

THESIS

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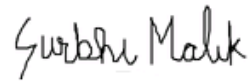


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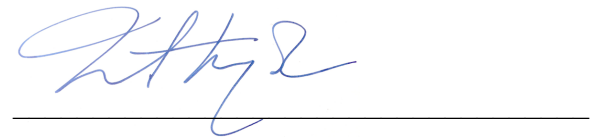
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EMBODIED EXPERIENCES OF CAREGIVING:
LITERATURE AS A LENS FOR THE HEALTH HUMANITIES

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A THESIS

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Abstract

In an age where rates of burnout and compassion fatigue are soaring, interrupting the throughline of care, both patients and caregivers alike are falling through the cracks. These bodies and persons, each of them both giving and receiving care, point to the critical need to understand the human cost and human triumph of healthcare. Each chapter herein engages with the embodied experiences of caregivers, informal and formal, demonstrating the weight of their work and how they are othered from those they care for, the community that surrounds them, and themselves. Departing from conventional methods of querying caregiving, this project bridges health and humanities, medicine and literature, in an effort to reframe care – who, with what body, voice, and illness experience, has access to that care. In probing several experiences of caregivers, I investigate the gaps in caregiving, thus calling for more attentive and holistic care for those bodies and persons that have fallen outside of the purview of routine Western medicine. The pain they endure, the disease or disability with which they are diagnosed, and the care that they give and receive, are located beyond the normative medicalized optic, in other words, the normative way that medicine *sees and categorizes* people and bodies. In engaging with a variety of texts, novels such as Marilynne Robinson's *Home*, Anne Enright's *The Green Road*, Tommy Orange's *There There*, and Karen Tei Yamashita's *Tropic of Orange*, alongside Stephen Frears's film *Dirty Pretty Things* and Porochista Khakpour's memoir *Sick*, I argue that the *unsharability* of pain, the gap between patient and provider, afflicted and othered, is greatly diminished by literature, no matter how queer or alt-normative their experience. My analysis thus attends to such experiences, as they are a stand-in and a voice for those real-world bodies and people like them.

Acknowledgements

“Just pay attention, then patch
a few words together, and don’t try
to make them elaborate, this isn’t
a contest, but the doorway
into thanks...”

-Mary Oliver, “Praying”

I am deeply grateful to Creighton University for enriching my Jesuit spirituality – without the interdisciplinarity emphasized throughout my Jesuit education I would not have been so urged to marry my love for literature with my passion for medicine. That education was best given by the dear professors that have helped me so greatly throughout my undergraduate and graduate years, and with this project in particular: Lydia Cooper, Brooke Kowalke, Surbhi Malik, and Matthew Reznicek. Each of these kind mentors has broadened my horizons, compelling me to make connections beyond convention and so bridge my two worlds in a distinct manner. They have introduced me to theorists that have proven foundational in my analyses, have edited my papers over and over again, and have relentlessly supported me. These many pages and I are in their debt.

My gratitude also extends to my parents, family members, classmates, and friends, who have cheered with me to celebrate, cried with me to mourn, listened to my ideas in their earliest stages, stressed with me in every café and library throughout Omaha, NE, and even have distracted me in the best of ways. The most notable of these is certainly Sean – who believed in me when I truly struggled to believe in myself.

Lastly, for teaching me at such a young age that I am capable of great things, I am grateful to my PaPa, who even in death continues to encourage me every step of the way.

For PaPa

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INTRODUCTION:

THE GIFT OF THE HEALTH HUMANITIES

The path that sped me along to where I stand today, a candidate for the Master of Arts in English, also a member of the Class of 2021 at University of Nebraska Medical Center's Physician Assistant Program, was a bumpy one. I've met with plenty of bewildered expressions and perplexed probing as to why I am both of these things, planted in the borderlands between science and the humanities. I've had to edit that elevator speech time and time again, each repetition becoming a bit more compelling, listeners' reactions evolving from pure pleasantries to authentic interest. Throughout my time in the Masters program, I have attended to narrative, as narrative informs (or should inform) care. A healthcare provider is best equipped to provide for a patient when meeting him or her with empathic understanding. Formal healthcare providers (i.e. MDs, PAs, NPs, among others), however, are not the only ones providing. Informal caregivers (i.e. mothers and fathers, daughters and sons, friends and lovers) are also burdened by their work. We are in an age where rates of burnout and compassion fatigue are soaring, interrupting the throughline of care, and both patients and caregivers alike are falling through the cracks. It is my hope, through this thesis, to map the vast and complex web of health and caregiving, thereby rescuing the caregivers that have fallen into the great gap below that web. These bodies and persons, each of them both giving and receiving care, point to the critical need to understand the human cost and human triumph of healthcare.

Now the question: how did this thesis begin? Three distant years ago, I ended my undergraduate thesis for the English major with a plea for more holistic care for two Native American characters beset with mental illness, care that was more attentive to pathologized illness such as theirs, cultural oppression, and the effects of homelessness. In writing this critique of Western medicine as such, I had slowly and methodically crafted a bridge between my studies in English Literature and my pursuit of a career in the medical field. This project not only met with local success but received warm reception at a small international conference in the Medical Humanities in Warsaw, Poland. Before participating in this conference, hearing from a number of scholars and students interested in the same research as I, I had not yet realized there was a community for such discussions, a space to stake such claims. That place and that paper were kindling for my career, both as a student in the humanities and also as a future healthcare professional.

Upon graduating with my BA, I celebrated my interdisciplinarity with the trip to Poland and then returned, my excitement settling comfortably around me without really tracing its hopes for an equally interdisciplinary future. In my naiveté, I fervently hoped that an acceptance letter from a Physician Assistant program was in my near future. I would finish my year working at an Internal Medicine clinic with a few more supplemental science courses under my belt, and I would begin anew.

How joyously wrong was I.

Met with rejection ‘not according to plan’, not entirely a surprise as admission to PA programs is highly competitive, I fumbled for what choice to make, for what to do next. New job? More classes? Volunteer, where? I hastily and luckily, and happily too, accepted

a job as a Medical Assistant at an Orthopedic clinic in Council Bluffs, IA. A new space, new start, new application cycle. Renewed frustration.

Over a tearful cup of coffee with a couple of English professors, I was suddenly presented with a new opportunity. There was an open seat, back in the hallowed halls of my interdisciplinary undergraduate degree, in the Masters of English program. Initially, I dismissed their kind invitation to apply. ‘Not according to plan’ rang through my head as I drove home, battering my emotions back down into their confused, tissue-cluttered corners of my brain. Or I should say it tried. Because then, simultaneously, some kind of joy surged through, light splintering that frustrated and feeble and fatigued ‘Not according to plan.’ What if? Could I? I thought back to my undergraduate thesis, my attempt at marrying my love for literature and my interest in medicine. I pulled up to my apartment and opened my Oldsmobile’s driver-side door, but stayed put in the blue seat, sun and spring fragrances pouring in over me. As I sat, I phoned a friend, she more than just another Creighton English professor, but a cherished mentor. Forty-five minutes later, I was left to ponder her sage advice.

Since I’m writing this introduction, and you are reading or listening, you must know how that story ends. I applied, and was accepted for the MA. I had little clue of what I was getting myself into, but I was thrilled. A new challenge. I began that year with my two classmates, now dear friends, sitting beside me in our English 600 classroom, staring at a 10lb anthology on literary theory, *The Critical Tradition*. We each voiced our intentions for the program, and mine were simply this: to explore medical humanities and narrative medicine through literature and thus enhance my ability to be a narrative-competent and empathic healthcare provider.

This has always been the root of my interests in the MA classroom. My studies here at Creighton, coupled with my engagement in interdisciplinary conferences (both planning Creighton's own "You Are Here," and attending others), work in the healthcare field, and volunteering in the community, have collectively reshaped and restructured my passion, nuancing both my writing process and the ways in which I engage with people and patients. I began the Masters program anticipating writing on mental illness in the novel, continuing where I had left off in my undergraduate thesis. But that intent widened, refocusing through the lens of the literature and theories encountered in my coursework, and then unfurled very rapidly into a hope to engage with caregivers, and not just formal caregivers, but informal and alternative caregivers – a daughter caring for her infirm father, or a mother caring for her children.

One of the theoretical texts that helped me imagine this project and engage with personal and pained narratives is Elaine Scarry's *The Body in Pain*, which has been foundational in my understanding of writing on ill and diseased persons. The subject of Scarry's text is the experience of pain, and she further divides this into three smaller subjects – the difficulty of expressing physical pain, the complications of power that arise as a result of that difficulty, and the nature of both verbal and material expressibility. Scarry's theory takes hold of the mystery of pain and attempts to give it reason, much more than detailing neurological pathways and providing the medical explanation for pain:

Physical pain happens, of course, not several miles below our feet or many miles above our heads but within the bodies of persons who inhabit the world through which we each day make our way, and who may at any moment be separated from us by only a space of several inches... Pain's triumph [is] this absolute split

between one's sense of one's own reality and the reality of other persons. (Scarry 4)

Scarry claims the difficulty of pain, and therefore also of any illness, disease, or disability, lies in its unsharability. Though she largely dismisses psychological suffering and contends that physical pain is more at risk of inexpressibility, her theory is still greatly applicable. Scarry explains that “whatever pain achieves, it achieves it in part through its unsharability, and it endures this unsharability through its resistance to language” (Scarry 4). This unsharability obviously imparts frustration, most evident in a patient's experience with a provider who minimizes his or her experience. But this is not the only example. Throughout this thesis I engage with the embodied experiences of caregivers, informal and formal, demonstrating the weight of their work and how they are othered from those they care for, the community that surrounds them, and themselves. Scarry contends that work in any sense of the term is a source of pain, “thus, the wholly passive and acute suffering of physical pain becomes the self-regulated and modest suffering of work. Work is, then, a diminution of pain: the *aversive intensity* of pain becomes in work *controlled discomfort*” (Scarry 170-171). The “absolute split,” what Scarry calls “pain's absolute triumph,” between an audience's reality and the reality of whom they are reading/watching/listening to, becomes much slimmer through the narrative. This is then what literature accomplishes: it bridges the divide between a patient's pain and a provider's access to that pain, thus validating and reifying the goal of the health humanities.

What Scarry does not address in *The Body in Pain* is the spectrum of unsharability – who, with what body, is more easily able to share his or her pain, with peers or with healthcare practitioners? I've thus met Scarry's analysis of personal pain with an array of

theories that attend to alt-normative experiences of illness and disease. The most impactful of these in drawing my thesis to a close is Gayatri Gopinath's *Unruly Visions: The Aesthetics of Queer Diaspora*, which proposes an alternative mapping that extends space to queered, othered, and alternative bodies and formations (physical and psychological), including those othered by illness and disability. She broadens and stretches the definition of "queer" bodies to extend to those who are simply "out of place and disoriented in the landscape of heteronormativity" (Gopinath 21). Through this study, Gopinath seeks to lend space to those cast into shadow by the dominant nation-state and its frameworks (i.e. Western medicine), those that are "deemed without value within the map of the global capital," thus bringing queered and othered bodies into the aestheticized picture" (5). She is making an important contribution not just to transnational and feminist dialogue, but to the health humanities and disability studies as well, in asking that we pay heed to "the everyday, the personal, and the discarded that typically falls outside the purview of official archives" (8). The persons and bodies within this study have fallen outside that purview, the pain they endure and the care that they give and receive is located beyond the normative medicalized optic, in other words, the normative way that medicine *sees* people/bodies. My thesis thus attends to their experiences, as they are not only informative, but a stand-in and a voice for those real-world bodies and people like them.

