanity. To these ends, Nel Noddings writes about “our fundamental relatedness, of our dependence upon each other” (49). Eva Feder Kittay, too, states that all humans move in and out of various states of dependency, such that requiring assistance is not the exception we might like to think it is but instead the norm. Kittay writes, “From this perspective, we reason that our societies should be structured to accommodate inevitable dependency within a dignified, flourishing life—both for the cared for, and for the carer” (“The Ethics of Care” 54). In many of these formulations, recognizing and acknowledging our inherent dependencies and interrelatedness is the first step toward a new framework of interdependence, where dependency is not a state one must strive to escape but instead a relationship or set of relations to be celebrated. In Joan Tronto’s words, “We will need to rethink our conceptions of human nature to shift from the dilemma of autonomy or dependency to a more sophisticated sense of human interdependence” (101).

Feminist care ethicists go on to note that our collective failure to honor our interdependence has material consequences, both for those seeking care and those providing it. According to Tronto, “[...] our desire not to be unequal and dependent results in a treatment of those who need care as inherently different and unequal” (145). In an

articulation of Kittay's "dependency critique," Rachel Adams adds that the stigma of dependency has important implications for those performing care work: "[...] as long as the bounds of justice are drawn within reciprocal relations among free and equal persons, dependents will continue to remain disenfranchised, and dependency workers [...] will continue to share varying degrees of the dependents' disenfranchisement" (41).

Feminist care ethicists position their framework of interdependence as an alternative to both the stigma of dependence and the celebration of autonomy. While movements toward independence have constituted important milestones in the disability justice arena, Adams notes that "[...] more recently, critics have observed that the emphasis on independence and productivity within the mainstream disability rights movement excludes those who are unable to represent themselves" (41). Kittay, too, writes in the preface to *Love's Labors: Essays on Women, Equality and Dependency* (2020) that she seeks to cut through the fiction of independence (xii), and writes in an earlier (2011) article, "I believe there is much that is problematic in an approach that extols independence as the route to a dignified life and sees dependence as a denigration of the person. I worry that the emphasis on independence extols an idealization that is a mere fiction [...]" ("The Ethics of Care" 57).

Yet embracing dependence comes with its own challenges, which Erevelles distills in her question: "Does the caring relationship always have to produce inequality?" (175). Many scholars have postulated reciprocity as a solution. Perhaps most prominently, Noddings argues that there is always some form of reciprocity in caring (74), which can include everything from a direct response to the care recipient's "happy growth" (74). For

Noddings, simply witnessing the improvement of someone we care about is a gift of reciprocity (24).⁷ More recent examples include Robert Stake and Merel Visse, who theorize that “suffering generates reciprocity” in that witnessing another’s suffering protects us from self-centeredness: when we think about how to help another, we are also helping ourselves (75). In a similar manner, Arthur Frank writes that asymmetry in care relationships is alleviated when “one who suffers has something to teach [...] and thus has something to give” (150). These various forms of reciprocity might be considered versions of what Kittay calls “exchange reciprocity,” or the idea that “[...] efforts I exert on your behalf will be met by some equivalent exertion on your part, immediately, at some specified time in the future, or when the need arises” (*Love’s Labors* 72). For many of these scholars, reciprocity is a solution to concerns about inequality: with reciprocity, a person in a state of dependence always has something to give.

While forms of exchange reciprocity are perhaps the most discussed in contexts of care, Kittay’s theorization of connection-based reciprocity will be significant principle for the analyses taking place in this chapter. Connection-based reciprocity relies upon social connections: it is not necessarily the recipient of care who is called upon to reciprocate, but instead members of the community to which the caretaker and care recipient belong. In Kittay’s words, “A connection-based equality calls upon those within the nested set of

⁷ Noddings’ theory of reciprocity tends to garner criticism. Fisher and Tronto argue that Noddings does not account for “the fact that caring is often difficult, unpleasant, collective work,” thereby ignoring “both power relations and the material conditions necessary for caring” (37). Sarah Lucia Hoagland argues against “the promotion of infant non-reciprocity-beyond-acknowledgement as a model for ethically relating to others” (110).

social relations to support the dependency worker sufficiently, so that she is not made unduly vulnerable as she answers to the vulnerability of another” (*Love’s Labors* 75). In contexts of professional nursing, we might think about how institutions function as the part of the community called upon to reciprocate for a caretaker’s labor. When a nurse is called to care for someone, we expect reciprocity to take place in the form of a paycheck, health care and other insurance benefits, professional support, and so forth. While this institutional framework may not exactly parallel the connection-based reciprocity Kittay describes, I imagine all of these examples as iterations of reciprocity performed by an entity other than the recipient of care.

Recent scholarship from disability studies and feminist care ethics suggests a need to move away from both the stigma associated with dependency and from the exclusionary pursuit of independence. Moreover, an emphasis upon celebrating interdependence comes with the collective, cultural task of imagining the ideal forms of reciprocity that might take place in an interconnected, interdependent world. Considering the potentials of interdependence between givers and receivers of care in a medical context also requires addressing how these oppressive systems preclude many recipients of care from comfortably and safely operating within the frameworks of interdependence. In what follows, I will use the above scholarly discussions of dependence and reciprocity to assess several nurse narrators’ ambivalent stances toward the idea of interdependence. The close readings I perform attend specifically to the implications of each narrator’s conception of dependence, discussing the relationship between dependence and racial privilege where appropriate, as a means of further theorizing a disability-centered care ethics.

EXTOLLING INDEPENDENCE: DeVANEY'S "BECOMING A NURSE"

"Becoming a Nurse" (2013) is a short essay about a nurse's interactions in a postoperative cancer unit. It becomes clear early on, as the narrator attempts to teach Debby how to suction her husband Jim's airway, that this essay is thematically invested in questions of dependence. As I will demonstrate, DeVaney's narrator intentionally and self-consciously exudes a tough exterior toward care recipients as a means of facilitating their autonomy. However, readers can recognize this narrator's belief in autonomy as a fear response to the inevitability of dependence. Ultimately, I argue that "Becoming a Nurse" depicts but does not fully explore the nurse speaker's fear of dependence, thereby opting away from recognizing the possibilities for care that might become available by embracing interdependence.

Much like Eddie Lucken's essay "Hitting the Bone," which I analyze in Chapter Three, DeVaney's "Becoming a Nurse" creates an antagonist out of its main narrator. However, where I interpret Lucken's antagonist nurse as a vessel for the speaker's apology, DeVaney's narrator is more a vessel for the essay's extolment of independence. For example, when Debby asks the nurse narrator what brought her to her current profession, the speaker discloses that the reason for her current nursing role is merely the lack of job openings in labor and delivery:

So here I am on this postoperative unit, working with cancer patients who have had disfiguring and life-altering surgeries. My patients have had their eyes, tongues, ears, and noses surgically removed. They're real-life Mr. Potato Heads, a piece always missing [...] Instead of holding hands and instructing my patients to push, I'm pushing them to be independent, to let go of my hand. (DeVaney 48)

While many feminist care ethicists draw from examples of motherhood to theorize dependency (for example, Noddings, Kittay, and Sarah Ruddick), DeVaney's narrator pointedly eschews any maternal connection with those on her cancer ward that she imagines having with a baby, "pink and soft and new" (DeVaney 48). Instead, the harsh language of disfigurement she directs toward her current care recipients suggests resentment. This narrator appears to assume that laboring mothers and newborn infants are the only ones whose dependence is excused.

In the above excerpt and in much of the essay more generally the narrator's tone remains dry, biting, and uncaring. This choice of narrative tone mimics that which the nurse uses with her care recipients. Two important truths regarding the nurse's in-scene and narrative tone become clear as one progresses through the essay: First, the nurse's performance of a hardened exterior is intentional and something she claims to have adopted over time. Second, she views her terse disposition as a means of facilitating a primary goal she has for the subjects of her care: their eventual autonomy.

The nurse's harsh tone as an intentional and strategic decision is clear in her interactions with Debby and Jim. In trying to help Debby learn to suction Jim's airway so that he can be sent home, she has little patience for Debby's hesitance: "I know her type. She'll talk for minutes, stalling, if I allow her" (DeVaney 48). When Debby reluctantly takes the suction tube into her hand, the nurse begins by guiding Debby's hand with her own, promising her support while letting the reader in on a secret: "The part I leave out is that I'm going to let go, like a first ride without training wheels. Tough love. It's the only way" (DeVaney 49). This scene extends the primary metaphor of the essay, where

handholding represents dependence more generally. The nurse narrator's literal letting go of Debby's hand symbolizes her larger commitment to the goal of autonomy. While Debby is not the one in the hospital bed (her husband Jim is the unfortunate target of the suction tube, and the nurse makes clear that he will be learning to suction his own airway soon enough) she is one of the subjects of the nurse's care—or lack thereof. The narrator's explanation of her own behavior situates her forceful, impatient attitude as a means of getting Debby to stop stalling—"tough love" she calls it. And her approach does, in fact, work: Debby suctions Jim's airway for the first time on her own.

For all practical purposes, the nurse's tough love appears to accomplish the task. Yet the violence required of such an approach deserves pause: is tough love really the only way? When read alongside feminist care ethics and disability theory, this scene provokes important questions: Focused exclusively on what she perceives as the necessity of autonomy, what opportunities for care does this nurse narrator miss? If she had afforded Debby those few minutes of stalling—just a moment of extended dependence—could this care encounter have lessened its grasp on the presumed ideal of autonomy in favor of a less violent chance to learn?

As the essay progresses, it becomes clear that at its crux lies the narrator's distinct fear of dependence, especially the dependence wrought by illness, disability, and aging. The essay suggests that this speaker's apparent intolerance for the objects of her care (disfigured, dependent adults) along with her romanticization of maternity nursing (laboring women, helpless newborn babies) is fueled by an entrenched ableism and fear of aging of which the narrator herself appears to be aware. We see this dynamic come through

in the passages where the narrator compares her current job to her would-be job delivering babies, and we can also observe it in how she depicts her interactions with Roger. Like Debby, Roger is in the hospital caring for his spouse. He, too, had to learn to suction his spouse's airway. However, unlike Debby's spouse, Roger's does not appear to be recovering after surgery; unlike Debby, the nurse narrator considers Roger to be "my true patient" (DeVaney 51).

In scenes with Roger, the narrating nurse's character transforms from a hard, uncaring presence to a sympathetic, generous caretaker. She fetches juice for Roger, tries to pick up the straw when Roger drops it, and asks him about his life. This shift is also made explicit by the speaker: "Roger [...] has worn a soft spot in my heart. For him, I am human" (DeVaney 51). Like many of the nurse's actions in the narrative, her behavior with Roger is motivated by fear: "I pity Roger, yes, but equal to that—or perhaps more so—I fear becoming him" (DeVaney 52). This excerpt functions as evidence that at least some of the ableism depicted in the essay is self-conscious. The narrator is put off both by Roger's age and by what she perceives as his helplessness in the face of his wife's illness and his dependence upon what little medicine can do to help. All these states of being are what the narrator fears and pities.

While I have thus far been critiquing this narrator's apparent fear of dependence, I want to complicate my analysis by acknowledging the material factors at play within this context that make a full embrace of interdependence difficult (if not impossible) both for the nurse and for the recipients of care. For example, the narrator alludes to visitors being discharged from the hospital with little-to-no at-home support: "I really wish we could

take you home!’ Debby’s voice bursts with longing. I stifle a laugh. She’s not the first to request my services as a medical butler” (DeVaney 49). This minor moment invites us to consider the material realities that may inform the speaker’s urgent push toward independence. This system of care means that hospital visitors have access to professional help only temporarily. In other words, the medical system is built on a premise of finite interactions and relationships, where extended professional help is either scarce, expensive, or both. In such unforgiving contexts, the ideal vision of rich, interdependent care relations seems far from reality.

That being said, my initial argument regarding this narrator’s unwillingness to conceptualize dependence as something other than childish and immature holds in the above example. The speaker’s initial instinct is to laugh at Debby’s longing for support and to suggest that care providers who extend care beyond the walls of the institution are merely indulging the whims of the care recipient. This is also where the speaker’s investment in whiteness comes into play: the notion that Debby’s husband needs to work toward independence and that any care outside of the institution will take place in the nuclear home and without community intervention demonstrates such an investment. Moreover, the speaker regards in-home health aides as “medical butlers,” further denigrating a portion of the care labor force that is consistently characterized by low wages and largely (more than 50%) comprised of people of color (“U.S. Home Care” 3-5). All this in mind, it is impossible to disentangle the nurse speaker’s suspicion of dependence from the white hegemonic contexts in which she works.

To continue complicating this analysis further, the fear provoked by the hospital nurse imagining her own dependence may be a rational response. As I have argued, this speaker explicitly represents and names her fear, but does not explore it more deeply. However, an analysis informed by this nurse's institutional context can recognize that the most evident form of reciprocity offered to a professional nurse—that is, financial compensation—does not always offer leeway for her own dependence needs. As Theresa Brown writes in her memoir *Critical Care*, “Our bodies get us from point A to point B, and a floor nurse spends her entire day moving from point to point. A crippled RN cannot work in a hospital as a nurse” (58). For the care provider, experiencing dependence can mean losing a job. Given these considerations, emphasizing independence is rational and understandable.

In Chapter Three I argue that Brown's memoir identifies ableism at play in her profession and in her culture more generally but does not adequately circumvent or critique it. We see the same issue here as well: not only does Brown's speaker fail to confront the ableism of her profession as something that could change, but the speaker also doubles down by casually employing the derogatory word “cripple.” DeVaney's speaker also seems to embrace the latent ableism within the hospital and within the broader culture, failing to recognize that such ideologies have been constructed and can therefore be deconstructed. The effect of this is a sort of residue created by the text, where a fear of dependency is legitimated by an ableist institution, but that ableism is left unchecked and made to seem legitimate.

THEORIZING RECIPROCITY: NEALON'S *BEAUTIFUL UNBROKEN*

Mary Jane Nealon's memoir *Beautiful Unbroken: One Nurse's Life* (2011) chronicles the narrator's experiences as a travel nurse in various professional caretaking scenarios. The text is part coming-of-age, including reflections on the speaker's childhood and nursing career. Part of this personal development includes a portrayal of her narrator's shift in mindset regarding dependence: The nurse speaker's view of dependence begins with the assumption that others' dependence facilitates her superiority. By the end of the memoir, she hasn't experienced others' dependence so much as she has experienced interdependence: those for whom she has cared have given her a privileged level of knowledge and an identity. In this sense, Nealon's memoir makes concrete some of the theories of interdependence and reciprocity described by feminist care ethicists such as Kittay and Tronto.

By portraying her childhood interest in nursing, the narrator demonstrates that her younger self extols the idea of being a person on whom others depend. For her young self, there is glory to be had in martyrdom. The speaker emphasizes her initial views of nursing by referencing the books she read as a child—books about “Kateri Tekakwitha, Indian saint. Clara Barton, founder of the American Red Cross. Molly Pitcher, who walked among Revolutionary War soldiers with water jugs and wiped their fevered brows” (Nealon 12). She specifically remembers “the hard yellow of the Tekakwitha book,” writing:

I practiced her caring gestures under my sheet, pretending it was a teepee, laying a hand on an imaginary sufferer. The sufferer with parched and cracked lips surrounded by pox lesions, who smiled up at me, the only one able to take their pain away. (Nealon 12)

Many of the books her younger self reads epitomize nursing as a site of feminine selflessness and sacrifice. Her fascination seems to stem not only from the heroism of these famous figures, but from the imagined scenario of being “the only one” who can help the sufferer. There is also a quality of religious zeal taking place in these recollections: the laying on of hands to revive others positions her as the special chosen one sent to perform healing miracles for the masses. In addition, the speaker’s whiteness is prevalent in this passage where she imagines herself in a teepee, apparently projecting a racialized exoticism upon the experience even while enacting a white projection of superiority and heroism.

The narrator’s departure from being delighted at the thought of others depending upon her takes place gradually as one progresses through the text. Part of the shift away from the imagined heroics of nursing takes place with the illness and subsequent death of her brother, at which point the speaker begins to ruminate upon “My inadequate white shoes, my inadequate hands” (Nealon 20-21). The shift also takes place as she encounters additional crises such as 9/11: “I had to look in the mirror day after day knowing that despite a life of wanting to be a saint, of wanting to be a nurse-detective, of wanting to be a hero [...] I had done nothing” (Nealon 201-202). At one point, her narrator works briefly in an emergency room; in a wry tone, she writes, “I hated the ER job. All the drunks and attempted suicides. The knife wounds, the car wrecks. I didn’t have time to minister, to practice my sainthood” (Nealon 107). This moment critiques her past self for nurturing a belief in her own sainthood. The passage is infused with a slight sarcasm, and the explicitness of her rationale for disliking the ER environment pokes fun at what her present-moment narrator sees as her own past naïveté.

By the end of the text, the speaker has not experienced the type of glory she imagined as a child; however, her narrator no longer feels as if her failed sainthood is truly a failure. Instead of sensing a lack, she realizes that her childhood vision of dependency was misinformed. The transformation of her views on dependency is marked by her sense that it is really she who is the benefactor of her own nursing efforts. In other words, she goes from valuing others' dependency as a way of manifesting her own superiority to prioritizing and honoring the ways interdependency has improved her life. One of the ways we can observe interdependency functioning for this narrator is in her understanding that nursing "helped me become the person I most wanted to be. It wasn't my identity as a writer that solidified in that second year [in her writing fellowship], it was my identity as a healer" (Nealon 160). As this moment demonstrates, it is the speaker's time away from nursing that solidifies just how much she depends upon care recipients for her own sense of self. Whereas at one time she may have envisioned sacrificing herself for another's survival, this new version understands that working as a caretaker has facilitated a deeper knowledge of herself.

In addition to the insights about herself that she has gained, interdependency also emerges in Nealon's text in the speaker's eventual stance that she has gained a privileged level of knowledge about the body and about life through her work as a nurse. The speaker marks this transformation quite explicitly toward the end of the text:

I had begun my life with the dream of a few women: Kateri Tekakwitha, Clara Barton, Molly Pitcher. I saw myself in a painting and I was cradling the head of a suffering man or woman. Now I was middle-aged and I had finally fulfilled the dream. I wasn't a saint, but I had been blessed to meet so many who were suffering that the body had finally delivered all the lessons it held. (Nealon 199)

Most striking about this passage is that the narrator appears to finally embrace not having become a hero, saint, or martyr and she does so without conveying a sense of disappointment or failure. She realizes that she hasn't failed in her goal of becoming like the women she'd read about as a child: she had succeeded in "cradling the head of a suffering man or woman." It is not the content of nursing that has changed in her experiences but instead her expectations of reciprocity. Instead of being rewarded for her efforts with fame and the sort of immortality that her nursing heroes have achieved, she is rewarded with the lessons taught by many suffering bodies. The narrator thus depicts herself coming to understand and accept the forms of reciprocity offered in response to her caretaking. In this sense, the text as a whole supports and provides evidence for the value of interdependence theorized in the work of disability scholars and feminist care ethicists.

But Nealon's memoir also leaves space to consider that her narrator's embrace of reciprocity and interdependence by the end of the text is informed by the relative privileges afforded to this speaker who appears to live comfortably within her means as a professional nurse. The narrator leaves clues throughout that suggest she is adequately compensated for her nursing. For example, she gets a job at the cancer center where her brother is being treated, which "came with an apartment, so I got to be across the street from the center" (Nealon 34). At one point she appears to be juggling financial choices, but this is framed as a positive opportunity rather than a burden:

My sister allowed me to move into her apartment in Jersey City so I could save money for the upcoming fellowship year [...] My senses were heightened by my happiness, by the smells of the ethnic restaurants, an urban garden: Ethiopian, Italian, Japanese. Was the world this beautiful all along? (Nealon 155)

I am not suggesting that this speaker hasn't invested time and effort into her caretaking practices and is benefitting unduly from the systems of exchange taking place. Instead, I'm arguing that any analysis of dependency relations—and particularly one invested in the potentials of disability-centered care—needs to consider the raced, gendered, classed, and other embodied configurations of its participants. The forms of reciprocity that Nealon's speaker comes to recognize (namely, her growing knowledge of herself and of human bodies) are only ever adequate in care contexts absent of violence and exploitation. In other words, the exchange reciprocity that Nealon's narrator comes to appreciate is made plausible because of other (largely unspoken) forms of connection-based reciprocity⁸—for example, an adequate paycheck, safe working conditions, and so forth.

The speaker in Nealon's memoir certainly experiences traumas—above all, those brought about by the deaths of her brother and others for whom she has cared. Fortunately, though, the memoir does not leave readers with a sense of her having experienced the trauma of financial hardship or threats to her physical safety. The current wellness of nurses in the United States, however, is such that only 25% report being in good physical health, 75.8% have high levels of perceived stress, and 65.5% are experiencing burnout—all of which is exacerbated by the ongoing Covid-19 pandemic (Mazurek Melnyk et al. 15). All of this is to say that Nealon's narrative supports and makes concrete the theories of interdependence and reciprocity forwarded by feminist care ethicists—but that it does so under a specific context in which her other high-level needs are being met.

⁸ Here I use the definitions of exchange and connection-based reciprocity derived from Kittay's *Love's Labors* (72) and developed on pp. 69 of this chapter.

BARRIERS TO INTERDEPENDENCE: BROWN'S *CRITICAL CARE*

Theresa Brown's *Critical Care: A New Nurse Faces Death, Life, and Everything In Between* (2010) gives us a complex depiction of dependency. On the one hand, the speaker describes encounters that provide evidence supporting Held's and Kittay's stances that inequality of power need not always amount to domination. On the other hand, Brown's narrator articulates a resistance toward becoming dependent herself. However, instead of indicating that this narrator believes there is something "wrong" with inhabiting a space of dependence, I argue that this discrepancy in attitude indicates the narrator's distrust of the healthcare system's treatment of disabled people. Ultimately, I argue that Brown's memoir helps complicate the viability of truly embracing interdependence. This is not to say that the idea of interdependence itself is flawed, but that its viability within institutions that are and/or have been violent is dubious.

Kittay and Held each distinguish between forms of dependency that are compatible with ethical care and dependency relationships that contain and/or facilitate violence. Kittay writes,

The inequality of power is endemic to dependency relations. Domination involves the exercise of power over another against her best interests and for purposes that have no moral legitimacy [...] Inequality of power is compatible with both justice and caring, if the relationship does not become a relation of domination. (*Love's Labors* 38-39)

Much of the care work performed by Brown's narrator appears to support and illustrate this view of ethical caring without domination. With Kittay's argument in mind, I suggest that a caretaker's conscious and careful negotiation of authority is an essential component of an ethics of care that centers disability.

Brown's memoir depicts scenes of care in which we can recognize this conscious negotiation of authority taking place. For example, her speaker subordinates herself to a man receiving treatment for cancer by insisting to the reader that "he knew more about his diagnoses and prognosis than I did," even though she was administering his chemotherapy (Brown, *Critical Care* 170). She also depicts herself responding more appropriately than the other nurses to Abraham—a "difficult patient":

Due to our general inexperience [...] Abraham thought most of us were fools. Maybe I didn't mind him as much as some of the other nurses because I myself felt pretty ignorant about wounds and dressings. I didn't mind going slowly and listening to his advice. (Brown, *Critical Care* 101)

In both examples, Brown's narrator appears comfortable ceding authority to care recipients. While in many cases disabled people are denied the authority of knowledge they have about their own bodies, Brown's narrator provides examples of a caretaker negotiating with recipients of care and taking measures to balance the power dynamics of her relationships.⁹ In this sense, *Critical Care* nuances notions of dependence relations by suggesting that individual, context-based shifts in dynamics can be at play within a given care encounter.

⁹ To avoid over-simplifying this analysis of authority, I will note that authority in care relationships is often complex, and dependence is not necessarily one-sided. Kittay's work in particular attends to these complexities: "To the extent that the dependency worker is vulnerable to the actions of the charge, the charge is obliged to behave in ways that address those vulnerabilities. Not only is the charge vulnerable to the actions of the dependency worker, but the dependency worker may also be vulnerable to the actions of the charge" (*Love's Labor* 70).