Marilynne Robinson's *Home* is where this project begins, where my vision for the thesis originally began to take place. Throughout the novel, Robinson affords her audience with deeply intimate stories of perfectly flawed persons, in the midst of doubt and suffering, dealing with faith and with family, all very human experiences. *Home* permits readers the access to the domestic space of daughter Glory caring for her dying father and

her behaviorally-aberrant brother. Instead of engaging with the obviously disabled bodies of Robert and Jack Boughton, I chose to speak to and for Glory, as her voice is lost in the work of giving care. I felt a connection to Glory, Robinson's narrative reaffirming my love for narratives, out of a deeply empathic response to her experience.

At that time, just after Thanksgiving of 2017, my grandfather's health was slipping quickly, as his Congestive Heart Failure, Hypertension, Kidney Disease, and Edema worsened. Medications multiplied and oxygen sats dipped lower. The little green house on Mexico Street, home to so many memories for my mother, our family, and for me became cluttered with signs of this decline – little bed on wheels moved into the den, oxygen tubing roping its way through the high-pile carpet, oxygen tank coughing in a methodical rhythm, adult diapers stacked in the hall. At the slightest suggestion of out-of-home care, Papa resisted, straining against the change. So he stayed at home, and a CNA visited two to three times per week to help him ambulate and bathe. But the brunt of the care fell to my mother's hands. She filled her days with driving, forty-five minutes to and from his house, to doctor's appointments, to the pharmacy and the grocery store, and with caring for him, administering medications on the hour, monitoring his swelling, feeding him ever-smaller bites, wetting his lips.

Eight hours away from all of this, I still felt frayed, from grieving for Papa's pain and my mom's building stress and much greater grief. The impending loss, the heartbreak for my mom, reverberated through everything, anxiety ripping through every obligatory social encounter, which didn't feel fun, and every seated hour of halfhearted classwork, which didn't feel productive. Turning to Glory and *Home* felt both a frustrating and fruitful distraction. Even after Papa's passing. Coming back to Omaha after his funeral services

was so difficult. I wanted to quit writing in those tough moments. But he would not have let me quit were he still living. He would have encouraged me relentlessly. The stakes of my work were greater than my grief. I had a voice for mourning, but the voices on the pages in front of me did not.

I returned to *Home* and to Glory because she is voiceless, left without a way to advocate for herself and her health, of body and of mind and of spirit, as I felt my grandpa, and my mom especially, were without during his decline. I dove out of myself and into Robinson's novel, and it rescued me from feeling so sterile.

This thesis thus begins with my chapter on *Home*, entitled "The Labors of Love: Glory as Informal Caregiver in Marilynne Robinson's *Home*," which keys in on Glory's role as informal, and depressed, caregiver. Through Glory's role as informal caregiver, *Home* exposes the taxing environment of full-time caregiving and ratifies the physical, mental, and emotional burdens that caregivers shoulder. Throughout this study, I explore and analyze Glory's role as caregiver: its beginning, the relationships it overwrites, its limitations, and its implications for Robinson's audience. Reading Glory through an embodied sociological lens speaks to the experience of female informal caregivers, how their caregiving is both vocation and oppression, and how more heed should be paid to these vital servants of ailing persons. Spatial analysis of the home also aids my conclusions, as labor meets with love in this domestic space and thus threatens the sense of home, mobility, and well-being.

Chapter Two, "Unhealthful Ardeevin: Mothers and Their Space in the Home in Anne Enright's *The Green Road*," also investigates care in the domestic space of an

informal caregiver, this time a mother instead of a daughter. Matriarch Rosaleen Madigan, caught between love and abandonment, between exile and return, lays at the spatial center of the novel and the theoretical center of the family, with all of her impossibilities. Through her character, “*The Green Road* extends Enright’s unsentimental exploration of ‘the drama of being a mother’” (O’Neill 185). This drama is embedded in the domestic space of Ardeevin, the Madigan family home, and in the family itself. This critical analysis of Enright’s *The Green Road* employs Gaston Bachelard’s *Poetics of Space* to demonstrate the unhealthful space of Ardeevin. Bachelard finds that the home itself can be taken “as a *tool for analysis* of the human soul(s)” within (Bachelard xxxvii). Thus, the health of the home implicates the health of those who inhabit it. This unhealthfulness is rooted in maternal inheritance; the domestic space that Rosaleen crafted is lacking a healthy maternal figure, thus her children’s sense of home is unhealthy and they are left searching for home, ever unwhole. This paper first turns to Rosaleen and the space she defines/inhabits in Ardeevin, and then focuses in on her two adult daughters, Constance and Hanna, their connection to the space of the home and their forms of mothering. With Bachelard’s *Poetics* the spatial framework, my analysis also turns to trauma theories, Bessel Van der Kolk’s *The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma* and Kathleen Costello-Sullivan’s *Trauma and Recovery in the Twenty-First Century Irish Novel*, in order to dissect each woman’s embodied experience of trauma and the *dis-ease* that accompanies it.

Chapter Three, “‘An Unattended Wound’: Motherhood, Loss, & Care in Tommy Orange’s *There There*,” also attends to mothers, each a distinct member of the novel’s “chorus of voices, each struggling with loss and isolation, yet moving toward connection

with one another” (Mulson). Many sons and daughters within the pages of *There There* suffer mentally/psychologically, physically, emotionally, and socially at the failings of mothers, whether from alcoholism or substance abuse, depression or suicide. These children, now adults with pained perspectives, lack a piece of their own history without their mothers. Throughout this chapter, I critically engage with the narratives of-and-without care in Orange’s novel. These narratives include the stories of the mothers themselves, whose voices are just as subdued, whose wounds are just as deep. The implications for this study of fiction extend beyond literary studies alone. Examining these narratives of care, or the lack thereof, contributes to conversation regarding caregivers, emphasizing that heed be paid to the voices of all caregivers, formal or informal, doctor or nurse, mother or daughter. The mothers of *There There* are all caregivers, informal, not taught how to mother but expected to, even when suffering deeply from trauma or mental illness. How can we expect these mothers, their “bodies unattended”, (Orange) to provide adequate care when they are not adequately cared for themselves? I again turn to trauma via Van der Kolk, as well as Bonnie and Edward Duran and Maria Yellow Horse Brave Heart, Barbara Gurr, and Paula Gunn Allen, whose criticism speaks directly toward Native American feminine experience.

From here my thesis evolves beyond informal caregivers, not to say that their bodies are not important enough to command this whole space, but to include other poignantly ‘othered’ embodied experiences of caregiving. Chapter Four, titled “Healing the Global City: Diasporic Physicians in Karen Tei Yamashita’s *Tropic of Orange* and Stephen Frears’s *Dirty Pretty Things*,” analyzes ex-physicians Manzanar and Okwe, *former* formal caregivers in the eyes of the State, but informal caregivers to their

communities. Both men exemplify Donald Pease's "diasporic subject," "stateless peoples and subalterns" who cannot benefit from, and exist outside of, the "new globalized economic order" (Pease 41). While these texts are certainly different from one another, they are both explicitly transnational texts, occupied by bodies and peoples that do not have home and cannot 'naturally' belong to a first world nation. The racial and transnational body in these texts is erased as it tries to enter into these nations, crossing borders illegally. In telling these stories, Yamashita and Frears are undertaking a task unfulfilled by medicine and healthcare, paying attention to bodies shrouded by a neoliberal and hyper-capitalist world.. The story of these racialized and disembodied physicians deserves to be told just as much as the story of the racialized and disembodied patient. Through their narratives, Manzanar and Okwe are calling for Gopinath's "alternative cartography," a remapping and healing of the heteronormative global city to include and adequately care for queer and diasporic bodies.

Like Chapter Four, Chapter Five, "Querying & Queering Caregiving: Reading Bodies Othered by Illness Via Porochista Khakpour's *Sick: A Memoir*", also attends to a queer, diasporic, and 'sick' body that is "out of place and disoriented in the landscape of heteronormativity" (Gopinath 21). This disorientation is often expressed by individuals with 'unruly' bodies, bodies that defy the heteronormative definitions of health and wellness and also refuse to be disciplined into normative ways of 'well-being'. Through *Sick*, Khakpour portrays herself as such a person, in her experiences as an Iranian American woman with complicated chronic Lyme disease. This chapter thus investigates why it is that nonnormative bodies such as Khakpour's are consistently denied existence by the Western, heteronormative, and hegemonic optic. She experiences so many different

symptoms and attempts an array of treatments from a multitude of formal and informal healthcare practitioners. But despite her attempts, she is largely ineffectively cared for by her caregivers, due to her ‘queer’ existence as woman of color navigating chronic unhealth, and her insufficient care for herself. Through this study, I shed light on her and other patients’ experiences of ‘queering’ via disease and healthcare, and analyze and critique caregivers’ perceptions of queer bodies, thus querying (or queering) caregiving for ‘others.’

This final chapter on *Sick* is the most conclusive, firmly staking its claim, and really the claim of the entire thesis, for improved care for bodies that are outside of the normative medicalized aesthetic and framework. These bodies include informal caregivers like Glory, Rosaleen, and the mothers of *There There*, as well as diasporic subjects like Manzanar and Okwe, and patients like Khakpour. Ending with *Sick*, I feel, provides the most convincing argument for how a caregiver should engage with another’s illness experience, and is thus absolutely pertinent to my transition from the humanities to Physician Assistant education. My pursuit of the MA in English has molded me into a candidate uniquely equipped to be an empathic and skilled healthcare provider. These narratives have versed me in stories of illness, disease, and discomfort, allowing me to meet Others in their space, unsettling me from my position of privileged distance. The fruit of my Jesuit education is this familiarity with disease, and the consolations and desolations that accompany these stories. I will leave this institution not unprepared, but sincerely and deeply enriched, better able to holistically care for the persons who will one day entrust me with their stories.

CHAPTER ONE:

THE LABORS OF LOVE:

GLORY AS INFORMAL CAREGIVER IN MARILYNNE ROBINSON'S *HOME*

The field of health humanities takes stories of illness and disease as its literature, employing those stories as meaningful examples to help shape healthcare provider perceptions to better serve patients. This field thus reaches beyond recognizing that fiction speaks truths to real life. Marilynne Robinson's 2008 novel, *Home*, takes as its subject the private space of the home, specifically the home of a retired preacher in the fictional midwestern town of Gilead, Iowa, in 1956. The narrative details the homecoming of daughter, Glory, and son, Jack, to their father Robert Boughton, whose health is rapidly declining. While the novel seems most occupied with Boughton's physical illness and impending death, it also extends narrative space to the respective suffering of Glory and Jack. The sister and brother are not affected physically as their father, but mentally, Glory with depression, and behaviorally, Jack with autism spectrum disorder.