However, Brown's memoir complicates the viability of interdependence as forwarded by mainstream feminist care ethicists through her speaker's distrust of healthcare institutions more generally. By illustrating her own experiences seeking care at the hospital where she works, the speaker draws attention to some of the many pitfalls in the American healthcare system that make embracing interdependence without ambivalence a nearly impossible task, despite its theoretical promise. When Brown's speaker injures herself in a fall, the narrative takes a turn toward exploring the experience of a caretaker-turned-care-recipient, a common trope of healthcare memoirs. Her initial reaction to her injury and sudden disability status is one of denial and embarrassment: "As a last resort I knew I could call an ambulance, a solution I found deeply embarrassing: as a nurse I take care of people who arrive in ambulances; I shouldn't need one for myself" (Brown, *Critical Care* 43). The embarrassment Brown's speaker reports at suddenly finding herself in need of help appears to be informed by implicit ableism. The sentiment of this passage might be read as evidence of the speaker's sense of superiority as someone on whom others depend, not someone who believes there is value to be had in changing roles and relying upon others.

The text soon indicates, however, that in addition to being informed by her own ableist beliefs, the speaker's begrudging attitude toward becoming dependent also has to do with a lack of trust in the healthcare system and perhaps some of the people working within it. This lack of trust is evident in her sense that she will be better cared for if she leverages her status at the hospital. She writes, "Because I'm a nurse, I know that whatever you can use to your advantage to get good care in a hospital should be used" (Brown,

Critical Care 45). The text contains several passages concerned with being treated “like a ‘civilian’ instead of someone in the know” (Brown, *Critical Care* 46), not necessarily because she believes she’s more important than others seeking care but because her experiences have shown her that the average hospital visitor may not necessarily receive good care. Her use of the second person in these sentences creates an effect of reading how-to instructions for leveraging quality care in an insufficiently caring system, a sentiment that is disconcerting coming from a nurse being treated at the hospital where she works. A major problem with mainstream theories of dependence comes to the fore here: the speaker can negotiate adequate care even in her dependent state, based solely on her privileges as a fellow care worker. Most seeking care do not have access to these same privileges, and some are treated in ways that do not resemble care at all based upon any number of overlapping factors, not the least of which may include disability, race, gender, class, and so forth.¹⁰

Among the passages communicating this speaker’s sobering expectations and experiences seeking care at her hospital is her encounter with Dr. X, who represents both the ableism in healthcare and the system’s inattention toward care ethics more generally. Brown’s speaker writes that she had to take the “wise-ass approach” (*Critical Care* 47) to Dr. X, asserting herself more aggressively than she otherwise might to get what she needs. Upon leaving the hospital on her new crutches she writes, “When Dr. X told me I looked

¹⁰ Numerous studies demonstrate the less-than-adequate care that some receive in traditional healthcare institutions. Some examples include: Clinical microaggressions, such as deadnaming and/or misgendering a transgender and/or gender non-conforming person (Freeman and Stewart 432); Health disparities among Native Americans stemming from racial discrimination of health care professionals (Purtzer and Thomas 276); and inadequate pain management for Black people (Villarosa).

like a gimp, he meant it affectionately—I am certain of that. But at that point I no longer wanted to be a nurse with attitude and sass; I wanted to be a patient, to be needy” (Brown, *Critical Care* 49). The doctor’s derogatory language is indicative of a more insidious and pervasive ableism at play, and the speaker’s readiness to dismiss the doctor’s language as playful poking is also disconcerting. Yet even as someone inhabiting a privileged subjectivity, she appears to recognize its harm, if not for its broader ableism at least for the way that it drains her spirit. The passage conveys a tone of exhaustion at having to fight for adequate and ethical treatment. At this point the speaker does not appear to resist or be embarrassed about dependence; by contrast, she reports wanting to be needy.

The text helps direct us toward recognizing that dependence—in the sense that one can be both dependent and feel safe—is itself a privilege. It draws our attention to the limitations of interdependence in its practical applications: celebrating interdependence the way it’s described in theoretical arguments requires trust among the parties involved with care, and trust in this speaker’s context (and certainly in many others like it) will require systemic and cultural change.

CONCLUSION: INTERDEPENDENCE THROUGH ANTI-RACISM AND ANTI-ABLEISM

White feminist care ethicists are not wrong when they call for a dismantling of independence in favor of a more nuanced culture of interdependence. However, it is the very whiteness and ableist nature of traditional clinical contexts that precludes many of us from safely practicing such an ideology. In other contexts, though, interdependence has been and continues to be the celebrated status quo. Community-specific sites including the

Black church that Thompson references (532) and the disability care collectives that Leah Lakshmi Piepzna-Samarasinha describes (26) function in just this way, as spaces where mutual aid flourishes.

In the texts included in this chapter, we see the ways that whiteness and ableism inform the narrator's reluctance to embrace an ideology of interdependence. Yet the myth of independence relies upon whiteness to persist and can therefore be dismantled by anti-racism and anti-ableism—and by an ethics of care that centers disability. In the following chapter, I continue these efforts to reimagine care ethics, asking whether the act of writing can itself function as an act of care. I follow the thread of three distinct themes that emerge from the nurse memoirs under consideration: authority, appropriation, and spectacle. Chapter Three tracks these themes in several different texts, interrogating the ethics at play when a nurse writer publishes others' stories and arguing in favor of considering a nurse's writing as an extension of caretaking labor.

Chapter 3: Literary Care Ethics in Nurse Memoirs

In a 2003 article about AIDS physician memoirs, Katrien De Moor writes,

The caring responsibilities of a doctor do not cease with the death of a patient. In fact, I would argue that these doctors *extend* their responsibility of caring for patients in their role of companion to their moral responsibility as authors, i.e., 'taking care of' the memories of patients in their role of witness. (De Moor, "The Doctor's Role" 220)

Her article goes on to discuss different components and possibilities of ethical life writing, or, as she calls it elsewhere, literary care ethics (De Moor, *From Ashes*). Such an approach to literature written by caretakers demands that we confront texts written by caregivers as not only *about* the act of caregiving and the ethical questions within care encounters, but also as an extension of care practices, demanding the same ethical considerations that any other care scenario might.

Some might disagree with De Moor's point that physician-writers have a responsibility to extend their roles as physicians into their roles as life writers. Most notably, G. Thomas Couser asserts that physicians are under no such obligation and, while Couser's writing is not directly responding to De Moor's article, it counters one of her primary arguments by its suggestion that a physician-writer's obligations as a physician do not extend to her responsibilities as a writer (Couser, *Vulnerable* 78). My goal is not to argue whether auto/biographical texts written by caregivers must obey the ethical standards to which they are held in their caregiving roles. Instead, this chapter will assume that, like ethical caregiving practices, pursuing life writing in an ethical manner is a worthy consideration for any writer. I will thus use De Moor's work as a starting point to continue assessing what a morally responsible auto/biographical text might look like. More

pointedly: How are these nurse memoirs written in such a way to “take care of” (De Moor, “The Doctor’s Role” 220) others’ memories?¹¹ Where do they fall short?

This chapter will not attempt to define which texts do or do not count as literary caretaking—plenty of texts have the potential to be re/framed in terms of care. The question of interest instead is, to put it bluntly: What literary constructions constitute *good* care, and in which contexts? In this sense, my methodology resembles that of Merel Visse and Robert Stake, whose work I quoted in the Introduction bears repeating: “We are not so concerned about what conceptually constitutes care, to view care as an object for the mind, and, most of the time, we do not aim to dwell on definitions. What we want is to join and enlarge the chorus of caring” (xiv). My analysis of each memoir therefore will not attempt to argue whether the text belongs under the purview of literary caretaking; indeed, I readily acknowledge that most of the nurse writers under examination here do not give any indication that their exigency for writing includes a perceived need for care. I will perform instead an assessment of the degree to which each memoir honors some of the ethical standards defined by the scholarship on this topic. I take as my primary texts *Beautiful Unbroken: One Nurse’s Life* (2011) by Mary Jane Nealon, *Intensive Care: The Story of a Nurse* (1987) by Echo Heron, *Critical Care: A New Nurse Faces Death, Life, and*

¹¹ DeMoor’s article specifically focuses on literary care for people who have died. Many of the examples I incorporate in this chapter also include those who have passed away; however, this is not the case for all of them. As I note elsewhere, one characteristic of nurse memoirs is that their relationships with those for whom they care are usually limited to the institutional context in which they take place. Once the recipient of a nurse’s care exits the institution facilitating their interaction, their relationship often meets a natural conclusion. In short, the professional caregiver can “take care of” another’s memory regardless of whether that individual continues to live.

Everything In Between (2010) by Theresa Brown, and “Hitting the Bone” (2013) by Eddie Lueken.

As I have argued in other chapters, a focus on nurse memoirs offers a unique vantage point for accessing the questions posed in this chapter. While bringing questions of literary care ethics to bear upon texts by doctors, family members, and other types of caretakers is also a worthy consideration, centering this discussion around professional nurses yields several benefits: First, nurses are positioned in an institutional hierarchy which often facilitates intimate relationships with care recipients. As caretakers, nurses are often closer in proximity to care receivers than doctors are—and yet not so close as, say, a family caretaker. This is to say that nurses share an intimacy with care recipients that is also often regulated by distinct boundaries such as time constraints, professionalism, and fatigue (or caretaker burnout). The unique relationships of care that emerge from this context are rich sources to mine for considerations of literary care ethics.

Second, hospitals as a setting for professional caretaking (and where most of the examples in this chapter take place) necessitate care relationships that have a conclusion. The hospital nurse builds a specific relationship with the care recipient that lasts only as long as the care recipient occupies the hospital and that is usually heavily informed by whatever care need has brought them there. Each care recipient exists in the nurse’s memory as the specific version of themselves that they were while in the hospital. The nurse has a unique vantage point of each care recipient, encountering that person in what is often their most vulnerable state. They are the purveyors of care recipient snapshots, taken at a crucial moment of time and informed by a finite number of care encounters. The

ephemeral nature of the care relationships depicted in these texts make them a worthy site for analysis because the text's extension of the caretaking becomes all the more productive and meaningful.

Lastly, studying caretaking produced by nurse memoirs also prompts us to consider the relationship between literary caretaking and caretaking in a medical context. What does it mean, in other words, to take care of someone who is not physically present? After all, Joan Tronto writes that the final phase of a caring process is care receiving, where "the object of care will respond to the care it receives. For example, the tuned piano sounds good again, the patient feels better [...]" (107-108). If the subjects of a nurse's memoir are no longer alive, or even simply unaware that they are featured in a published text,¹² who stands to benefit from an act of literary caretaking?

I pause here to offer two possible answers to this question. The first suggestion I will make follows the arguments put forth by De Moor and Couser, who insist that care for the dead can and does take place, regardless of the fact that a deceased person is no longer able to respond. De Moor's version of this argument is to assert that a writer can "take care of" someone's memory (De Moor, "The Doctor's Role" 220), suggesting that the act of memorializing a person via auto/biography has a posthumous benefit for our collective memory of them. Couser, on the other hand, suggests that it is possible to harm someone who has passed away: "[...] while in some sense the dead are invulnerable to harm, their interests survive them, and a posthumous setback to those interests may be regarded as

¹² Plausible, since nurses often change names and other identifying features for the sake of privacy (Brown, *Critical Care* xiii; Heron, *Intensive Care* "Author's Note")

posthumous harm to them” (Couser, “The Obituary” 7). If we accept this argument, it follows that a posthumous *progression* of one’s interests can be regarded as beneficial to them, and thus an act of caretaking.

To the extent that a text produces ethical literary caretaking that centers the interests of disability justice, a second answer to the question of who benefits is: All of us. Just as Donald Pollock views physician autobiographies as social acts, so too should nurse memoirs be read in terms of how they respond to and (re)form the cultures of caretaking. Pollock writes, “Physician autobiographies must also be understood as social acts that respond to—and reproduce—the social and cultural conditions of medicine, as well as the social position and values assigned to physicians by readers” (Pollock, qtd. in De Moor, *From Ashes* 160). One way of applying this viewpoint to an assessment of nurse memoirs is to argue that, by contextualizing, modeling, and generating disability-centered caretaking, these texts stand to contribute in a broader sense to more just circumstances of care, both for those who give care and those who receive it.