Most of the current scholarship on *Home* does not recognize Glory as the central figure of the narrative, let alone a mouthpiece for voicing the ethical implications of caretaking, because she often recedes into the background of her own narrative. *Home* is "told in free indirect discourse from the viewpoint of 38-year-old Glory;" much of the novel describes the other characters and events in great detail, but little of Glory herself is described ("MG" 89). Instead of using the narrative space to tell her own story, Glory is telling her brother Jack's story, and extending all of her efforts to help her father, giving his voice more power than her own. Jeffrey Gonzalez, in "Ontologies of Interdependence,

the Sacred, and Health Care: Marilynne Robinson's *Gilead* and *Home*," addresses Glory's decision to stay in the Boughton home with the hopes that Jack's son will one day return. He recognizes Glory's agency in this decision, instead of labeling it regressive, as readers of the novel often do. Gonzalez however chooses to focus more on interpreting Robinson's ethical argument instead of granting Glory the analysis she requires. William Deresiewicz, in his review of the novel, and Jennifer L. Holberg, and Susan Petit, in their literary criticism, claim that the story does belong to Glory, instead of Jack or Robert Boughton.

I align myself with these three scholars, and will employ their studies to explicate Glory's importance in the narrative, specifically utilizing Petit's analyses to explain Glory's role as informal, and depressed, caregiver. I argue that through Glory's role as informal caregiver, *Home* exposes the taxing environment of full-time caregiving and ratifies the physical, mental, and emotional burdens that caregivers shoulder. Throughout this study, I will explore and analyze Glory's role as caregiver: its beginning, the relationships it overwrites, its limitations, and its implications for Robinson's audience. Reading Glory through an embodied sociological lens speaks to the experience of female informal caregivers, how their caregiving is both vocation and oppression, and how more heed should be paid to these vital servants of ailing persons. Spatial analysis of the home also aids my conclusions, as labor meets with love in this domestic space and thus threatens the sense of home, mobility, and well-being.

In their article "Informal Caregiving and Its Impact on Health," David L. Roth and colleagues define an informal caregiver as "a person who provides some type of unpaid, ongoing assistance with activities of daily living... to a person with a chronic illness or a disability" (Roth *et. al* 310). The American Association of Retired Persons (AARP) 2015

Report, *Caregiving in the United States*, shares that 60-percent of all caregivers are female, 85-percent of which “provide care for a relative, with 49-percent caring for a parent or parent-in-law” (*Caregiving* 6). Pam Orzeck, through her years of research on women caregivers, explores the “emotional biographies of caregivers [in bereavement, which] are often centered on the caregiving role, its prominence, salience, and meaning in their lives,” in order to demonstrate the effect that caregiving has on identity (Orzeck 148). Orzeck elects to study women specifically because they “may experience the caregiving role differently as they typically take on more of the emotional tasks,” thus putting themselves at higher risk of emotional injury (146). AARP speaks at great lengths to the stresses and strains of caregiving, reporting that “the longer a caregiver has been providing care, the more likely she or he is to report *fair* or *poor* health [...] 22-percent of caregivers felt their health had gotten worse as a result of caregiving” (*Caregiving* 10). Their studies also show that caring for a parent or spouse, especially if affected by a chronic or long-term condition, is more emotionally stressful than caring for another relative or a non-relative. Marjorie Silverman employs body related social theory to explore the link between the body and caring. Konstantina Vasileiou and her associates, in their study “Experiences of Loneliness Associated with Being an Informal Caregiver: A Qualitative Investigation,” also explore the challenges set by informal caregiving, and assert that the “inability to ‘solve’ the problems that the person they cared for faced” is what causes their loneliness. This loneliness is “located within a context of powerlessness whereby caregivers lack control and efficacy” (Vasileiou 7). *Caregiving in the U.S.* identifies that only 16-percent of caregivers “say a health care provider has asked what they need to take care of themselves” (*Caregiving* 12). The emerging studies on informal caregiving all speak to the unmet needs

of these caregivers. Robinson's character Glory is a spokesperson for these caregivers; analysis of her character and her role as caregiver will echo these studies, bringing light to the role that is often obscured by the privacies of the home.

Marjorie Silverman, in her study "Sighs, smiles, and worried glances: How the body reveals women caregivers' lived experiences of care to older adults", provides a helpful overview of embodied sociological criticism. In this study, Silverman aims to "validate the importance of the subjective, everyday lived experience" of family caregiving (Silverman 289). The majority of informal caregivers are women, as is evident historically and in AARP's report, and thus they are often overlooked because caring is viewed as a part of "natural femaleness." Silverman's study involved monitoring a number of caregivers in their daily performance. The observed findings showed that "caregiving requires a high and consistent degree of emotion management, and simultaneously, of body management" (294). The data also demonstrated "multiple examples of the women divesting in their health, or depriving themselves of their bodily or health needs, confirming in part what research has shown about the prevalent self-neglect or negative health behaviors among caregivers" (294). Silverman closely probes the embodied aspects of caregiving and asserts that healthcare practitioners should use similar methods to pay heed to informal caregivers. The results of her study are directly applicable to *Home*, as the narrative provides a close look at Glory's embodied experience of caregiving.

Exploration of Glory's character and use of embodiment as critical theory requires conversation with Elaine Scarry's text, *The Body in Pain*. The subject of this text is the experience of pain, and Scarry further divides this into three smaller subjects – the difficulty of expressing physical pain, the complications of power that arise as a result of

that difficulty, and the nature of both verbal and material expressibility. Scarry's theory takes hold of the mystery of pain and attempts to give it reason, much more than detailing neurological pathways and providing the medical explanation for pain.

Physical pain happens, of course, not several miles below our feet or many miles above our heads but within the bodies of persons who inhabit the world through which we each day make our way, and who may at any moment be separated from us by only a space of several inches... Pain's triumph [is] this absolute split between one's sense of one's own reality and the reality of other persons. (Scarry 4)

The Body in Pain speaks directly to my analysis of Glory because the entirety of her experiences, most notably those moments that occupy present time in Robinson's novel, are marked by pain and the difficulty of expressing that pain. Glory's role as caregiver to her father and to her brother Jack is one of physical and psychological pain; she is the embodiment of caregiving and the tolls that it takes on a person. Scarry also elucidates the connection between work and pain, making *The Body in Pain* even more applicable to *Home*. Work in any sense of the term is a source of pain, "thus, the wholly passive and acute suffering of physical pain becomes the self-regulated and modest suffering of work. Work is, then, a diminution of pain: the *aversive intensity* of pain becomes in work *controlled discomfort*" (Scarry 170-171). Through Robinson's exquisitely detailed novel, the "absolute split" between her audience's reality and Glory's reality (the reality of caregivers) becomes much slimmer. Glory's suffering is exacerbated by her work as caregiver and stifled by its unsharability. She has to accept and control her discomfort, her

true discomfort only fully revealing itself in the insomnia that plagues her, in the quiet tears brought about by the depressing novels she chooses to read.

Home does not often allow Glory voice or agency, but it certainly provides an intimate account of Glory's thoughts. *Home* thus invites Robinson's audience to transcend Scarry's absolute split and attend to Glory's psychological suffering. Though Scarry largely dismisses psychological suffering and contends that physical pain is more at risk of inexpressibility, her theory still applies to analysis of *Home* and Glory's repressed torment. Scarry explains that "whatever pain achieves, it achieves it in part through its unsharability, and it endures this unsharability through its resistance to language" (Scarry 4). Robinson confronts this unsharability of pain in sharing the interiority of both the Boughton home and Glory. Informal caregivers occupy a physical and mental space of pain, both of the loved one they tend to and their own muffled pain. The homes of these caregivers and ill persons are not explored publicly, thus they do not afford the same visibility that a public healthcare facility affords. *Home* counters this in offering us a novel whose cover image is a bedroom, a rocking chair, or a front porch swing, depending upon the edition (Picador 2008; Farrar, Straus, & Giroux 2008; Harper Perennial 2009). These intimate and domestic images are representative of Glory's place in the narrative, confined to the domestic sphere. In the beginning of the novel, Robert Boughton remarks, "It was a good house [...] meaning that it had a gracious heart however awkward its appearance" (Robinson 4). Glory then asks herself, "Why should this staunch and upright house seem to her so abandoned? So heartbroken?" (4). Boughton may as well have said, "Glory was a good daughter, with a gracious heart despite her lack of place in the world," and Glory seems to be asking herself, "Why am I so abandoned and heartbroken?" The closer we come to the intimacies

of the Boughton household, the closer we come to knowing the entirety of Glory's depression and heartbreak, her psychological pain that resists the intimacy of language.

Petit has written three articles regarding *Home* and has thus analyzed Glory's character most of any scholar of Robinson's work. Petit asserts that because many readers overlook her, they "do not seem to realize that she (Glory) is suffering from depression" ("Mourning Glory" 90). Petit identifies the cause of Glory's depression as the discovery that her fiancé, who remains unnamed, "never intended to marry her – that he was, in fact, already married" (89). She also explains that Glory's incomplete mourning for Jack's daughter exacerbates this depression. Contrary to Petit's analysis, I find that the moment when Glory was faced with the news of Jack's illegitimate child, which was not disclosed to any of the other Boughton children, is when she first took on the burden of caregiving and, consequently, when she was first met with grief and the early stages of depression.

The novel begins with allusions to Glory's depression, her return home to Gilead to live with her ailing father brings her sadness and stagnancy: "'Home to stay, Glory! Yes!' her father said, and her heart sank" (Robinson 3). "Caregiving is often called the 'unwanted career,'" certainly valid in Glory's case, but it is the only available outcome for Glory (Orzeck 145-146). Her narrative beginning foretells her fate. She returns home not by choice, but because "she had to be somewhere... what an embarrassment that was, being somewhere because there was nowhere else for you to be" (37). We learn the true reason for Glory's homecoming later, that her fiancé never marries her and she is without her teaching job. Glory's reflections wax and wane throughout, not often revealing the full story or truth at one moment. The first mention of Jack's illegitimate daughter is early in the novel, as Glory recalls her naïve reaction to the unexplained birth.

Glory had not really understood why misery was any important part of her parents' response to the situation [...] she was fairly sure she would not have minded having a baby. Imbecile as she was then with loneliness and youth [...] It was disturbing to remember how happy she had been then, in the very middle of [her father's] deepest grief. (Robinson 17-18)

The three years of that child's life brought Glory more responsibility than she had known before, and she took to it with grace and happiness. Though she was the youngest of eight, she seems to have been shaped for caregiving. While Boughton's heavy grief over the family's responsibility to the young girl was present, it was certainly Glory that decided to take Annie Wheeler and the baby in, to try and give them the care that they were due, that they were lacking because of Jack's quick departure: "She was almost old enough to drive, and she was fairly sure she knew how it was done. So she took her father out into the country to see the baby" (18). Glory takes on care for four at this moment of her adolescence: for Annie, the baby girl, her father, and most importantly, for Jack. Glory feels estranged from Jack in the novel's present time, but he was the brother she felt closest to in her youth; he had not ignored her "so completely as the others" (54).

Jack's immoral conduct and misinterpretation of social rules here can be attributed to his purported autism. Though Glory does not comprehend Jack's behavior, her allegiance leads her to care for him beyond his realization, when he is far away from the visible melancholy of his father and the resounding anger of Gilead. Petit demonstrates how Jack's autism spectrum disorder explains his conduct after impregnating Annie.