LITERARY CARE ETHICS: AN OVERVIEW

The term “literary caretaking” that I will use throughout this chapter comes from De Moor’s 2003 article, in which she proposes the phrase “literary care” to define “witnessing that is constructed, implicitly or explicitly, as an extension of practices of care and a continuation of the caring process” (De Moor, “The Doctor’s Role” 208-209). Throughout this chapter I use the term “literary caretaking,” a slight departure from De Moor’s use of the term “literary care.” This terminology invokes the phrase “taking care

of” that Joan Tronto includes in her phases of caring. For Tronto, “taking care of” involves “assuming some responsibility for the identified need [for care] and determining how to respond to it” (106).¹³ As I will demonstrate, these memoirs usually respond to the need for care in one way or another. While the question of whether a text is capable of “care-giving”¹⁴ is beyond the scope of this chapter, my opting for the phrase literary caretaking should not be read as a dismissal of literary “care-giving” possibilities but rather a starting point for (re)framing the discourse in and around caretaker auto/biographies.

I will begin by making explicit some of the connections that already exist between theories of care ethics and of life writing. By doing so, I hope to make clear that the project of theorizing a literary ethics of care has important foundations in life writing scholarship, even if such foundations have yet to be fully explored and articulated. From there, my review of literature invested in life writing and literary care ethics will be organized according to a growing level of specificity: scholars interested in the ethics of writing about others, the ethics of writing about others with illnesses or disabilities, and lastly the ethics of writing as a caretaker about those for whom one cares. This structure is intended to explicitly call upon the complex layering of ethical concerns embedded in the project of caretaker auto/biographies such as the nurse memoirs included in this chapter. Lastly, among the many topics offered by the scholars included in this section, I end by

¹³ In Tronto’s phases of caring, “Taking care of” is nestled between “caring about,” wherein one recognizes the need for care, and “care-giving,” where one directly (and often physically) meets the need for care (106). My use of the term literary caretaking is intended to suggest that the memoirs under consideration are intricately tied to and often seem to exist somewhere between “caring about” and “care-giving,” just as the phrase “caretaking” exists between the two in Tronto’s schematic.

¹⁴ Defined as “the concrete (sometimes called hands-on) work of maintaining and repairing our world” (Fisher and Tronto 44).

emphasizing three that bear the most relevance to assessing disability-centered care ethics in nurse memoirs: authority, appropriation, and spectacle.

Although not explicitly connected to care, those who study the ethics of life writing, and many who theorize life writing more generally, are often implicitly invested in discussions of care ethics. This is because theorists understand auto/biography as inherently relational—just as feminist care ethicists describe the relational nature of care. Sidonie Smith and Julia Watson write that “Relationality invites us to think about the different kinds of textual others—historical, contingent, or significant—through which an ‘I’ narrates the formation or modification of self-consciousness” (86). Any interpretation of literary care ethics therefore demands that we pay attention to the relationships constructed in and through a text and how the writer—in this case, also the caretaker—negotiates her relationship with her subjects. Fisher and Tronto’s often-cited definition of care helps emphasize this point of relationality: we can care for ourselves, others, our environment, and so forth (40).¹⁵ The ethics of life writing and ethics of care both attend to the complicated relationships created by and within auto/biography and care encounters, respectively; my use of the term literary care ethics is meant to signal this distinct overlapping of academic fields that are not always placed in direct conversation with one another.

¹⁵ Their full definition, which I quoted in the Introduction of this project, reads as follows: “On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web” (Fisher and Tronto 40).

A more explicit theoretical overlapping of life writing and care ethics takes place in the work of Merel Visse and Alistair Niemeijer, who discuss autoethnography as a praxis of care. They write, “A caring praxis accordingly unfolds through the interplay of people when working on an autoethnography. The participants are interdependent people whose selves and whose narratives are not static and separate, but constituted by the relationship they have with one another” (302). Their understanding of autoethnography as a process of “interdependence” implicitly speaks to an interest in confronting concerns related to authority and hierarchy, which becomes especially pertinent to a literary analysis of nurse memoirs. While Visse and Niemeijer’s description takes a process-oriented approach to the act of composing an autoethnography, I intend to draw from their insights to assess the way each text constructs the relationship between auto/biographical subjects as a primary methodological approach to the questions posed in this chapter.

Even when not explicitly connected to care, the wide array of research on the ethics of nonfiction representations of others stands to make a unique contribution to addressing the questions posed by this chapter. Merete Mazzarella’s essay “Writing about Others: An Autobiographical Perspective” (2015) interrogates an autobiographer’s ethical responsibilities regarding the act of telling others’ stories. To circumvent any claims of fully knowing her mother, who is heavily featured in her autobiography, Mazzarella describes the meta-discourse involved in reminding readers of her speaker’s position as an outside observer: “I describe her from the outside, I record what she said and did, but I never enter into her consciousness or pretend to know what she was thinking or feeling beyond what she was telling or clearly showing me” (187). Mazzarella’s technique is an

attempt to negotiate authority and avoid the type of appropriation De Moor describes as a major consideration of literary care ethics: One means of ““taking care of” the memories of patients” (De Moor, “The Doctor’s Role” 220) is to position one’s auto/biographical speaker as an outsider rather than an expert in another’s life story.

While the above scholarship is certainly important to the work of theorizing disability-centered literary care ethics, there are also those who speak more explicitly about ethical depictions of illness and disability. De Moor channels the social implications of disability by noting that physician-writers take better care of people seeking care when their writing demonstrates a concern for the social and political dimensions of AIDS. She describes the means with which each of the physician-writers appear to avoid constructing AIDS as a private, isolated experience (De Moor, “The Doctor’s Role” 217), again channeling the possibilities of a literary care ethics that considers the social dimensions of illness and avoids an overly medicalized rendering of the care recipients included in the text.

Likewise, Couser’s book *Vulnerable Subjects: Ethics and Life Writing* (2004) describes concerns related to the vulnerability and autonomy of life writing subjects, particularly subjects whose disabilities and/or impairments raise the stakes of (mis)representation by others. Tom Shakespeare, too, touches upon the importance of ethical disability representation in life writing. He levels critiques at physician-writer Oliver Sacks who, according to Shakespeare, dwells too much in bizarre medical cases and, in doing so, creates conditions of voyeurism not unlike a freak show (Shakespeare 137-138). Each of these examples is concerned in some way with the gaze to which an

auto/biographical text caters. Auto/biographical texts (and the speakers in them) cannot purport to render ethical literary caretaking if they make medical spectacles of their subjects or overly-indulge the pleasure, horror, and intrigue of their readers. As my analysis in this chapter will show, the line of over-indulgence in this regard is a difficult one to draw; nevertheless, it remains an important ethical consideration for literary depictions of subjects with illnesses and disabilities.

Among the scholars interested in the project of representing illness and disability in life writing is Arthur Frank, whose work also moves us deeper into considering the implications of a caretaker producing an auto/biographical text. The ethical pitfalls of appropriation and objectification that De Moor and Mazzarella describe are also topics of interest in Frank's *The Wounded Storyteller*, in which he uses the language of narrative "colonization." Frank relates the story of an acquaintance who had a reconstructive surgery and whose surgeon asked permission to publish the process in a medical journal. He writes that he imagined the article would include his acquaintance's personal ordeal, but that it did not even record his name: "Thus in 'his' article he was systematically ignored as anyone—actually anything—other than a body" (Frank 11-12). Later in his book, Frank describes what he perceives to be the importance of empathizing with others' stories without colonizing the narrative—defining empathy in a way that resonates with Nel Noddings's notion of "feeling with" another (30). He writes, "The goal is empathy, not as internalizing the feelings of the other [...] The other's self-story does not become my own, but I develop sufficient resonance with that story so that I can feel its nuances and anticipate changes in plot" (Frank 158). Frank's articulation of "resonance" is especially promising

for my attempt at merging the ethics of care with the ethics of life writing; his description constitutes a theoretical consideration of narrative, but also implicitly relies upon a discussion of how life writing can most ethically constitute an act of care.

A common concern regarding caretaker auto/biography that emerges from the literature on this topic is that of the expanding medical gaze. While one could read Frank's example of the "colonized" narrative as a physician's need to protect the privacy of those for whom she cares, it is also a medicalization (and therefore a flattening) of what Frank knows to be a complex narrative. Mazzarella also observes the "similarities between the clinical gaze and the biographical one," both of which she says study people for purposes beyond merely learning about them (179). Mazzarella, like Frank, locates a possible misuse of an auto/biographer's authority: appropriating another's story for one's own purposes, or in such a way that misrepresents (however intentionally) their experience.

Likewise, De Moor's article notes that the very genre of physician writing (and here I would add caretaker writing more broadly) can manifest as an expansion of the medical gaze beyond the confines of the clinic and can also be read as an appropriation of care recipient experiences, reinforcing power imbalances that already exist in many formal caretaking relationships ("The Doctor's Role" 225). On this point, she writes,

When doctors become concerned with the 'whole' person, they also extend their socio-medical gaze (and ear) onto the patients' broader lives and, in the case of the doctor-writer, even gain power over the patients' stories and public remembrance. In fact, this reveals some of the limits of these doctor memoirs in general: on the whole, these are necessary and admirable writings that attempt to break through certain silences surrounding HIV/AIDS but narratives that nevertheless are *about*, not by, marginalized people. (De Moor, "The Doctor's Role" 226)

By analyzing AIDS physician memoirs with an eye toward literary care ethics, De Moor directs us toward important questions about what rhetorical choices constitute ethical literary caretaking and which shortcomings may be inescapably embedded in the genre of caretaker auto/biography.

As this overview demonstrates, there are several varied and complex elements to consider in an assessment of care ethics within caretaker memoirs. I therefore offer the following three topics as an organizing principle and as a loose set of concepts for my analysis of the nurse memoirs included in this chapter: authority, appropriation, and spectacle. The first topic, authority, includes the possibility (and perhaps inevitability) of caretaker narratives to expand the authority of the clinical gaze. In the analysis portion of this chapter, considerations of authority largely have to do with the degree to which the text is self-conscious of its own power and/or of the hierarchy of the in-text caretaking relationship(s). Second is appropriation, which refers to the degree to which caretaker-writers exercise power over and/or center their own concerns within a care recipient's narrative. Literature discussing appropriation often addresses the ethical importance of avoiding over-engrossment or "colonization" (to use Frank's language) of another's story. The third and final topic I will emphasize is spectacle, usually having to do with texts that position disability and impairment as a spectacle and the reader as voyeur. My discussion of spectacle in this case also includes questions about how auto/biographical caretaker texts address social and political dimensions of caretaking. These three topics are closely related and impossible to disentangle from one another, both within the scholarship on literary care ethics and in how they operate in an auto/biographical context. All of these have to do in

some way with the power one wields when writing publicly about others, especially vulnerable others who are not in a position to respond publicly for any number of reasons.

In what follows, I assess the concept and possibilities of literary caretaking as it emerges in the memoir *Beautiful Unbroken: One Nurse's Story* by Mary Jane Nealon. I read Nealon's memoir as a form of auto-theory, demonstrating that her protagonist perceives the text as a form of caretaking and further arguing that, in this narrator's conception of literary caretaking, the reader is also asked to play an important role. The remainder of this chapter follows the template I have introduced above, pairing each primary text with the themes of authority, appropriation, and spectacle to draw out pertinent features of each text that speak to the question of what elements constitute ethical literary caretaking. While several primary texts will be cross-referenced between sections, organizing according to these three topics of interest is intended to guide the discussion toward an understanding of disability-centered care ethics according to the aforementioned scholarly discussions already taking place.

LITERATURE AS CARETAKING: NEALON'S *BEAUTIFUL UNBROKEN*

Mary Jane Nealon's memoir *Beautiful Unbroken: One Nurse's Life* (2011) details the narrator's experiences as a nurse and writer, both vocations informing one another in complex ways and coming to comprise major aspects of the speaker's identity. Nealon's memoir spans various periods of her life: from scenes of her childhood to her experiences as a traveling nurse, and from grappling with her younger brother's death from cancer to working in one of the first AIDS wards in New York City. Her narrative constitutes a

prolonged meditation upon care that frames the act of writing as an extension of care practices. Furthermore, beyond incorporating the individual details and stories of those for whom she cares, Nealon's speaker asks readers to actively participate in the text's caregiving exigency via direct moments of testimony.