Because autistics are prone to ‘misinterpreting rules, particularly social ones,’ Jack may not have known [...] what Annie wanted [...] Jack tells Glory that he did not know how to deal with his ‘shame’ when Annie had the baby and that ‘the best [he] could do’ was to leave town, as if his very presence was a source of pain for others. (“Living In Different Universes” 43)

Glory takes on this burden of caregiving without fully understanding Jack’s shame and the reason for his societal dysfunction. She begins to transition into the role of informal caregiver, an identity that she will embody for the rest of the narrative and likely the rest of her life. As Pam Orzeck describes in her article, “Identities in Transition: Women Caregivers in Bereavement,” “typically, what occurs is that the caregiving role subtly emerges out of an existing familial role” (Orzeck 146). This existing familial role is present in Glory’s compensation for what is lacking in Jack’s absence. Glory’s mother said to her once, shortly after Annie gave birth, “‘I believe that boy was born to break his father’s heart’ [...] That evening Glory wrote the first of her letters to Jack [...] [asking] that he call or make a visit home for their father’s sake” (Robinson 56). She wrote Jack letters with the “great hope” that he would come home and marry Annie, and drove her father out to the Wheeler home, “tense with responsibility, because she had only begun to drive, and excited and protective because suddenly her parents seemed to depend upon her” (57, 56). In “all the certainty of her youth,” she was so impressionable and thrilled to be of importance to the family in any shape or form (57).

While Glory’s parents were away for a Saturday, though “she had not spoken to them about her plan,” she convinced Annie to come apple picking and pie-baking (Robinson 233). Glory delivers Annie and the baby into the kitchen, the essence of the

Boughton home, in hopes of connecting her more closely with the Boughton family. Glory picked up the baby, who was beginning to “kick and fuss [...] and the baby struggled and wept and yearned away from her [...] ‘You just ain’t her mama,’ the girl said. ‘No use crying about it’” (234). At her own hearth, Glory is denied motherhood. This moment is of utmost significance for Glory’s role as informal caregiver: because she cannot be the mother to Jack’s daughter, she is resigned to caregiving. Her inability to mother and to care for Jack’s daughter, and the subsequent death of the child, is what brings on her insurmountable grief and the beginnings of her depression. While she says, “no one was at fault,” Glory blames herself. Her father reminds her of this in one of his final lucid conversations: “Have you put it aside? We thought you would never get over it. It nearly scared your mother to death the way you mourned for that child” (295). Here lies the significance in the child’s namelessness: if Glory were able to succeed in mothering her and adopting her and Annie into the family, the child would have had a name and would not have died so tragically at such a young age. Glory is swallowed up by this ‘failure.’

The grief that Glory experiences after the girl’s death is consistent with the way that many caregivers respond to the death of the care-receiver. Women in Orzeck’s research study “expressed common feelings of hopelessness, helplessness, and difficulties adjusting to their new status as ‘noncaregiver’ [...] Many of the women did not have identities to reclaim, as they had abandoned them along the caregiving trajectory” (Orzeck 156). These women shaped their identities around the care-receiver, and thus did not know how function ‘normally’ when the care-receiver was no longer a part of their lives. Orzeck’s conclusions extend to Glory. Even in her adolescence she had begun to shape her present and prospective identity around this child and around the hope that she would be a

mother to a child like her. It is out of her inexperience with grief and with caregiving that she finds difficulty with transitioning after the child's death. Where is she supposed to turn? Her difficulty is compounded by the depression, situational or not, that accompanies the death.

The implicit lack of closure for Glory in mourning the girl's death is what causes her to consistently turn back to "that old habit of hers, of making *a kind of happiness* for herself out of the thought that she could be [the] rescuer," in all of her described relationships (Robinson 248). She found happiness when the child was alive and subconsciously must believe that she will find happiness when she fulfills the same caregiving role again. She next fulfills a caregiving role in her relationship with her fiancé, the only extra-familial, romantic relationship she alludes to throughout the narrative. While Glory certainly did not begin the relationship, after he sought her out she easily identified him as the one 'in need,' perhaps even suffering from depression himself, as he was unsatisfied enough with his life to seek out a "vulnerable woman" (Jack's rather reductive title for Glory) and feed off of her need for him. Glory devoted an unimaginable amount of herself toward caring for this man, who, like Jack's daughter, remains unnamed. If Glory's relationship with him was successful and healthy, only then would he be able to be named and fully enter into her narrative. She invested both physical and emotional capital in her role of their relationship, and reaped only imagined benefits. She kept his letters and reread them over and over again, "she would notice a phrase, something about loneliness or weariness or the view from a train window, the intimacy of the ordinary and her heart would stir" (209). Signs of his weakness and his need fed her craving for connection and caregiving. And while she searched his writings for signs of care, he kept

a close record of the debts he owed her, only monetary debts of course, and not the emotional toll.

She blushed when she thought of it [...] He said, ‘It will take some time to repay you in full, since the total is quite large [...] I am sorry if I seem to have misled you.’ She could not let herself remember the lonely pleasures she found in living so simply, actually enjoying the renunciations and the economies that would some time make possible – what? – ordinary happiness. That kind of happiness she saw in the luncheonette, passed in the street. (Robinson 22)

She did this out of her need for the ‘intimacy of the ordinary,’ for any hope of the simple happiness she found when caring for Annie and the young girl. Glory’s limited and imagined intimacy with her fiancé further crippled her, sinking her into deeper depression, isolating her from her surroundings, and resigning her further to the caregiving role. But Glory is not the unknowing victim in this relationship; she “colluded in its fraudulence by not breaking off with the fiancé when she first realized he never intended to marry her” (Petit 98). She suspends her own abilities in order to better care for others. This is exemplified in her youth, her betrothal, her career as a teacher, and her return to Gilead where she cares for both her father and for Jack.

As do many caregivers, Glory “comprise(s) [her] body by directing [her] physical capital towards the care receiver rather than [towards herself]” (Silverman 290). She suppresses her own physical needs to better fit the caregiving role. In his condescending yet brotherly fashion, Jack tells Glory that he knows she never shared a bed with her fiancé as he did with Della, out of his intuition of “vulnerable women.” Glory’s pride is wounded,

and Robinson's audience is reminded just how much Glory was deprived of in her early assumption of the caregiving role. She was essentially sterilized in assigning herself this identity. Jack says, "'you were spared that, (a child of your union), at least.' [Glory] drew a deep breath" (Robinson 149). Glory is pained by his comment; she so much wanted to be a mother and she has been denied children because of her perpetual role as informal caregiver. Glory embodies a purely feminine role and space, the production of care as emotional capital, as opposed to the production of a male role, but she does not command it in the fashion as a mother might. Her narrative is almost entirely confined to the Boughton home, and within that home Glory is restricted to feminine spaces.

The kitchen is the place she embodies most fully; it is there where she dresses Jack's "wounded hand", cares for him closely for the first time (62). And it is there where she tends to the grief of her father and brother through flour and salt and baking powder, "as if [the grief] were a sickness, and she had nothing better to offer them than chicken and dumplings. But the thought that she could speak to them in their weary sleep with the memory of comfort lifted her spirits a little" (253). These feminine spaces are certainly motherly, but they are assumed without Glory having passed through the ritual stages of a mother. She has no ownership over these spaces either, she recedes into the home that she grew up in and is given just as much power as she was given as a young girl. Glory does not have a place of her own in the home "since the private sphere is often the location all things old, sick, or dirty," so she, as any informal caregiver has "very little respite from social expectations and hence they (and their bodies) are constantly performing" (Silverman 290). Robinson rarely affords description of Glory in her bedroom, save for those moments when she is racked by insomnia and loneliness. Glory never relaxes and

instead endlessly tends to the needs of her father and brother via her feminine capabilities in the kitchen.

In addition to being denied of feminine descriptions and compared to the other women of the narrative, Glory is also repeatedly denied agency and place in the novel. Because she is a woman she is not permitted the same space that the men of the narrative are. When Teddy comes home as their father's health slips perilously closer to death, Boughton says, "I want you boys (Jack and Teddy) to promise me you will help each other" (Robinson 261). Glory is there of course, but she is not addressed, not asked to promise, because it is expected of her. Her thirty-eight years of caring are proof enough that she will continue to care. Such moments of exclusion are frequent. Boughton once tells Jack, "A man with three fine brothers doesn't have to deal with the world on his own, like some kind of lone wolf." Jack responds, "Glory is helping me, aren't you, Glory?" Before Glory can answer, their father says, "That's good" (140). Glory's powerlessness in these moments, and in much of the novel, resonates with Vasileiou's descriptions of the powerlessness felt by the caregivers in her study.

There are multiple references to the fact that Glory is not a man, for instance, when Boughton is discussing the names of his children, he says, "Glory would have been Robert, but she wasn't a boy" (185). Glory interrupted the male lineage that Boughton had imagined in granting a child with his namesake. She was meant to be a boy, therefore her femininity is stunted, she must fulfill some other role than one that is fully feminine and maternal. If Glory were a man, she would not have been limited by vulnerability and would not have been confined to informal caregiving. Glory addresses this herself when reflecting on her childhood.

If she had been a man she might have chosen the ministry. That would have pleased her father. [...] She seemed always to have known that, to their father's mind, the world's great work was the business of men, of gentle, serious men well versed in Scripture and eloquent at prayer [...] They were the stewards of ultimate things. Women were creatures of a second rank, however pious, however beloved, however honored. (Robinson 20)

Ministers are caregivers for the community; they baptize infants and bless the sick, marry the young and bury the old. The ministry is a position of power, especially in a small Iowa town like Gilead where those "well versed in Scripture" were revered. Ministers inhabit holy spaces, but these spaces extend into the surrounding community. The church is an intimate place, but it is public, not private like the domestic sphere. It makes perfect sense that Glory chose to be a teacher then, when she is not permitted the pulpit. Classrooms are spaces of learning as are churches. Once she is dismissed from her school, what is left for her but to care for her ailing father and continue along the path she assumed when Jack's daughter died. In her womanhood she is given the hardships of a minister without the benefits. Caregivers, like ministers, "must fulfill the necessary tasks of their role and perform these with the requisite emotion and body management" (Silverman 294). Glory as informal caregiver has to repress her own physical and emotional needs without the 'glory,' social and eternal, that accompanies a position in the Church. Glory's womanhood was thus tainted with loneliness, "the sense that everything could have been otherwise... a palpable darkness," which Jennifer Holberg describes as "gendered inadequacy" (Robinson 20; Holberg 292).

But Glory's depression does not in the least diminish her faith. She accepts the pains of depression as she allows her faith to prescribe her behavior. Raised in an environment so imbued with Christian morals, Glory resigns herself to caregiving in an extremely Christ-like manner. Though the novel is inundated with references to Jack as a Christological figure, Glory is assuredly more Christ-like. Glory assumes her role with deference, observing her father's guidance as Jesus obeyed the commandments of his Father.

Deeply unhappy and lonely though she finds herself. Glory tries nevertheless to be what her name implies: the real presence of God to her family. Even though she does not have answers for the nature of the soul and cannot stomach debates about predestination, like Martha to Jack's Lazarus, she tries over and over again to manifest light and life—as much with food [...] as with understanding, both equally sacramental. (Holberg 293)

Her given name thus prescribes her actions – she is meant to glorify both God and her father through her every word and work. When her father falls ill and she is no longer detained by caring for her fiancé, Glory has no option other than to return home. The care that Glory provides for her father, Robert Boughton, is the most obvious instance of informal caregiving, most similar to the roles of countless daughters who return home to care for their ailing parents. As is typical to these relationships, Boughton still considers himself to have control over the household. He recognizes his declining health but he continues to cling to the burdens that he carried as a younger man. He is without his parish now, resigned to life in his ivy-wrapped and outdated home. Since he does not have his role as pastor, he stoops his shoulders further and settles under the heavy burden of worry

that surrounds his mysterious son Jack, the Prodigal Son. While Robert is so consumed with his grief for and love of Jack, he overlooks Glory's needs despite his affection for her.

Many readers respond to *Home* out of disdain for Jack and for the grief he has caused both Robert Boughton and Glory. I cannot help but feel empathetic toward him, he has led a difficult life and continues to suffer from several bad decisions he made in his younger days. Those decisions can be attributed to his autism spectrum disorder, which also explains his atypical behaviors. Jack's autism makes him even more difficult for Glory to care for, more so than if she were merely hoping to clean up the messes of his deviant past. She cares for him even in his absence at the promptings of her father, with her countless trips to the grocery store before Jack's homecoming, the many "weeks of trouble and disruption." As the cream pies began to spoil and the heads of lettuce began to wilt, she'd thought of smuggling it all out of the house by night to the neighbor's dogs, as it was food "tainted with bitterness and grief" (Robinson 29). The overflowing refrigerator was the result of her father's hope for Jack; he thought that by filling up the kitchen, the central space of the home, with food, an economic symbol of love, Jack would embrace and understand the love that his father, and Glory, had always extended to him. Jack's autism however would prevent him from understanding and from expressing emotional attachment in return, "like many autistics, he is emotionally immature, a problem no doubt exacerbated by his return to his childhood home" ("Living in Different Universes" 44).

The compounded care that Glory has to provide for her father and Jack wearies her. Jack gets the DeSoto running and drove the company out into the country, unintentionally driving very near to the Wheeler home, a place so central to the grief that all three of them carry. When they've made their way back home, Jack goes to help his father to the front

porch. Glory says, “‘Let me help.’ She took her father’s other arm, and they walked him into the house, slowly, carefully. Her helping did nothing to lessen her father’s pain, but it did spare Jack from being the sole immediate cause of it” (Robinson 165). There are several moments such as this throughout the narrative, where Glory intercedes on Jack’s behalf to save him from further shame. In an attempt to help mend Jack and Ames’s relationship, she gives up her Sunday morning to stay home with her father so that Jack can go to church. Boughton delights in this and wrings his hands hopefully all the while Jack is away. At the news of Ames’s homily, Glory says “I will never forgive him,” and Boughton mourns Ames’s rejection of his namesake. At the sound of the telephone, Boughton says, “If it’s Ames, tell him I’m dead” (167).

Though Jack is a source of pain for Glory and their father, he is also their saving grace. Before Jack’s homecoming, Glory was resigned to unhappiness, to care for her father until his death, to remain in the cluttered Boughton home, and to teach in Gilead’s schools. Jack’s return gave their father a hope and Glory a purpose. At one of the many points that Jack says he is going to leave Gilead, he admits “if we were to leave, we would be forever alienated from our little sister, on whom we have become surprisingly dependent.” Glory says he certainly would become alienated from her, and at that, Jack laughs and rubs his eyes, “thank you. A good brisk threat can orient a fellow. But what is this? Now you’re crying!” [Glory] said, ‘Never mind.’” (Robinson 165-6). Yet again, Glory’s ownership of her sadness is subsumed by Jack’s presence. It is only through his eyes and his words that we witness her psychological pain. Scarry explains that physical pain “does not simply resist language but actively destroys it,” as does psychological pain (Scarry 5). Therefore Glory’s voice is suppressed even further, not only does she bear the

weight of her own pain, she has to care for her father and Jack, enduring their wounds as Christ suffers the sins of his sheep.

Some of the most touching moments within *Home* are those that Jack allows Glory to fully care for him, instead of shying away from her touch, suspicious of her motives. Jack asks Glory for a haircut after she finishes grooming her father.

“Well, sure.” She was surprised. They had always been so careful of him, almost afraid to touch him. There was an aloofness about him more thoroughgoing than modesty or reticence. It was feral, and fragile. [...] Even his father patted his shoulder tentatively, shy and cautious. Why should a child have defended his loneliness that way? But let him have his ways, their father said, or he would be gone. He’d smile at them across that distance, and the smile was sad and hard, and it meant estrangement, even when he was with them. (Robinson 170)

Here again is further evidence to support a diagnosis of autism spectrum disorder in Jack. His mistrust of Glory, of his father, and of Christianity as a whole are the result of his impaired social functioning (Petit 44). Jack largely resists intimacy with Glory, but permits closeness in the kitchen; he is most a part of the Boughton home when he allows Glory to care for him, in turn allowing Glory to fulfill her role. The above scene occurs in the kitchen, as do all tender moments between Jack and Glory, hearkening back to her early attempt at caring for Annie and the unnamed child.

Feminine and embodied descriptions of Glory are largely withheld in *Home*, as are descriptions of her emotional response. The one description of Glory’s appearance is even limited to describing material; “Of course plain, respectable dresses hung in her closet,

suitable for the classroom. There were the cardigans and low-heeled shoes of that other life. No reason not to wear them” (Robinson 19). The wardrobe of a schoolmarm, or a “thirty-eight year old schoolgirl,” as she often describes herself, is hardly the symbol of fertility and femininity. The other women of the novel, all mothers, act as foils to Glory and represent what she cannot attain: Glory’s own mother, Annie, Della, and Lila. While Glory occupies the space of an informal caregiver, a typically feminine role, each of the other women exists as purely feminine and motherly. Glory’s mother has no other role than that of mother. She passed along the rituals of motherhood to Glory, such as the recipe for chicken and dumplings. Annie gave Glory a glimpse of motherhood at a young age, and deprived Glory of the mothering that she yearned for in not allowing herself or her daughter to become part of the Boughton family. Glory’s emotions toward Annie are never revealed, though she most likely feels sorry for her in one way, and begrudges her in another for withholding Jack’s daughter.

Glory does however express emotion toward the other woman of Jack’s life, Della. Glory describes hatred toward her for causing Jack such grief and not responding to any of his letters. Similar to Annie, she likely pities Della, for the interracial relationship that has endangered her, and envies her for the loving relationship that she found in the midst of hatred. Jack describes Della as his lover, the mother of his child, and as a daughter, when he speaks of her family. Glory muses, “It must have been this Della who kept him safe despite everything they feared, who may have kept him alive, and in any case who had made the world a tolerable place for him for a while” (232). Glory interprets Jack’s relationship with Della as caring in nature, as it is the only way in which she can understand a relationship, having never experienced intimate love herself. Jack hoped to make a life

with Della in Gilead, he “used to think [they] might slip into Gilead under cover of night, throw a little gravel at Ames’s window, say [their] I-do’s, get his blessing” (208). But the political climate of the day made it impossible, and Della had to leave St. Louis to return to her family, leaving Jack to return to Gilead “because everything had fallen to pieces” (208). Jack and Della managed to cultivate happiness in a political climate that tries to stamp out of the life of interracial relationships such as theirs. But the fact that they found happiness is what binds Glory further. She was unsuccessful at finding love and could not bear a child; she is without hope for the majority of the novel. Della brings Robert to Gilead to search for Jack, and they leave shortly thereafter to look for him in St. Louis; they have hope that they will find him. Della’s persistence seems to invigorate a similar sentiment in Glory. She watches Della leave Gilead and realizes “she could never change anything” about the house – the softness in Della’s eyes, Robert touching the tree in the front yard (323). Glory imagines “new love would transform all the old love and make its relics wonderful” (323). This new love is that of Jack’s little family. Once she pictures his son Robert coming back to visit Gilead, Glory is firmly resigned to caregive for the remainder of her days. While she may have initially hated Della, now she feels that Della and her son are members of the Boughton family and deserve the care she has been giving to every Boughton since she was a girl.

Lila, the fourth mother of the novel, also embodies what Glory cannot become. Lila is described as having a “stalwartly maternal frame” (160). She is always tending to her ill husband, her rambunctious son Robby, and to her fruitful garden; “Could you use some salad? It’s coming in faster than I can eat it myself and my men aren’t much for greens” (160). She possesses a power over her world that Glory that does not. Lila enters into the

porch conversations with the men, while Glory stands at their shoulders or behind the screen door. Lila thus has mobility that Glory does not. In one of the most important parts of the narrative, Lila answers Jack's question about predestination without skirting around the answer like Ames and Boughton have been doing. She says, "A person can change. Everything can change" (227). Jack thinks he is damned to hell for the actions of his unruly youth, but Lila challenges this assumption. Her response is crucial for Glory as well, because Glory thinks she is also damned, not to hell, but to a life of caregiving and loneliness. This is the question that Glory grapples with throughout the novel: whether or not she is capable of change. This too is a question for many informal caregivers. Glory's time is chiefly occupied by sitting, waiting, listening, reading; an accurate representation of life for informal caregivers. Glory pensively remarks to Jack, "This is a nightmare I've had a hundred times. The one where all the rest of you go off and begin your lives and I am left in an empty house... waiting for someone to notice I'm missing" (298). Jack looks about the house, and Glory realizes, "Dear Lord, he is missing it all in anticipation... if he dies I will still have to keep it [the same], because I have seen him look at it this way" (299). These are thoughts that encompass Glory when she still believes she does not have agency, finding that her fate has been decided for her. Here is where I agree with Jeffrey Gonzalez's limited analysis of Glory. Her decision at the end of the novel to stay in Gilead, to keep the house just the same for Jack's son Robert, is not a point of regression, but one of power, when Glory accepts her identity as informal caregiver out of the hope that young Robert will answer his father's prayers. Lila raises the argument that Glory can change, and Della helps Glory to decide if she will change. Instead of *resigning* to life in Gilead, Glory makes a firm but hopeful decision to stay, because "maybe this Robert will come

back someday [...] And I will think, He is young. He cannot know that my whole life has come down to this moment. That he has answered his father's prayers. The Lord is wonderful" (324-325). Her final prayer answers the novel's questions of change and agency – both are certainly possible for informal caregivers when they are given a voice.

Analysis of Glory thus far has pointed to the labors, guilt, and identity of informal caregivers as a whole. Glory endures the pains of depression and loneliness, "exacerbated by the requirement of constant attentiveness to the cared-for [persons]," as do many caregivers who are similarly isolated from their family, their world, and themselves (Vasileiou 6). When the novel draws to a close, Glory chooses to stay and care for the Boughton home and family. She no longer resigns her body to care but willfully elects to remain, asserting her agency in her own narrative for the first time, a crucial decision that rescues informal caregivers like Glory who have suffered such stagnancy. There is no one overarching solution to the emotional, psychological, financial, and physical burdens of informal caregiving. However, Glory's narrative can speak for caregivers, giving their often voiceless voices a space, thus "validating the importance of the subjective, everyday lived experience" of women like her (Silver 289). Robinson's novel *Home* clearly echoes Silverman's innovative study, as it provides a personal account of caregiving and asks that better care be given to a woman who labors out of love.

CHAPTER TWO:

UNHEALTHFUL ARDEEVIN: MOTHERS AND THEIR SPACE IN THE HOME IN ANNE ENRIGHT'S *THE GREEN ROAD*

A sense of home, or a search for the home, haunts any narrative concerning the family. The family is rooted by the space and the idea of the home, especially evident in Anne Enright's 2015 novel, *The Green Road*. Elizabeth Bowen remarks, "We not only require, we are as humans completed, by what the home gives us - location. Identity would be nothing without its frame" (Hepburn 163). Enright's novel is searching for just that, location and identity. Rosaleen and her children are caught in this quest, but so too was Enright when she was writing the novel. Enright, in an article she wrote for *The Guardian*, described her writing of *The Green Road* as a "touch of midlife madness," a return to the "dramatic west coast of Ireland and a way of writing she had always resisted" ("A Return to the Western Shore"). With the change in location, Enright began to question who she really was, and she let the wind of the green road, or the "boreen," blow those questions out of her mind.