Nealon's memoir suggests quite explicitly that she views the act of writing as an extension of her care. Having lost her brother and witnessed the deaths of many men with HIV/AIDS, her call to write down her recollections appears to gravitate toward a consideration of the "dying boys" (Nealon 47) that her narrator encounters throughout the text. Nealon's speaker describes carrying a notebook to write poetry about her brother's death, going on to say, "Eventually, I tried to remember every detail of Tony the baker, every detail of Jack. I used my fine-point pen and my journal to keep all the dying boys from completely disappearing" (Nealon 47). Her initial description of "Tony the baker" signals that her narrator is interested in these people beyond their physical, medical experiences and wants to record everything she can recall about each person. Evoking the image of a "fine-point pen" goes on to corroborate her claim that she cares about the details—and details are indeed often what one encounters in Nealon's memoir, as I will later demonstrate.

Not only does she include specific descriptions of people for whom she cares, she incorporates various rationales for undertaking the labor of literary caretaking: "To keep all the dying boys from completely disappearing" (Nealon 47). The speaker's engagement with literary care ethics is depicted as a means of memorializing the dead, an endeavor that

resonates with De Moor's argument that literary care entails "'taking care of' the memories of patients" ("The Doctor's Role" 220).

Nealon's narrator goes on to note that, while her literary care is not exclusively oriented toward the biological/medical, she does find it meaningful to keep autopsy reports "because I wanted to remind myself of all the ways the body could turn on itself. I knew I would always have the names of the men I'd cared for, but I also needed to keep the unique ways they died, their special suffering" (Nealon 145-146). Yet again we are being asked to recognize the narrator's attention to each care recipient as an individual, both in and beyond their physicality. The above excerpt is relayed in the context of caring for people with HIV/AIDS, which communicates the sense that Nealon's speaker seeks to interrogate and subvert cultural impulses to generalize or stereotype people with the virus. Attending to the particularities of each person's experience with HIV/AIDS is therefore one means of writing against the broad, harmful cultural narratives of the virus that I briefly touched upon in Chapter One. Nealon's literary care ethics takes on a political purpose in the sense that her writing asserts that these people mattered and that they continue to matter after their deaths.

In addition to incorporating the individual details of people for whom her speaker cares, Nealon's memoir incorporates stylized testimonies that demand the reader's direct engagement. Such moments extend the practice of literary caretaking by asking the reader, too, to bear witness to certain particularities of others' experiences. One poignant example of this takes place once more in the context of the HIV/AIDS epidemic:

Imagine a gray box, lined with felt; there is nothing in it except a white stone. Imagine a made bed in a cloister under solid-brass crucifix, or a feather on the lawn, or imagine instead, a man covered with purple sarcoma lesions in a chair by a window, the light on the outline of his face. The bulging outline of his tumors there. Can you see his hands? They are swollen and gray with barely healed needle sticks from last week's chemotherapy. (Nealon 110)

The passage is notable in the text because it is marked by a sudden shift into the second person: the speaker begins by commanding the reader to imagine, and later probes deeper by asking "Can you see his hands?" as if to ensure that the reader is engaged with the task of bearing witness. As Leigh Gilmore writes, testimony "bears witness to harm in a public forum" (307). Therefore, one reason for thinking of this example as a form of testimony is that its use of the second person marks it as distinctly and self-consciously public. One can certainly perform testimony without the use of the second person, but in this instance, the speaker's direct engagement with the audience emphasizes the passage's function as a public speech act.

The use of metaphor in this example is also a means with which the speaker engages the audience: the metaphor facilitates readerly empathy in that it asks the reader to imagine simple objects of familiarity (a stone, a box, a feather) that help assign meaning to that which may be unfamiliar (the sick man, the lesions). All of it amounts to a rich depiction of a sickroom in which both the man and the space itself yield layered interpretations. The room begins as a gray box lined with felt, then a cloister and a lawn; in this way, the space of the room with the chair by the window is soft, sacred, and delicate, seemingly enclosed and spacious all at once. So, too, does the description of the man begin with a white stone, a made bed, and a feather, evoking suggestions of innocence, tidiness, simultaneous

fragility and strength. Part of the work of this testimony is that it counteracts popular assumptions of HIV/AIDS and people with the virus as dirty and infectious, condemned to illness because of some moral failure (Sontag 112-113). As I noted in Chapter One, all of these (mis)perceptions are rooted in homophobia, xenophobia, and a misplaced sense of moral superiority.

Importantly, the speaker's testimony exits the realm of metaphor and arrives at physical descriptions of the man who, although remaining unnamed in the passage, comes to be preserved within and memorialized by the caretaker's depiction. While I have argued that the speaker's use of metaphor acts as an access point for the reader's engagement, Nealon's narrator maintains her commitment to detail and to keeping track of others' "special suffering" (Nealon 146).

This passage enacts a twofold approach to a literary ethic of care in that the speaker's testimony both preserves and memorializes the man in the chair and entangles the reader as a secondhand witness. As Frank writes, "Testimony is distinct from other reports because it does not simply affect those who receive it; testimony *implicates* others in what they witness" (143, emphasis in original). The use of the second person, the metaphorical subversion of harmful HIV/AIDS stereotypes, and the more granular, detailed depiction of the man are all methods that the speaker uses to activate the reader's response. Rather than being allowed to remain passive observers of the narrator's experiences, we are instead made secondhand witnesses to and participants within an instance of literary caretaking.

The approach of implicating the reader in a narrator's act of literary caretaking is also worth observing in a short essay by Christopher Lance Coleman entitled "Don't Ever Forget Me." The title alone uses a second person address in much the same way as the example from Nealon's memoir: just as Nealon's narrator has asked the reader to imagine and to actively engage with the text, so too does Coleman's essay implore the reader to remember the "me" that we come to know in the essay. The "me" of the title primarily refers to the residents of Our House, the first AIDS hospice in Oregon (Coleman 106-107).

By end of Coleman's essay, it becomes clear that the speaker is enacting care by memorializing those he encountered in Our House and by telling the reader to honor their memories in a more political way: "At Our House, the guys would often say, 'Don't forget me.' 'I won't forget you,' I would promise. I can remember every single one of their faces. We cannot forget them, and we cannot forget AIDS" (Coleman 111). At this point, the speaker has introduced us to some of the faces he has vowed to remember, and he has also detailed more political concerns that come with remembering HIV/AIDS: that the U.S. healthcare system is not prepared to provide for people who are now able to live with HIV/AIDS into their old age, that young people have not been adequately warned about the effects of HIV/AIDS on their bodies, and that, ultimately, there is a lack of vigilance regarding HIV/AIDS and a false sense that the crisis is over (Coleman 110). The speaker's demand that "we cannot forget AIDS," then, includes caring for and about people who have died from HIV/AIDS by remembering them as people and by allowing experiences of past care to inform our collective care efforts moving forward.

I have thus far argued that instances of literary caretaking can (and often do) leverage the reader's imagination as a means of expanding the care effort from narrator to audience. We have observed such tactics in *Beautiful Unbroken*, when Nealon's speaker directs the reader to imagine the man by the window, and also to some extent in "Don't Ever Forget Me," in which Coleman's narrator invokes the reader's empathy and directs our attention toward opportunities for further care efforts. In what follows, I have paired Eddie Lueken's essay "Hitting the Bone" with the ethical topic of authority to dissect how the essay's speaker reckons with disparities of power inherent to care relationships and how problems of authority inform the essay's composition.

AUTHORITY: LUEKEN'S "HITTING THE BONE"

In her autobiographical essay "Hitting the Bone" (2013), Eddie Lueken describes her experience as a nursing student caring for Mabel Tate, a woman with bone cancer and a DNR order. The essay functions primarily as the narrator's critique of her failure to provide adequate care for Miss Tate, emphasizing her past mistake of striking the bone in Miss Tate's leg with the needle of her morphine shot. There is a valid argument to be made that this essay is not in itself a performance of care: after all, it does not contain an explicit apology to Miss Tate, nor does it have the power to revise the violence of their interaction. Either gesture would function as what one could reasonably consider an act of care. However, there are important ways in which we can conceptualize this essay as an example of literary caretaking. For one, the narrating voice demonstrates evidence of seeing and caring about Miss Tate in ways that her past self does not, retroactively testifying to Miss

Tate's pain in her last moments of life. The tone of the piece is also apologetic, even if the content is not explicitly so; this remorse becomes the text's primary redemptive quality, creating an implied apology to Miss Tate without centering the interests of the nurse narrator. This section will investigate the complicated care performed by Lueken's essay, ultimately arguing that the text problematizes (both in form and content) the in-scene nurse's misuse of authority.

Lueken's essay reads like an act of self-flagellation, owning up to her violations against Miss Tate by alternating between wry depictions of immaturity and more critical representations of her past coldness. The speaker notes that nursing school "had been a boring, bloodless disappointment," and "I was ready to do something dramatically heroic" (Lueken 26). She also describes herself as "giddy with anticipation" (Lueken 31) upon realizing that she may have her first experience administering morphine. Even after her character learns that Miss Tate may stop breathing if administered additional pain medication, she portrays her immediate response as follows: "My heart raced. I could be giving my first shot!" (Lueken 30). Such moments characterize her past self as fundamentally naïve, not only with regard to the responsibilities and tasks associated with a nursing career, but also in relation to Miss Tate's condition. Her response to her supervisor's question—"Should you give a dying woman with advanced bone cancer her pain medication, or withhold it because she may stop breathing?" (Lueken 30)—is depicted in such a way that indicates her narrated self did not seriously consider the decision and its consequences. Instead, the speaker exposes her past self's glee at being able to exercise her medical knowledge and power despite the consequences. By underscoring the flippancy of

her reaction to the scenario, she ultimately reveals an underlying assumption that Miss Tate's unconscious, disabled body is no longer valuable, except to practice medical interventions.

While some of the narrator's self-critique seems rooted in assessing the immaturity of her past self, concerned only with the heroic possibilities of nursing care, other self-critiques represent her character as altogether cold and uncaring: her narrated self becomes the antagonist of the essay. Such moments of uncaring coldness include her sense that "hosing her off might work better" than giving Miss Tate a bed bath (Lueken 27). Upon recognizing that care for Miss Tate will require more tedious care work than heroic drama, she writes, "Denture care for someone who was lying in the fetal position, looking as though she'd never eat again, wasn't the kind of action I had in mind" (Lueken 26). Quite troublingly, the in-scene nurse seems to devalue Miss Tate *because of* her disability: lying in pain and apparently without hope of recovery, the disabled, would-be recipient of care appears unworthy of attention to the young nurse.

These moments of the nursing student's coldness appear to be informed by the distance between the narrated "I" and the narrating "I" (Smith and Watson 72-73) — distance both in terms of time and character. The temporal separation between the two "I's" is most evident by the use of past tense, which remains stable throughout the essay. By giving the reader examples of the in-scene nurse's thoughts, which appear to be frequently bereft of compassion or care for Miss Tate, the narrating "I" creates an implicit judgement against the in-scene version of herself. Such strategies of self-narration have the effects of both making the past self an antagonist in the essay and of implying some level of self-

critique: the narrating “I” does not appear to condone the thoughts or actions of the narrated “I” leading up to the violent act of hitting Miss Tate’s bone.

The most obvious self-critique in this essay occurs as the narrator depicts the violence of her needle hitting Miss Tate’s hip bone. In this formative moment, she writes:

The needle penetrated her skin and glided through her muscle. It was easy—that is, until I felt the abrupt vibration of the needle running headlong into the old woman’s hip bone. It stopped hard and fast, akin to a car hitting a concrete wall. My stomach lurched. Mabel Tate’s dreadful predicament—her unrelenting pain, her reliance on strangers, her debilitating condition that had stolen her voice—all of it was buried in that brittle, cancerous bone; the bone I had jabbed with the beveled edge of a big needle. All of it reverberated through my hand. (Lueken 31)

The titular moment of “hitting the bone” is written as both a depiction and interpretation of violence: we witness the narrated “I” hitting Miss Tate’s bone during the morphine injection, and we are also made privy to the narrating “I’s” understanding of what that violence means. Violence exists on more than one level in this scene: most obviously, it comes in the form of the material violence to Miss Tate’s bone, but it also includes the destruction of Miss Tate’s sense of autonomy and the pain of having her voice stolen. In this sense, the reader can witness the narrating “I” caring about Miss Tate and seeing her more fully than the narrated “I” appeared to—at least in the version of the event we are given. The narrating “I” critiques the in-scene nurse for her confident presumption that she knows Miss Tate’s body, and it also incorporates an attempt at understanding the totality of Miss Tate’s circumstances, an attempt that the in-scene nurse never seems to engage.