Up on the green road, these questions were made beautiful [...] And when I sat back at the desk, sufficiently windblown, with a little wildness still running in my blood, I started to write a book about love and abandonment, exile and return, all those impossibilities. ("A Return to the Western Shore")

Matriarch Rosaleen Madigan, caught between love and abandonment, between exile and return, lays at the spatial center of the novel and the theoretical center of the family, with all of her impossibilities. Through her character, “*The Green Road* extends Enright’s unsentimental exploration of ‘the drama of being a mother’” (O’Neill 185). This drama, and the madness that Enright admitted to while writing, is embedded in the domestic space of Ardeevin, the Madigan family home, and in the family itself. This is also then, like Robinsob’s *Home*, a drama of an informal caregiver, and an unhealthful one at that.

The questions of space and identity that haunted Enright also haunted Gaston Bachelard in his exploration of home, *The Poetics of Space*. In the family home, “Bachelard discovers a metaphor of humanness. No other writer closes so accurately, so deftly, with the meanings of domestic space” (Bachelard vii). Bachelard dissects a person’s connection to space. One of the central questions he asks is, “how can secret rooms, rooms that have disappeared, become abodes for an unforgettable past?,” implying that the house is an intimate, topographical map for all who’ve inhabited it (xxxvi). Thus, in applying Bachelard’s *Poetics* to *The Green Road*, the house of Ardeevin can be taken “as a *tool for analysis* of the human soul(s)” within the novel (xxxvii). Bachelard illustrates that “the house we were born in is physically inscribed in us [...] a group of organic habits” written into our very being (14). He employs the example of making one’s way to the attic in the dark; we instinctively know the way because we’ve absorbed the map and memory of the house. The space of the home, physical and mental, is imprinted on its inhabitants. As identity meets with the space of the home, so too does identity meet with health. One’s identity rests on healthfulness, or the lack thereof. Therefore health and home are intricately intertwined as well. This critical analysis of Enright’s *The Green Road* will employ

Bachelard's *Poetics of Space* to demonstrate the unhealthful space of Ardeevin. This unhealthfulness is rooted in maternal inheritance; the domestic space that Rosaleen crafted is lacking a healthy maternal figure, thus her children's sense of home is unhealthy and they are left searching for home, ever unwhole. This paper will first turn to Rosaleen and the space she defines/inhabits in Ardeevin, and then will focus in on her two adult daughters, Constance and Hanna, their connection to the space of the home and their forms of mothering.

With Bachelard's *Poetics* as the spatial framework, this analysis will turn to both literary theory regarding trauma and analyses of Enright's novels. Kathleen Costello-Sullivan traces trauma through the contemporary Irish novel in her book, *Trauma and Recovery in the Twenty-First Century Irish Novel*. Costello-Sullivan is interested in how writing/representing trauma can "catalyze a move toward recovery and away from the stifling silences of the past" (Costello-Sullivan 5). One such traumatized body that she points to is the mother. The mother is also emphasized in Bessel Van der Kolk's encounter with trauma, *The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma*. His book reflects on his many patients' embodied experiences of trauma, and thus serves as "both a guide and an invitation - an invitation to dedicate ourselves to facing the reality of trauma, to explore how best to treat it, and to commit ourselves [...] to using every means we have to prevent it" (Van der Kolk 4).

Much of the criticism regarding Enright's *The Green Road* concerns motherhood and mothering, thus they'll be helpful in considering Rosaleen and the domestic space that she has constructed, and in analyzing Constance and Hannah as (un)healthful mothers. In Laura Sydora's article, "Motherhood in Enright's *The Gathering*," she dissects "the specter

of feminism” within the novel, which “ultimately materializ(es) the real conditions of womanhood and historiciz(es) maternity within the [Irish] national narrative” (Sydora 239). In “A Bionian Reading of the Mother in Anne Enright’s *The Green Road*”, Margaret O’Neill frames her analysis of the novel with William Bion’s interpretation of Samuel Taylor Coleridge. Rosaleen’s journey on Christmas night out on the green road is “like one that on a lonesome road, doth walk in fear and dread” (O’Neill 181). In identifying the many names by which Rosaleen is known, O’Neill explores Rosaleen and her role as mother “beyond preconceived ideas of motherhood,” how she is possessor and possessed by her children (181). Maria Amor Barros-Del Río looks to the fragmentation and vulnerability of the family in *The Green Road*, attributing it to modern globalization and a “collateral casualty of the Celtic Tiger in Ireland” (Barros-Del Río 35). As she credits Enright with shaping a beautifully fragmented narrative, she explores each character’s fragmentation and unfolds the emotional distance between them, reasoning, “collective fragmentation is captured in flashes of individual experiences and this formal disruption provides a kaleidoscopic view of family ties and extenuates the feeling of estrangement” (38). Her conclusions will aid analysis of the home as space, as there is a ‘collective fragmentation’ around the home and thus the mother-to-child relationship.

The novel begins at the Madigan home, “a house that had a little river in the garden and its own name on the gate; *ARDEEVIN*” (Enright 3). The name Ardeevin stems from “ard,” meaning height or peak, and “aoibhinn,” meaning delightful or pleasant, ironically implying that the home is the epitome of wonder, the perfect childhood home. It does not maintain this guise for long though, as we quickly witness a mother prone to taking “the horizontal solution,” as Dan likes to call it (13). Rosaleen Madigan is, according to

Constance, a woman always afflicted, always something the matter with her. Her head is in a fog when we very first meet her, and she sends Hanna to Considine's Medical Hall for Solpadeine, an analgesic with addictive properties. Rosaleen is plagued by depression, turning to pain-killers and the solitude of her bedchamber for care, either leaving her children to fend for themselves or "flying down the stairs at them" when they dared disturb her peace (13). A mother "ensconced," asleep or dead, rendered the house "fully tragic" (13). Bachelard reminds us of the verticality of the home: "we go both up and down the stairway to the bed-chamber [...] Twelve-year olds even go up it in *ascending scales*, in thirds and fourths [...] What joy for the legs to go up four steps at a time!" (Bachelard 26). Such joy is sparse for the Madigan children when their mother is absent, a ghost haunting the first floor in her stead.

There was a shaft of cold air twisting in front of the cracked hearth in the front room that was actually someone's ghost, she thought. The house was its weirdly empty self, with their mother 'sequestered,' as Dan used to call it. Horizontal. With her mother dead. [...] her mother - who was warm and actually, beautifully alive... (Enright 32)

It is spatially significant that she took the horizontal solution not on a settee in the sitting room, or something of the like, but in her bed-chamber, a room that oneirically and physically looms over the rest of the house and over her and her children's consciousness.

It is Hanna's return from her trip to Galway with Dan, and the news that Dan has a girlfriend, that seems to finally rouse Rosaleen from her sequestered state. Hanna is afforded a few sweet moments of mothering, as she shares stories with her mother and they

recite Padraic Colum's "An Old Woman of the Roads" together: "O, to have a little house! To own the hearth and stool and all!" (Enright 33-4). The joined expression of this poem is significant, as are all poetic references in the novel. They both are innocently wishing for what they do not fully possess, "a house (or home) of [one's] own." Bachelard notes that the space of one's being is in itself a work of art, a poem. In reading, speaking, or inhabiting a poem, "the poem possesses us entirely [...] expressing us by making us what it expresses; in other words, it is at once a becoming of expression, and a becoming of our being. Here expression creates being" (Bachelard xxii). Rosaleen and Hanna, in expressing this poem of homelessness, are rendered homeless. Ardeevin is not a whole and healthful home, leaving them both with a longing that goes unfulfilled. The mother-daughter moments abruptly end when Rosaleen notices the filth of the tea towel she used as a headscarf, and when she realizes she has had a moment of intimacy with Hanna. When Hanna wanders into the "steamed-up" kitchen, looking for something to eat, she finds "the only thing cooking was dirty dish-rags [...] 'I thought I could do some cheese on toast, said Hanna and her mother said, 'I made him [...] He is my son and I don't like him[...] And there's no getting out of all that, because it's a vicious circle and I have only myself to blame" (Enright 34). The vicious circle is unrelenting and the chapter ends as it began, with Rosaleen's head in a fog and Hanna sent on another trip to the drug store for another box of Solpadeine. Rosaleen finds the promise of Ardeevin unfulfilled. Her depression renders her a shell of a mother, thus rendering the domestic space into a shell as well. Without Constance there to cook, Hanna is left to yet again make her cheese on toast, and yet again sent to Considine's, her mother's dependency her only example of attempted healing. With

this example, it is no great surprise that Hanna depends on alcohol as a coping mechanism, unsatisfied with her motherhood as was Rosaleen.

Hanna's chapter is Enright's most definitive example of Rosaleen as a mother who withholds, a mother who does not properly mother, thus also providing the most fruitful and intimate illustration of the home itself. "Through Hanna's eyes," Enright is able to intimately portray the mother-to-child, specifically mother-daughter, relationship, thus "devot(ing) the first chapter to depict the intricate relations that sustained the family," or, more accurately, those relations that fail to sustain (Barros-Del Río 40).

In Ardeevin, the reader is allowed to walk the different rooms and spaces of the house as the characters' changing moods are presented and their domestic life is depicted. Undoubtedly, the house is the place where these relations take form, so after the spread of the siblings, it is the only evidence of that former community [...] the family house in *The Green Road* is the place that embodies memories and meaning to essential notions of self. (Barros-Del Río 40-41)

The novel, beginning with the different rooms and spaces of Ardeevin, and characters, introduced with regard to their spatiality, is grounded in the home and in the traumatic memory of the home and of their mother. Beginning with Hanna's experience of Rosaleen and of the home, the novel proceeds to fully "trace the consequences of familial [...] dysfunction," all beginning with the maternal (Costello-Sullivan 18).

Rosaleen's existence in her home as mother was defined by her horizontal solution, her corpse-like presence in the bed-chamber, with an occasional "flying down the stairs" to scold her children. But how does she exist in Ardeevin when her children are no longer

there? With her husband many years in the grave? The house has become a shell, one of the imaginative spaces that Bachelard analyzes in his *Poetics of Space*. While Rosaleen sits at her kitchen table writing Christmas cards, beckoning her children home for Christmas of 2005, Enright's audience glimpses the shell-like qualities of Ardeevin and of Rosaleen herself. She is shrouded by an "embarrassment of silence" as she writes and voices another poem, Emily Lawless's "Fontenoy. 1745" (Enright 144). In Enright's *Guardian* article that I've referenced above, she describes the figures of this poem, Irish soldiers, as "the first lost Irish generation" ("A Return to the Western Shore"). As Padraic Colum's poem rendered Rosaleen and Hanna homeless, Rosaleen's voicing of Lawless's lines renders her lonely and lost, as were Lawless's figures: "'Oh, little Corca Baiscinn,' she said, also out loud, and looked to the darkening window where her reflection was beginning to shadow the pane. Or someone's shadow" (Enright 144). She is a ghost of herself, the clock on the wall "stopped these five years or more," the paint on the walls "a dusty rose, a colour which was unremarkable most of the day and then wonderful and blushing as the sun set. Like living in a shell" (145). Ardeevin is a shell without the Madigan family, and Rosaleen is a shell of herself without her health, afflicted with chronic headaches, depression, and now with the tremors and amnesiac state of Parkinson's disease, "the pity of it - an old woman" (166).

The house at Ardeevin is not only a home defined by Rosaleen and her existence as mother - it is also defined by the many bodies that've inhabited the place before her. As the space of the home imprints on the beings that reside(d) within it, so too does the house soak up the characters of those bodies: Rosaleen certainly, but her husband Pat, and her father John as well. Bachelard identifies the shell as a type of domestic space, a kind of

home. A shell is characterized by both emergence and “motionlessness” (Bachelard 111). A creature too long entrapped in its shell must be “preparing a ‘way out.’ This is true of the entire scale of metaphors, from the resurrection of a man in his grave, to the sudden outburst of one who has long been silent” (111). Rosaleen is this creature that Bachelard illustrates, especially when we consider her escape on Christmas night, “an over-excited creature emerg(ing) from a lifeless shell,” a kind of “repressed being” (111). A shell may imply that the creature within is small and weak, but Bachelard imagines that the shelled being is capable of “the most decisive type of aggressiveness, which is postponed aggressiveness, aggressiveness that bides its time” (112). This description is readily applicable to Rosaleen, holed away at Ardeevin, rendered apathetic and amnesic by her Parkinson’s. In her old age and ill health, she is now Bachelard’s repressed being because of the oneiric qualities of Ardeevin. Bachelard’s domestic space is so powerful because of its “always too contingent history of the persons who’ve encumbered it” (8). Rosaleen daydreams about Dan joining her in the kitchen; she catches “the sound of mischief upstairs and (looks) to the ceiling. But there were no children up there any more, she had chased them all way” (Enright 155). She’s left alone with the true ghosts of the house, not Dan, not the sounds of mischief, but that of her husband and her father, two men who defined and limited her existence and ability to feel fully at home in Ardeevin. Instead of her own ghost haunting the first floor, “her father’s ghost was a cold twist of air turning on the broken hearth,” her husband’s presence filling the space that her father did not (164).

After Constance drops groceries by and hastily leaves again, Rosaleen stands in the hallway in front of the stairs, “pull(s) herself up the stairs, one two [...] and then she came down again, to stand in the middle of the hall” (161). But does she make it up the stairs?

Hard to say, it's written in a oneiric quality that Bachelard would argue is Rosaleen's dream of having made it up the stairs in years past. In this dreaming of going upstairs, she recalls what her husband used to say to her, lying beside her: "I don't know what I am doing here' [...] He did not know what he was doing in this place - what he had been doing - if he had not wasted his life on her [...] Pat Madigan always knew who he *was*" (162). This spiteful reflection demonstrates, purely and simply, that Rosaleen does not know, and arguably never did know, who she is - not as woman, not as mother. Not only did she distance herself emotionally from her husband and her children, she distanced herself from *her own self*. Pat was permitted more than a confined existence to Ardeevin, something that Rosaleen seems to despise him for. And he still figures over her, even in death.

The big bedroom was directly above her now, its two windows facing the morning. And in the centre of it - just over her head - the double bed where her father lay dying, and then died. It was the bed where she herself had been conceived, and it was also her marriage bed [...] in it, all the pomp of her family life: kisses, fevers, broken waters, the damp of their lives, the sap [...] The bed was above her, ready to fall through the plaster, the place where her father died [...] the bed where Pat Madigan himself finally died... (Enright 161, 163).

Rosaleen does not exist without her role as carer, whether that was for her father, her husband, or her children. Caring is the 'damp' and the 'sap' of her life, and she has grown to resent it. Throughout this chapter, in the kitchen, underneath the bedroom, Rosaleen continually utters lines from James Clarence Mangan's poem, "Dark Rosaleen." This is a third poetic reference in the novel that seems to resign her to Ardeevin forever. The final two lines of the poem read, "Ere you can fade, ere you can die, / My Dark Rosaleen!"

The ode to the poem, “Dark Rosaleen,” and her descriptions of her father and of her husband are near-traumatic, veiled in fear and loneliness, not in warmth the memory of a loving father and husband might ideally recall. She feels abandoned by her children, but also by her father and her husband, and is forced to contend with the space that remains after their departure, spiritually and bodily, from the house: “A living symbol, Rosaleen engages in the construction of her own abandonment as her thoughts repeat the lines from Mangan’s poem” (O’Neill 183). As she dreamily floats up to the second floor of the house, she dwells on more of Mangan’s lines: “She pulled herself up the stairs, one two. *Shall glad your heart, shall give you hope, / Shall give you health, and help, and hope, / My Dark Rosaleen!* And then she came down again, to stand in the middle of the hall” (Enright 161). In peering up the stairs, willing herself up, “one two,” as she recalls the given lines, Rosaleen is dreaming into her healthful past, recalling the time when she was once able to bound up (or down) the stairs “four steps at a time” (Bachelard 26).

For Bachelard, homes are only oneirically complete if they have stairs - the stairs permit dreaming oneself into the past, both past-home and past-body. Permanent childhood is constituted by the space and the daydreams of the house, and “through this permanent childhood, we maintain the poetry of the past” (16). “Dark Rosaleen” is this poetry of the past, both Rosaleen’s own past and the past of feminized and exiled Ireland. She, a part of the history of feminine subjectivity in Ireland, is “consigned to the realm of motherhood,” her female identity rendering her “silent, idealistic, [...] largely invisible within the hegemonic historical narrative of the state” (Sydora 241). Rosaleen embodies the reality of maternal femininity in Ireland, as the “prioritization of the family as woman’s greatest contribution to the state converts the female body into a passive receptacle for childbearing

and reduces the act of sex to its capacity for reproduction” (250-251). The poem itself, as O’Neill elucidates, “allegorizes” Ireland as a “longed-for maiden,” trapping Rosaleen in this same kind of longing: the longing of her father’s wishes for her, still alive in his death; her husband’s bodily longing, not for sex but for the conception of children; and her children’s longing for their mother (O’Neill 183). Rosaleen dreams of retreating to a past where she reclaim her body and her sense of self, beyond the gate of Ardeevin and the green road. But “where else [could] she be?” (Enright 165)

[...] there was something wrong with the house and Rosaleen did not know what it was. It was as though she was wearing someone else’s coat, one that was the same as hers - the exact same, down to the make and size - but it wasn’t her coat, she could tell it wasn’t. It just looked the same.

Rosaleen was living in the wrong house, with the wrong colours on the walls, and no telling any more what the right colour might be [...] And where could you put yourself: if you could not feel at home in your own home? If the world turned into a series of lines and shapes, with nothing in the pattern to remind you what it was for. (Enright 165)

Rosaleen is essentially homeless, reduced to silence by the empty and haunted space of the house. The emotion she evokes is reminiscent of Bachelard’s “intimate immensity,” a chapter on the contemplation of grandeur (Bachelard 183). This contemplation of vastness has the ability to invoke global intimacy and freedom. For Rosaleen, contemplating the world beyond Ardeevin renders her terribly lonely, longing for the intimate immensity that her children have come to know by going out into the world, an act she has never been able

to do because of her health and her restricted role as wife and mother. As a means of bringing life back into the shell of Ardeevin, reverifying her and its existence, she compels her children in the postscript of her Christmas cards to come home for the holiday, because she has, very suddenly, “decided to sell the house” (Enright 166).

When the children all converge in Ardeevin, they meet with a clash. Emmett especially dreads going back home, a place he thought was “like living in a hole in the ground, where no one he truly cares for can join him because of the risk - *“I am sorry. I can not invite you home for Christmas because I am Irish and my family is mad”* (Enright 215; 212). They not only have to confront each other and their mother; they also have to confront the space of home and of many largely traumatic memories. Rosaleen’s decision to sell the house, her escape on Christmas night, and her flight from Dessie McGrath’s home at the news of Constance’s major surgery, all point to her attempt to evade the prescription in James Mangan’s poem: a death similar to that of her father and husband. Her departure, physical or spiritual, from the home(s) makes a subconscious attempt at self-definition, beyond how she is defined by her familial and domestic ties. *“Where did it begin?”* Rosaleen asks herself, out on the dreamlike green road; *“And where is the end of it. How long would she have to continue, being like this. Being herself”* (Enright 259-260). The choppy chapters that detail her wandering constitute what Margaret O’Neill calls a “search for existence or meaning [...] a movement from the known to the unknown” (O’Neill 184). This unknowing, along with the language that Rosaleen speaks, suspend her time on the green road in an oneiric state. Rosaleen’s reality is distorted here, evident in her meaningless wandering, losing the way, her speech: *“fuh fuh fuh fuh”* (Enright 273). This distortion could certainly be the result of her Parkinson’s, as the disease presents with

apathy, spatial unawareness, and amnesia. This distortion, whether linked to her Parkinson's or not, results from a violent spatial upheaval. It does not align with a Bachelardian daydream, but rather a kind of nightmare; her departure from an inhabited state illustrating Bachelard's "dynamic rivalry between house and universe" (Bachelard 47).

Bachelard calls the encounter with the space of the universe as that which occurs when we leave the house and its "warm substance of intimacy" (Bachelard 48). However, it is not this warm substance of intimacy that Rosaleen leaves behind. Instead she leaves behind her unhealth (or attempts to), along with the memory of that which was unfulfilled; the familial relationships that were born cold, and without intimacy. When she is crawling along the green road, through the cold of Christmas night, "in addition to the loss of speech, Rosaleen loses the ability to walk in the *womblike darkness* dragging one foot after the other until she eventually slows to a crawl" (O'Neill 185; emphasis added). This is reminiscent of Bachelard's 'permanent childhood', enacted by one's spatial relativity. As Rosaleen is a permanent mother, she is also a permanent child because of her place within Ardeevin, her childhood *and* adult home. This was the place where she walked past the study in an *anxiety* over disturbing her father's work. As she has resided there throughout the entirety of her life, it is no wonder that she is tied to it so strongly, every piece of her rooted in Ardeevin's dampness. Crawling on the green road, close the famine house, she recalls Pat again: "What did it mean, when the man who you loved was gone? A part of his body inside your own body and his arms wrapped about you. What happened when all of that was in the earth, deep down in the cemetery clay? Nothing happened" (Enright 266). Rosaleen felt she "did not exist. Oh no. Rosaleen did not matter" (273). The cold, and "a

deep trembling,” take ahold of her, at the same time she is filled by Pat’s voice, “*Where have you been, all this time?*” (274). As she navigates the dream-like brink between reality and unreality, between Bachelard’s house and the universe, her dead husband confronts her with the question that has been haunting her: Where has the true Rosaleen been? She has been ever-defined by her relationships - first her father John Considine, then her husband Pat Madigan, then her children - “she had fallen into the gap” between her children; between home and homeless, health and unhealth, loved and unloved (266).

The act of what Kathleen Costello-Sullivan calls “‘*presencing* suffering’ - making it tangible and thereby claiming a kind of narrative ownership,” is evident throughout Enright’s novel (Costello-Sullivan 22). The narratives of Rosaleen and her children are presencing suffering through their every bitter and jaded complaint, their disparate chapters allowing specifically the children the opportunity to ‘presence’ themselves apart from the Madigan family and apart from the space of Ardeevin. But what they do not do is presence their suffering to one another. According to Barros-Del Río, it is “only when Rosaleen gets lost walking the Green Road that her children are finally able to come to terms with the woman she is at present” (Barros-Del Río 46). I disagree - instead of ‘coming to terms’ with who Rosaleen deeply and truly is, I find that her children are still denying her true reality. With her absence, they are fully realizing her presence and her connection to the space that was, and still is, their home. Rosaleen’s exit from Ardeevin brings her children to a “ritual observance of an outside world that had entered the kitchen and filled it, silently, on this night. It was already here” (Enright 268). It takes a man called John Fairleigh, a man who Dan assumed was “some kind of impostor,” to wrench them to reality and contend with their mother’s ill health (277).