The conclusion to the essay makes explicit what has been an implied critique of the past self: that the self being depicted was not a good nurse. Importantly, we don’t see any reassurance from this speaker, narrating from the future, that the main character does turn

out to be a good nurse—even though she narrates from many years later. Nevertheless, the explicit recognition of failure to render care functions as the redemptive moment of the essay. After Miss Tate’s death, the essay reads as follows:

As I stood in the quiet room, it suddenly occurred to me that I might not turn out to be a good nurse. I tried to shake the bad feeling by picturing myself valiantly performing CPR on a trauma victim in the ER, but all I could see was Miss Tate’s frown, her spiky shoulders, her long silver hair that someone else had braided for the last time. (Lueken 33)

Although the narrative does not provide a present tense explanation of how the main character develops following this incident, the various interpretations and details provided by the narrating “I” suggest a greater recognition of the person Miss Tate was, a recognition that the nurse before the incident does not possess. These final lines of the essay indicate the narrated “I” comes to an understanding that, while she tries to imagine good nursing care includes valiant performances of CPR, a good nurse is instead the one who braided Miss Tate’s hair for her. The essay helps suggest that meaningful caretaking in the form of the braided hair often takes place outside of more curative interventions—an understanding which bears striking resemblance to the themes and conclusions discussed in Chapter One.

Ultimately, Lueken’s essay problematizes unchecked authority in care encounters by criticizing the speaker’s past misuse of power and enacting literary caretaking that models a suspicion of claiming to know another person. While I have demonstrated that “Hitting the Bone” enacts its own criticism of authority, I now move toward a discussion of what we might read as a different misuse of authority from that featured in Lueken’s essay: appropriation. In the next section, I interrogate the possibilities of appropriation within Echo Heron’s memoir *Intensive Care*, arguing that unchecked empathy and over-

prescribed imagination on the part of a narrating caretaker can have the effect of over-extending narrative authority at the expense of memorializing another's story.

APPROPRIATION: HERON'S *INTENSIVE CARE*

Echo Heron's memoir *Intensive Care: The Story of a Nurse* (1987) details the speaker's experiences coming of age through nursing school and toward her eventual career as a nurse working in emergency rooms and intensive care units. Scenes in this text are filled with emotion, and it becomes clear from the first chapter that this speaker is not one to shy away from dramatic retellings of her life's events. In theorizing the various components that might comprise an ethics of literary caretaking, Heron's text stands out as a productive site for focusing on questions of empathy (and what might constitute an over-extension of empathy) precisely because of the emotion-packed style in which this text is composed. I argue that *Intensive Care* incorporates scenes where, in the speaker's attempt to empathize with and care for others, the speaker over-extends her narrative authority in a way that raises ethical concerns.

Heron's text incorporates several examples where the speaker appears to be employing her empathic impulse to imagine details of care recipients' personalities and histories. In many of these cases, the speaker comes dangerously close to over-writing the care recipients' narratives with a narrative of her own invention. While it may be possible to read these instances of over-narration as the speaker's attempt to honor others by giving them memories, personalities, and character traits, we can also read them as an over-extension of narrative authority.

One such example comes early in the memoir as part of the text's prologue: in this scene, the nurse begins her workday in an acute coronary care ward. She slips her uniform on, noticing an old blood stain on the pants from a care recipient whose name she cannot remember. Heron's speaker briefly notes that she feels guilty for not remembering the man's name, signaling that this caretaker is one for whom care relationships are especially meaningful. The narrator explains that she has been assigned to care for a man in bed two, and that the report from the on-duty nurse was "tedious and un-informative." She performs various assessments of the unconscious man in bed two, detailing some of his physical traits and his proximity to death before bringing the family in, one by one, to say goodbye. At this point, a young boy comes in, presumably the man's grandson, and the narration continues:

The boy reached out to touch the older man's face and caught himself. He would not make this real. This was his grandfather, a man he had loved all his life. He would not give him up to the world of these ugly tubes and sterile smells. His grandpa was the smell of pipe tobacco and apples. He was the tall, balding man always telling stories. (Heron 3-4)

Without any explanation as to the origin of the above information, the reader can deduce that Heron's speaker has taken some liberty in describing the grandfather and his relationship to the young boy. Not long after this excerpt, Heron's speaker will go on to note: "I thought about his life, his work, and wondered if he'd ever gone fishing. 'What kind of man were you really?' I asked aloud" (Heron 5).

The speaker's curiosity pertaining to the dying man's life and character further compounds one's suspicion that her descriptions of him are invented based on the family's interaction with the man, and possibly based on the speaker's own experiences that are

being projected onto the unconscious man. In the scene, the speaker's empathy is not only for the grandfather, but for the rest of the family as well—especially the grandson, whose internal dialogue and motivations are also made susceptible to the narrator's imagination. While this scene does not entail a colonizing of the care receiver's narrative in the manner that Frank describes, where a text neglects an individual's personhood in service of medical, research-oriented goals (11-12), it does seem to have an effect of colonizing the man's life story with a new story of the speaker's own creation.

To clarify, I am not arguing that Heron's speaker is harming the man by imagining a story for his life; indeed, doing so may constitute an important vessel for the nurse's caregiving. Such is the function of narrative in medical practice according to Rita Charon, who describes the process of filling gaps in knowledge with fiction as a practice in reflection (5), imagination acting as a "hypothesis" or "a tool with which to get to the truth" (6). Heron's speaker communicates a philosophy similar to Charon's in later passages of the memoir. For example, she attempts to comfort for a woman whose child died after a drowning accident: "I thought that if for just a split second I changed places with the woman, it would help me say just the right words, the ones I'd want to hear" (Heron 84). Imagining trading places with someone is similar to the act of inventing a story for them: both are imaginative enactments meant to understand another person's character, personality, and way of being in the world. In this case, imagining the woman's story—giving shape and texture to her pain after losing her child—helps the nurse to arrive at a care response: "[...] nothing I thought of saying would come close to touching the woman's anguish. In the end I said nothing at all and rocked her in my arms until Dr. Mahoney

arrived” (Heron 88). In this case, the nurse’s position as an attendant between visits from the doctor facilitates the emotional demands of her profession. Occupying this unique space in an institutional hierarchy, the speaker appears caught in a sort of medical limbo where the demands for her care are not physical but instead emotional.

However, while I acknowledge that imagining another’s story can be a useful tool for care, I maintain that the act of *publishing* an invented life story for a dying person introduces ethical ambiguity to which those invested in literary care ethics should be attuned. Making public her imaginative renderings of the man in bed two and his relationship to his grandson makes an implicit claim of understanding him—a claim against which Mazzarella argues when she writes about opting out of presumptuous descriptions of others’ thoughts and motivations (187). Including invented stories for others’ unknowable lives produces an effect that reads more as a self-congratulatory depiction of caregiving prowess than as an authentic attempt at honoring another’s story.

Other passages included in *Intensive Care* continue to speak to the trope of empathy and to the ensuing ethical ambiguities taking place as a result. Again, the text makes clear that the nurse’s imagination is a tool used in service of providing care; however, as with the man in bed two, the speaker’s well-intentioned description of Sondra Nelson reads as only a placeholder for what might have otherwise become an authentic connection between caregiver and care receiver. Looking upon the dying Sondra Nelson, Heron’s narrator says,

The laboratory saw the patient in terms of how good the veins were, and the pharmacy saw a body as a certain number of kilograms for proper drug dosage calculation. Even the nurses saw the patient as a unit of work: acute, intermediate, or self-care. Who saw the patient as someone’s mother or a loved husband or simply a valuable human being? I looked at Sondra Nelson and imagined her laughing as

she ran down a sunny beach. She was a woman who'd loved, laughed, hated, and cried; she had walked in the rain, eaten chocolate ice cream cones [...]. (Heron 300)

As with the man in bed two, the speaker does not give any indication that she had learned information about Sondra Nelson's life from her or her family. While the text includes dialogue between the narrator and Mrs. Nelson after this scene of her resuscitation, the speaker's imagined version of Mrs. Nelson motivates her decision to persuade the family to allow her to have a peaceful death. In other words, the text represents moments of empathy as vehicles for care decisions, but it does not take on the responsibility of testifying to the lives of the subjects who populate its pages. The speaker's argument in the passage with Sondra Nelson is well-taken: Seeing subjects of care in their full personhood sometimes requires the labor of empathy and imagination. However, it is also true that, by essentializing the nature of Sondra Nelson's life within the pages of her memoir, the speaker overrides the granular details of Mrs. Nelson's story. Sondra Nelson's narrative, then, becomes consumed by a generalizable account, and the presumed "details" of who this woman is remain caught in tropes of sentimental, generic Americana. Such a turn toward the generic leaves one wondering: Would it be more ethical or less so for the speaker to meditate upon the effects of not knowing, rather than to presume to know?

One way of complicating the interpretation that I have thus far offered is by considering that, while Heron's narrator does take liberties in describing others' lives, she often signals to the reader that she is doing so consciously. Regarding Sondra Nelson, she explicitly says "I [...] imagined her laughing" (Heron 300). Likewise, regarding the man in bed two, one could read the speaker's question "What kind of man were you really?"

(Heron 5) as a means of drawing the reader's attention to the invented elements of the man's character. Nevertheless, I maintain that the specific contexts in which this narrative takes place should make us pause and consider that inventing a story or personality for someone does not constitute taking care of that person's memory. The specific contexts to which I am referring include the subjects' potential vulnerabilities as both (a) physically unwell or dying, to the extent that they are seeking acute medical care and (b) lower in the hierarchy of authority than the nurse caregiver and writer. As Couser writes about the subject in a similar auto/biography, "Her impairment makes her subject to harm (abuse and exploitation) in her life; and it also renders her vulnerable to misrepresentation in her husband's writing because it deprives her of the capacity to take part in, examine, respond to, or resist that representation" (*Vulnerable* x). Even though the narrator in Heron's memoir is signaling a conscientious made-up representation of her subject(s), the degree to which those care recipients are unable to participate in their own representation contributes to my suspicion regarding the ethics of this speaker's rhetorical choices.

My critique of this narrator's use of her imagination for filling in the blanks of her care recipients' stories and personalities is not predicated upon any notion that auto/biographical texts need to contain (or even can contain) strictly factual depictions of oneself or others. Most scholars of auto/biography agree that the inconstant, precarious nature of "truth" in life writing should shift our attention from "assessing and verifying knowledge to observing the processes of communicative exchange and understanding" (Smith and Watson 16-17). Artist, memoirist, and disability activist Riva Lehrer, reflecting upon her process of painting others' portraits, goes so far as to argue: "[...] whether you

create a portrait or a child, you can't make another's body except by pulling it through your own" (Lehrer 11:02:00-44)¹⁶. Truth in auto/biography is always precarious, and depictions of ourselves and of others are always informed by the writer's biases in one way or another. Regardless of whether a writer relies upon strict "facts" in representing others, literary caretaking demands a writer create a fuller portrait of her subjects than what is made possible by generic character tropes.

While I have thus far been questioning whether/how imagined narratives for others' lives might affect the care receivers, Heron's text also asks us to consider how such literary pursuits of empathy might impact the caretakers. Burnout is a common theme in caregiver memoirs, and *Intensive Care* is no exception; the text both depicts Heron's character taking on the emotional labor of empathy and engages in empathic renderings of its own. Including different layers of engagement with emotional labor enables the text to depict the speaker's process toward burnout, culminating in the narrator's confession toward the end of the book: "I was where I swore I would never allow myself to be: burned out, acting out the role of the hard, uncaring nurse" (Heron 356).

One possible reading of the narrator's trajectory toward burnout is that Heron's text purposefully models the type of emotional investment that, when left unchecked, contributes to caregiver exhaustion. Each instance of empathy, whether it is the narrated

¹⁶ Lehrer writes that, in the act of representing another person, we draw unconsciously upon our own bodies and experiences. She calls this process leakage: "Leakage is unintended and below my conscious awareness, yet it alleviates the sense that I am alone in my body. It happens because I want to understand my subject, see through their eyes, but it's just as true that leakage is a fantasy taking place in the hothouse of my brain, and that you, my collaborator, may not share that sensation in the least. Maybe you've raised your walls and shields and I can't even tell" (Lehrer 11:02:00-44).

caregiver or the narrating voice performing the emotional labor, might then be read in service toward the larger narrative goal of tracking the speaker's burnout, including her persistence in thinking about the subjects of her care after the workday is over, her stress and sleeplessness, and her eventual ulcer. In other words, while I have thus far been critiquing the speaker's imaginative indulgences for the ethical implications they might hold, her speaker also critiques them—albeit primarily for the emotional toll they take on the caregiver.

The implied self-critique of empathy for how it contributes to caretaker burnout is also a useful critique of the systems in which nurses work and of how those systems make demands on nurses' labor without providing adequate resources. Fisher and Tronto write that one contradiction of caretaking involves:

[...] asymmetry between responsibility and power [...] Where responsibility is great but power is limited, women are expected to compensate for deficiencies in the caring process [...] Where the contradictions involved in taking responsibility become too great, women suffer from burn-out and disillusion. (43)

The depiction of Heron's speaker comforting the woman until the doctor arrives provides an example of this phenomenon: the nurse finds herself in a position where her responsibility is to care for the grieving woman and turns toward empathy and her own imaginative prowess to do so.

The depictions of and engagement with empathy in *Intensive Care* indeed serve many purposes: they model one caregiver's use of imagination in her ethic of care, they track the function of emotional investment and how it relates to caregiver burnout, and they also create a fuller picture of the narrator as an empath who appears to approach care not

merely as a process or action but as a “disposition” (Tronto 104). Yet the degree to which one emerges from Heron’s text with an adequate understanding of who those care recipients were is a point of ethical concern if we agree that a primary role of literary care ethics is (or should be) to care about and for the memory of others. In the next section, my analysis will draw from scholarship suggesting that a literary care ethics that centers disability will (among other things) avoid creating literary spectacle and will attend to the social construction of normalcy and its consequences.

SPECTACLE: BROWN’S *CRITICAL CARE* AND NEALON’S *BEAUTIFUL UNBROKEN*

In terms of theorizing an ethics of care that centers disability justice, a crucial methodology of ethical caretaker memoirs is to avoid spectacularizing disability and creating the conditions of voyeurism, and to instead “pay more attention to the construction of normality, and the taken for granted assumptions which underlie it” (Shakespeare 138). In what follows, I will consider the extent to which a selection of nurse memoirs interrogates conditions of normalcy. Ultimately, the examples I draw from demonstrate an astute recognition of the social elements of disability and of how cultural constructions of normalcy frame people’s experiences with disability. At the same time, however, I argue that both examples limit their meditation upon normalcy to the realm of individual misfortune, rather than assessing the need for cultural change.

In Theresa Brown’s memoir *Critical Care: A New Nurse Faces Death, Life, and Everything In Between* (2010), the speaker recognizes the constructed nature of “normalcy” both in her work as a caretaker and in her personal experiences with disability. However,

the conclusions that Brown's narrator draws in relation to confronting the imposition of normalcy stop short of meaningful intervention. For example, the speaker asserts that normalcy is fundamentally a social construction when she observes that her perception of what counts as "normal" shifts over time. She writes:

When I first started working as a nurse, the hospital seemed like the least 'normal' place I had ever been. We stick tubes in every possible human orifice [...] measure their urine, count their bowel movements. The craziness *is* normal, and the only thing that's really normal is the fundamental humanness that unites us all. (Brown, *Critical Care* 127)

The speaker asserts a care ethic that resists subscribing unquestioningly to mandates of normalcy. Moreover, the narrator recognizes normalcy as a social construct because the things that count as "normal" shift as one enters the hospital and spends more time inside.

She also recognizes the impositions of normalcy when she experiences disability resulting from a broken leg. Using the context of this experience as leverage in her memoir, the speaker describes the ableism of clinical nursing, which, in her experience, does not make meaningful accommodations for access needs—even those needs which are temporary, as is the case with the narrator's leg. Having been relegated to exclusively administrative duties because of her leg injury, Brown's speaker writes:

Pain hurts, disability leads to exclusion, and enforced inactivity induces desperation. I've seen these truths evidence in all my patients; now I have learned them for myself. We all only have one body. Take care of yourself, use caution, and whatever you do, if at all possible, don't get hurt. (*Critical Care* 59)

The speaker astutely recognizes the importance of access and its relationship to inclusivity; she touches briefly upon some of the social implications—exclusion, lack of access, emotional and physical pain—of a hospital environment that remains ironically

inhospitable to a worker's disability. Yet toward the end of the excerpt, the speaker concludes with advice that doubles down upon individual responsibility, rather than including a more subversive critique of bureaucracy and the enforcement of normalcy. The narrator thereby falls short of acknowledging that, although we are united in our "fundamental humanness"—a humanness that sometimes needs needle pokes and urine measurements (Brown, *Critical Care* 127)—our systems and cultures often fail to accommodate those different needs. Although the narrator certainly recognizes the need for institutional change, the final sentiment here shies away from disability advocacy and instead reverts to a more individualized, ableist mindset: try not to get hurt.

Likewise, the narrator of Mary Jane Nealon's *Beautiful Unbroken: One Nurse's Life* (2011) also practices an ethics of care that includes observations about the construction of normalcy and the consequences for deviating from what's considered normal. However, like the above example from Brown's memoir, Nealon's restricts its conclusions about normalcy to the realm of the individual. The most poignant example of this comes in a scene with a man named Gene, who has lost his left ear and eye in a boating accident. The narrator observes, "The remaining portion of his face was handsome, the unshaved side of his head covered with sun-bleached blond curls. He looked up at me to see how I would react to him, and I looked him squarely in the good eye" (Nealon 97). We can read the narrator's avoidance of overly-spectacularized or gruesome descriptions of Gene's post-surgery face as an act of literary caretaking. The literary approach to caring for Gene includes an insistence upon looking into his good eye—much the same way that the in-scene caregiver chooses to approach Gene. Thus, readers are not invited to become voyeurs

at Gene's bedside and are not made privy to the explicit details of his appearance. Instead, both the in-scene nurse and the nurse narrator respect the process of Gene's recovery and take care not to react (or invite readers to react) in a way that objectifies him as a spectacle.

In one sense, we can read this scene as a double act of caring: Gene is not made the object of a reader's fascination, and readers are not asked to abandon their ethics as respectful, second-hand witnesses. As Rosemarie Garland-Thomson writes, "The face to be saved in staring encounters is not the face of the staree, but the face of the starrer." She describes staring as a "process of social choreography" and argues that any faux pas in a staring encounter is due to the starrer's "breach of social etiquette" ("Ways of Staring" 179-180). Taking care not to make Gene even more uncomfortable with his new face, the nurse narrator avoids staring altogether. Moreover, by applying her in-scene care ethics to the literary composition of this moment, the nurse speaker mediates any harmful staring with which the reader might otherwise engage.

It's important to distinguish that the narrator does not appear to avoid looking at the injured side of Gene's face altogether—she simply avoids a dramatized, voyeuristic description of it. The in-scene nurse must tend closely to Gene's wounds, but apart from noting the missing ear and eye, the narrator includes only a single, matter-of-fact description of the injured half of Gene's face: "Each slice of skin had been reattached like a fan and sewn together with hairlike blue sutures" (Nealon 97). I make this distinction mainly to suggest that a full avoidance of engaging with Gene's injury may very well amount to a reification of the "normal," as if to say that Gene hasn't "lost" everything because he still has the normative, handsome half of his face. The narrator does not ignore

Gene's injury, and instead opts for a more conservative description of Gene's skin grafts to model a form of looking that is not staring.

Yet it is difficult to say whether the narrator's engagement with Gene's injuries amounts to a full cultural critique of mainstream approaches to disability—especially disabilities that are visible and often provoke the types of stare encounters that Garland Thomson describes. The narrator models a looking-without-staring literary care ethics and goes on to mourn the stares that Gene and his family will likely endure. However, the speaker stops short of a more radical social critique of staring. For example, she wonders about Gene's wife and future child: "Now she would be stared at when she was with him. And when they did have a baby who was whole and good looking, would the child be embarrassed by Gene's face? Would he feel shame when his friends met his father?" (Nealon 98). In this example, the speaker recognizes Gene's new social reality and the impacts it might have on his family. Yet the rhetorical questions in this passage might suggest a sense that feeling shame would be a logical and appropriate response to getting stared at—a reading of Gene's situation that seems far from hopeful or empowering. Garland Thomson writes about the possibilities for people who tend to draw others' stares to reclaim the staring process, even in the wake of the exhaustion and trauma resulting from being stared at ("Ways of Staring" 181). One could argue that the narrative critiques our culture's habit of staring at and commenting upon others' bodies simply by virtue of resisting the stare itself. However, while the narrator explicitly suggests that it's a shame Gene and his family are going to get stared at, it does not explicitly suggest that the starers

themselves should be ashamed—or, as Garland Thomson puts it, that the starers need to save face (“Ways of Staring” 179).

I have argued that Brown’s memoir *Critical Care* and Nealon’s memoir *Beautiful Unbroken* both recognize the social elements of disability; at the same time, I have also argued that each stops just short of a call for cultural change. In making this second point, my intention is to point toward the unique potentials for nursing memoirs (and any form of literary caretaking) to undertake an agenda of broader social and political critique based on firsthand experience. While it may be valid to assert that nurse memoirs are not responsible for undertaking the additional labor involved with such critique, it is my position here that ignoring or failing to attend to such possibilities can constitute a reification of harmful, ableist ideologies, however unintended such consequences may be.

CONCLUSION: IMAGINING NEW FORMS OF CARE

In making the above assessments of the literary caretaking emerging from each nurse memoir, I wish to return to a suggestion raised by the introduction to this chapter: A text that produces ethical literary caretaking that centers the interests of disability justice stands to benefit all of us. I have analyzed several nurse memoirs with an emphasis upon the topics of authority, appropriation and spectacle—and with an acknowledgement that there remains a rich array of ethical considerations that I have not yet had space to touch upon.

Leah Lakshmi Piepzna-Samarasinha writes about the importance of being ambitious and imaginative when it comes to recognizing forms of care: “I don’t think there

is any one single answer to the need for care [...] I want us to keep dreaming and experimenting with all these big, ambitious ways we dream care for each other into being” (39). My hope for this project is that, by (re)framing literature as an extension of caretaking practices, we can acknowledge a caretaker’s literary pursuits as an extension of the labor of care and as a meaningful vessel for continuing to care about others. Another implication is that it challenges caretaker writers (and all of us secondary witnesses) to consider their literary care ethics in the same way that we think about care ethics more broadly, asking how the writer’s form and rhetorical choices enact the ethics of care depicted in the text itself.

Of course, this meditation upon the possibilities of literary caretaking raises additional questions of interest to scholars and activists involved in feminist care ethics and disability: How can our engagement with literary caretaking contribute to the material, daily needs of those receiving care? How can it exist as a means of articulating further allyship between professional caregivers and those for whom they care, such that it supports the interest of all parties and minimizes exploitation, neglect, and ableism? These are big questions for which I have no clear answer; I offer them here as an opportunity for further discussion and as an invitation for others to continue theorizing concepts of literary care ethics into our discussions of health and disability justice.

Conclusion: Crises of Care and Covid-19 Nursing Testimony

Nurses have continued to care for us during the Covid-19 pandemic, risking their jobs, their health, and their lives. This conclusion is intended to honor the work they've done and continue to do, even in absence of structural support or adequate public health guidelines. I begin with the argument that the texts nurses produce in the wake of Covid-19 are additional sources of literary caretaking: nurses continue to offer their testimonies as extensions of their already overwhelming caregiving labor. Throughout years of crisis marked by resource scarcity, staff shortages, and so much uncertainty and fear, nurse testimonies bear witness to millions of deaths, expose institutional failures, and call out urgently for legislative changes and stronger political leadership. In what follows, I will discuss several examples of such testimony and unpack the care they perform, ending with a brief account of the nursing crisis confronting the United States and our national failure to care for the nurses who have cared so diligently for us.

To understand testimony as a sub-genre of autobiography I draw from Shoshana Felman's definition, which describes testimony as a discursive practice. Felman writes, "What the testimony does not offer is [...] a completed statement, a totalizable account of those events. In the testimony, language is in process and in trial, it does not possess itself as a conclusion, as the constatement of a verdict or the self-transparency of knowledge" (5). Acts of testimony are always necessarily incomplete; this remains true for testimony taking place during the Covid-19 pandemic, still ongoing as I write this in the summer of 2022, more than three years after the virus emerged. The authors included here respond to a crisis that is ongoing, describing their exhaustion even while there remains no end in sight. Leigh

Gilmore writes, “When violence is part of ‘what happened,’ then testimony must be part of ‘what’s next’” (307). Yet we must understand these nurses’ writing as both responding to violence and existing in its wake, as the violence continues and as the virus proceeds to kill thousands of people each day.

With this context in mind, I first turn to the testimony of a travel nurse named Lawanna Rivers, who posted a Facebook Live video on November 7, 2020. In the video, Rivers describes the atrocious conditions of a hospital in El Paso, Texas, stating, “Out of all the Covid assignments I’ve been on, this one here has really left me emotionally scarred. The facility I’m at has surpassed the one I was at in New York” (Rivers, qtd. in Collman). She goes on to detail a “pit” where people with Covid are placed and doctors refuse to enter. She says, “The morgue was so full of bodies that they had ran out of room, so once the doors opened the pit they come wheeling in a body already in a bag. Lined them up with the rest of our alive patients [...]” (Rivers, qtd. in Collman). Later, Rivers says, “I have never experienced, and have no words, for what I just experienced in El Paso, Texas” (qtd. in Collman). This video is an expression of trauma, where language fails to fully describe the effects of her experience. It is also an explicit rendering of the labor of testimony, which demands an intense, often painful engagement from the speaker so that others can be brought to bear witness second hand. It functions as an act of caretaking in that it honors the lives of those who were subject to the hospital’s malpractice and cannot

testify about their own mistreatment. Rivers' testimony asserts others' personhood¹⁷ in the face of inhumane treatment. She does this, for example, when she rebukes the doctors who abandoned people in need of care, leaving them in the pit to die. She takes care of the memories of patients, as Katrien De Moor writes ("The Doctor's Role" 220), by confronting and publicizing the horrible circumstances of their final moments.

The same argument might be made for a piece from *The Washington Post* in April 2020, which includes the first-person testimony of an ER nurse named Mikaela Sakal. In her testimony, Sakal recounts her experience working for a hospital in Detroit during the pandemic and her decision to quit after failing to convince administrators to hire more staff. This testimony employs several key devices that work to convey the urgency and trauma of the experience and to bring the audience closer to the events she describes. For example, she uses the second person throughout: "You need to be everywhere at once. That's how it feels. You don't go to the bathroom. You don't eat. You're lucky if you find time in a 12-hour shift to get water" (Sakal). The second person invites the reader to imagine themselves in such a scenario: the audience is literally being inserted into the narrative of Sakal's testimony and asked to bear witness to the trauma of the emergency room during the Covid-19 pandemic.

Her writing also uses short sentences in sequence, which performs the very urgency described by the content of the testimony. Sakal says, "Alarms are going off every minute.

¹⁷ Here I'm drawing upon Evelyn Nakano-Glenn's definition of care: "Caring can be defined most simply as the relationships and activities involved in maintaining people on a daily basis and intergenerationally" (Nakano-Glenn 5). We can read Rivers' assertion of others' personhood is a gesture of "maintaining people" in the ways Nakano-Glenn describes.

Pump alarms for the patients' life-sustaining medications. Monitor alarms. Oxygen alarms. Heart-rate alarms. Some beep, some chime, some ring. Every one could mean a crisis." The form is such that the pace of the text speeds up, almost as if the reader is being made to experience the maddening urgency of so many alarms. Again, we are being made a second-hand witness via the testimony of this ER nurse.

Sakal's text is doing much of the same work as Rivers' video: calling for accountability. She details not only the demands such circumstances have made on her but also the consequences of such circumstances for those seeking care, whose alarms continue to sound without adequate response from an understaffed hospital. In doing so, she speaks to what Karen Foli calls "insufficient resource trauma," which occurs "when nurses don't have the staff, supplies, knowledge or access to other professionals to fulfill ethical or professional responsibilities." She names her institution, the Sinai Grace Hospital in Detroit, which she feels should be held responsible for undue trauma. Her claim that "It was impossible" is an indictment of her hospital's failure to provide adequate staffing, treatment resources, and protective equipment—all while demanding the impossible of their existing staff.

The urgency of moving constantly with very little (if any) time to connect with the people one is assigned to care for is part of the trauma of nursing during the pandemic. Sakal's testimony speaks to this element of her experience when she says, "You spend every minute moving from patient to patient, trying to keep them stable and alive." Yet her text also does some of the work of memorializing individuals, simultaneously describing the chaos of moving rapidly among patients and the intimate knowledge of one man's

death—a death that is caused by an overcrowded hospital and the very necessity of moving quickly among its inhabitants:

It was maybe 5 o'clock in the morning. I was responding to alarms and trying to keep an oxygen mask on one lady [...] and meanwhile, this other patient was in a room pretty far out of sight because we didn't have any other space. His blood-pressure medication must have run out. [...] This patient had come from a nursing home and he was a lot older. He was incredibly sick. It's a lot to process. There's sadness and guilt and so much anger at the situation. But we had to keep moving. We had to do the after-life care, and there were other alarms going off. (Sakal)

The very act of speaking about the man is evidence that, despite what little she knows about him, she continues to hold him in her memory—and now in the public memory, as well. Her testimony makes clear that his death was caused by too many people in need of care and too few nurses to provide it. She includes an expression of guilt and anger that cues us to think about the structural and institutional failures contributing to the eventual mistake that caused his death, and toward the trauma she experiences being subjected to such circumstances and pain. Sakal's interview testimony is therefore working on multiple levels in terms of what De Moor defines as “the sort of witnessing that is constructed [...] as an extension of practices of care and a continuation of the caring process” (“The Doctor's Role” 208-209). For the above reasons, we can consider the nurse speaker using testimony to extend the performance of after-life care that she mentions toward the end of the passage.

Sakal's description of what she witnessed in the Covid-19 ER resembles a snapshot in that she manages to capture a brief yet powerful moment. Plenty of examples of photographic testimony emerging from the Covid-19 pandemic create a similar effect, evoking the realities that caregivers face during this extended emergency. Two photos from a collection by Karen Cunningham, an intensive care nurse in New York, create a snapshot in much the same way as Sakal's interviewed testimony (see fig. 7). The photos depict two unnamed patients, one of whom is being intubated while the other is on oxygen after coming off a ventilator. Such snapshots (including Sakal's) recount a specific moment in time for each of their subjects. To a certain extent, these photographic



Figure 7. "Nurse anesthetists intubate a patient, risking exposure to aerosolized virus particles." (Left); "A patient receives oxygen after being taken off a ventilator." (Right) from Karen Cunningham; "A City Nurse"; *The New Yorker*, 4 May 2020.

testimonies memorialize their subjects: the care recipients depicted in each nurse's text now exist in a public archive by virtue of each nurse's testimony.

Yet each of the subjects is anonymous: we know very little about the figures featured in these testimonies. In the photo on the left, the angle does not provide access to the patient's face. In both photos, the subjects of care are out of focus: the sharpest elements of each photo are the side of the nurse's covered head on the left, and the woman's hand

gripping the hospital bed on the right. In all three examples—Cunningham’s photographs and Sakal’s interview—the patients’ identities themselves are out of focus. The nurses capture an ethereal image of these subjects of care during the traumatic blur of a hospital shift. In other words, the formal elements of each snapshot mirror the circumstances in which the nurses encountered them: chaotic, traumatic, and urgent. By making public such intimate experiences, both Sakal and Cunningham extend the caring process beyond the moment in time captured in each snapshot.

The nurses who testify to the trauma and injustices of the U.S. response to Covid-19 do not do so without risk. Acts of public testimony, particularly those that openly critique institutions, often come at a cost for the nurse writer. Within the past several years of the Covid-19 pandemic, there are several instances of caregivers testifying to an institution’s unsafe practices only to be fired from their jobs soon thereafter (Kristof). Theresa Brown, one of the nurses whose memoirs I have discussed at length in this project, argues that hospitals restricting employees’ speech during the pandemic “relates to the continuing corporatization of American medicine,” where hospital profits take precedence over safe and equitable caregiving environments (“The Reason”). Ultimately, nurses calling for policy reform to address staff shortages are a threat to the healthcare industry’s bottom line, and they are therefore often punished for speaking out. Yet, as we’ve seen in the above examples, nurses continue to respond to an ethical imperative to publicize maltreatment taking place behind hospital walls. The testimonies emerging from the Covid-19 pandemic accentuate a truth that was apparent long before the pandemic began:

safe, equitable working conditions for caregivers is directly connected to the availability of safe, equitable care for all of us.

However, safe, equitable working conditions are hardly what we're delivering for U.S. caregivers. The World Health Organization estimates that 80,000-180,000 care workers died from Covid-19 between January 2020 and May 2021 ("Health and Care"), and an estimated 3,600 health care workers died during the first year of the pandemic in the U.S. (Spencer and Jewett). Deaths of care workers in the U.S. are also tied to racial and class inequities within the workforce, such that two thirds of the estimated deceased are people of color and more than one third are people who were born outside of the U.S., with care workers from the Philippines disproportionately impacted. Lower-paid caretakers such as nurses and support staff are far more likely to die of Covid-19 than higher-paid physicians (Spencer and Jewett). Workers such as nursing assistants, home health aides, housekeepers, cooks and so forth also risk their lives during the pandemic, with very low pay and less access to protective equipment than doctors and nurses. These workers, too, are overwhelmingly women and people of color (Kinder).

While the death tolls and lack of protections for low-income caregivers is itself evidence of unsafe working conditions, further evidence demonstrates the harsh working conditions caregivers face. Anecdotes from nurses detail incidents of being called names, bitten, choked, punched, and kicked by patients (Kessel and Knight). On top of that, administrators intentionally understaff hospitals to maximize profits, a practice that has been ongoing for many years but that the Covid-19 pandemic has brought into stark relief (Kessel and Knight). Fewer nurses results in dangerous and exploitative working

conditions for caregivers—and inadequate attention for those seeking care. While about one third of nurses experienced burnout before the pandemic, that rate has more than doubled. Now, 92% of surveyed critical care nurses reported that stress and negative experiences during the pandemic would shorten their careers (Cueto).

Nursing shortages impact all of us, leading to the dangerous conditions that Sakal's testimony illuminates, where one patient died because an understaffed hospital forgot his blood pressure medication. According to Kimberly Wills O'Connell, a nurse for 35 years, "There have been many instances where patients have died that shouldn't have died. I know that unequivocally" (qtd. in Kessel and Knight). Similarly, Marci Keating, who is leaving the profession after 24 years of nursing, says, "I will never work in a hospital setting again. I will never subject myself to that sort of frustration, and I will never be part of what's being done to patients in a hospital that way" (qtd. in Kessel and Knight). In short, the pandemic has made it more obvious than ever how little care we have directed toward the professionals we expect to care for us.

Considering the risks these nurses take in speaking out, it becomes even more incumbent upon us to respond by demanding conditions for caretaking that stand to serve all of us—this is, after all, the promise of an ethics of care informed by a disability framework. As *The New York Times* reports, one solution involves passing laws that limit the number of care recipients for each nurse (Kessel and Knight), thereby curbing the overwhelming effects of massive demands for care. Without further action, we stand to face a projected shortage of half a million registered nurses in the U.S. by the year 2030 (Zhang et al. 235). What some news headlines are calling a nursing shortage is not truly a

shortage of caregivers, but instead a shortage of jobs being offered by profit-driven hospitals and a shortage of caregiving professionals able to work under such exploitative conditions (Kessel and Knight).

Reading nursing testimonies emerging during the Covid-19 pandemic through the lens of disability-centered care ethics demonstrates that it is not only the virus impacting our health and safety. Our approaches to giving and receiving care are shaped by the social, cultural and political structures that make it possible for “the pit” in El Paso, Texas to exist, for low-wage caregivers to go without protective equipment, and for overwhelmed nurses to be ostracized from the profession for speaking up. This project has helped define caretaking that engages in efforts of feminism, anti-racism, and disability justice. The pandemic has made it clear that a movement toward this type of disability-centered care is as urgent and necessary now as it ever has been.

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