“How was she in herself?”

“Sorry?” said Emmet.

[...] “Our mother is absolutely fine.”

“She’s just a wonderful person,” Dan intervened, in a pathetic, upbeat kind of way.

[...] “She was never bipolar,” said Constance, utterly shocked.

[...] “Was she in any way despondent?”

Constance gave a small cry.

“Don’t worry. We had an elderly woman out for two nights running, September two years ago. And she wasn’t fantastic, in all fairness, but she was absolutely fine.”

The siblings were quiet then.

“It’s a good clear night,” he said, and looked at the map again. “Talk about Christmas.” (Enright 276)

He pushes them to face her absence, and in doing so, despite their repeated denial, they silently, slowly, and dumbfoundedly recognize her, their ‘despondent’ mother with all of her faults. Without her presence in the house, Ardeevin simply is not the same, impossible for it to be the same without its primary ghost. Rosaleen’s journey along the green road is an attempt to find herself and thus find a new kind of domestic space, but it also “represents a renegotiation of the balance of assertion and recognition in the mother-child relationship. Rosaleen requires her children’s recognition in order to experience a sense of self” (O’Neill 187). John Fairleigh, in bringing them to a recognition of their mother, then settles them

into their unease - “Talk about Christmas.” He misinterprets Ardeevin as a “space for cheer and intimacy,” as a family home should be, a “space that is supposed to condense and defend intimacy” against the impending outside universe (Bachelard 48). They have each personally realized the detriment of their childhood home, its lack of ‘cheer and intimacy,’ and the detriment of and to their mother.

After Constance brought the colossal Christmas dinner to the table, she took “her accustomed place, and there they all were [...] for a moment they pretended like nothing had happened,” no tears were shed, no house was intended for sale (Enright 238). They pretended:

This room would always be the same, and always theirs. It was older, now, of course [...]

The people inside the room were older, too. All of them so child-like still, despite the absurd grey hairs and the sagging skin in which their familiar eyes were set [...]

Each of them silently shouting that she could not take it away from them, whatever it was - their childhood, soaked into the walls of this house. (Enright 238-239)

As Rosaleen returns to a childlike state on the green road, so too do her children return to the fear of their largely motherless childhood. Though she was an inadequate mother, she was at least rooted to their home. But losing her further, to the cold and dark green road, felt frightening and “unbearable. Their concern was also a concern for themselves, of course. Some infant self, beyond tears [...] A searing want [...] the force of it, thus huge need for a woman [...] They did not know who she was - their mother, Rosaleen Madigan”

(Enright 284). Despite not knowing their mother, they did know that home and the childlike longings that it housed.

This ‘searing want’ leads this paper to regard the children of Ardeevin, now fully grown, two with children of their own. Rosaleen’s daughters, Constance and Hanna, illustrate the maternal inheritance of despair that is rooted in Ardeevin. This analysis will begin to trace their respective unanswered quests for health and for home. Let us return briefly to Ardeevin, before Rosaleen finangled her way out of the home and into the universe on the green road. The Christmas dinner provides Enright’s audience with the most intimate illustration of mother and Dan-and-Emmett, Constance-and-Hanna, of caregiver and her children; oh, “the power Rosaleen had over her children” when she insists on her serious intent to sell the house (Enright 240). This power she lords over them draws its lifeblood from the walls and windows of Ardeevin, a space she rendered insufficient with her insufficient mothering. In *The Body Keeps the Score*, Van der Kolk’s seventh chapter, “Getting on the Same Wavelength: Attachment and Attunement,” attends to caregivers, and how they shape young children. The child’s attachment to caregiver and therefore the place of caregiving provides, in the best case scenario, him or her with a secure base;

As we grow up, we gradually learn to take care of ourselves, both physically and emotionally, but we get our first lessons in self-care from the way that we are cared *for*. Mastering the skill of self-regulation depends on a large degree on how harmonious our early interactions with our caregivers are. Children whose parents are reliable sources of comfort and strength have a lifetime advantage - a kind of buffer against the worst that fate can hand them (Van der Kolk 112).

Each Madigan child, Constance and Hanna especially, were not provided with this ‘secure base’ that Van der Kolk speaks toward. Instead their narrative lives indicate what he calls a “disordered attachment” (Van der Kolk 122). Disordered attachment materializes in two distinct forms: “One group of mothers seemed to be too preoccupied with their own issues to attend to their infants. They were often intrusive and hostile; they alternated between rejecting their infants and acting as if they expected them to respond to *their* needs” (122). The other kind of mother is timid, “fragile” even, “they didn’t know how to be the adult in the relationship and seemed to want their children to comfort them” (122). Rosaleen seems to embody both forms of disordered attachment, as she is both hostile to her children, especially to Constance-as-adult, and too fragile to be motherly. Her hostility is most apparent when Constance delivers her groceries as she writes her Christmas cards. She calls after Constance when she’s left, “‘Lose some of that weight!’ [...] The woman was her daughter, she could say what she liked” (Enright 160). And her fragility is evident in her headaches and her ‘horizontal solution,’ as discussed early in this analysis - making Constance assume the role of mother (cooking, cleaning, et cetera) at an early age; and leaving Hanna to fend for herself, resorting to cheese on toast for many meals, and travelling to the drugstore to meet her mother’s bodily needs. Van der Kolk asserts that such mothers result from unfit mothering themselves, physical or emotional abuse rendering them similarly abusive toward their own children. Rosaleen’s presence in Ardeevin as mother garners energy from her anxious, but vaguely detailed, childhood at Ardeevin. Thus so too do Constance and Hanna soak up the inadequacies of their childhood and apply them to their motherhood.

Bachelard contends, “our house is our corner of the world. As has often been said, it is our first universe, a real cosmos in every sense of the word. If we look at it intimately, the humblest dwelling has beauty” (Bachelard 4). Ardeevin surely has its simple and small beauty, but what more clearly defines the Madigan home are its hauntings, as illustrated manifold throughout this analysis. The ghost of their mother’s body, the fog that ever-shrouded her head, haunts Constance and Hanna, so that they too have fallen into the gap between existence and non-existence, loved and unloved, Bachelard’s intimate space and the wide, gaping universe ready to swallow them whole. Estévez-Saá points to Enright’s attention to feminine bodies; how she “vindicating and emphasises the bodies of these maternal characters, bodies that have traditionally and conventionally confiscated in fiction” (Estévez-Saá 49). As Rosaleen’s body was subsumed by Ardeevin and her role as mother, Constance and Hanna’s bodies are similarly scarred: “[their] scars left by excesses in their way of living as well as by physical and psychological illnesses” (49).

Constance’s body has been altered after having given birth to three children, also because of the impact of the consumerism in which she is immersed and is, mostly, menaced by cancer [...] Hanna, the most beautiful of the Madigan children, suffers a chronic depression – probably due to having recently experienced maternity but also because of her professional failure in her career as an actress – that compels her to drinking and self-laceration (49-50)

As with their spirits, their minds and bodies have fallen into the gap as well, between health and unhealth.

Constance expresses a longing for her past body, the one that “had given her so many surprises, over the years” (Enright 74). Now her body is toxic and fat, “*Fun for all the family*, she thought, her body was a fabulous object, even Dessie her husband seemed to relish it. But Constance was fed up with herself,” expressing the same kind of tired frustration that Rosaleen voices (74). Despite their similar quips, Constance provides quite the contrast to Rosaleen. Rosaleen is the picture of Van der Kolk’s disorganized attachment, where Constance is a perfectly attentive and *constant* (consider her well-suited name) mother and daughter - so attentive that she denies her own bodily needs, even considering, “All [she] wanted to do was make people happy. Why was it her job to fix them? Not one of the people she cared so much about knew where she was [...] ‘*What will I buy for dinner, if I have cancer?*’ (96, 99). She describes her motherhood as having passed her by; Constance, still in the thick of mothering, “whose children were coming up to teenagers now, with no gap - or none that she could discern - between breast-feeding and breast cancer, between tending and dying. Who did not know what else she could do” besides mother (90). This mothering does not disclude caring for her own mother, who Constance worries over while in the hospital queue for her screening and diagnostic mammograms. She notably thinks back to Rosaleen “still out in the old house *in Ardeevin* [...] a hundred small things wrong with her [...] and] a house that was falling down around her ears” (94-95; emphasis added). She did not believe “there was a cure for grief, but she did think an anti-depressant might cut the worst of” Rosaleen’s affliction, as “she was on a little Seroxat herself, since her father got sick” (94). As Rosaleen is tied to Pat Madigan’s lingering memory, so too is Constance, still mourning the parent who parented, dreading continuing to care for the parent who still lives and never properly parented.

At the Christmas dinner table, Rosaleen announces that she will move in with Constance, a surprise to both Constance and her husband Dessie, sending Constance into a fit of “heifer-like” tears (Enright 237). What does Constance weep for? The loss of her already extremely limited freedom in her own house, or the loss of Ardeevin itself? Constance has been ever-possessed by her role as caregiver and by the space of the home. Bachelard writes that “the houses that were lost forever continue to live on in us” - I find Constance’s weeping as a realization that simply getting rid of Ardeevin will not un-inscribe it from her very being (Bachelard 56). She must contend with her reality, and try to bridge the gap that she is in danger of falling prey to.

Hanna too is a victim of the gap between love and unloved, health and unhealth. She is another mother, to a boy she treasures and detests all at the same time, the product of her unfulfilling relationship with Hugh that was supposed to “solve something fundamental in their lives” (Enright 188). Her son is not a baby that they had together, rather, “Hugh made a baby in Hanna,” she was only the carrier and carer for the baby (189). The girl “worried and fretted and was in charge of the baby. Because oh, if the baby lost his soother [...] then a hole would open in the universe and Hanna would fall through this hole and be forever lost” (190). She has a toxic body like Constance, not fat but fixated - on a need for alcohol, as if it might relieve the rift deep down inside her, the rift that began many years ago in the days of her youth at Ardeevin. When Hanna is sent to Casualty after her horribly bloody encounter with the wine bottle, she was given “no offer of pain relief” (186). No one in the hospital asked her “about post-natal depression and this was almost disappointing. (‘No, I’ve always had it,’ Hanna wanted to say, ‘I had it pre-natally. I think I had it in the womb’)” (187). What an ode to the maternal inheritance of the novel, this

pre-natal depression that she speaks of. The space of Ardeevin, crafted into something wholly disappointing, rendered those within entirely disappointed with themselves. “Take a fucking pill,” Hugh tells her, as if this will mend the traumatic “abodes of [her] unforgettable past” (Enright 187; Bachelard xxxvi). But Hanna still holds her home in high esteem, as if the space and her relationship with her mother can be rectified. Once Rosaleen has her children all gathered under the same roof, having shared her intention to sell the house, Hanna says, “‘You know, Mammy, it’s our house too.’ Rosaleen looked at her. She said, ‘Beautiful. Beautiful Hanna Madigan,’ depriving her of her identity, intelligence, and reality (as woman and as mother) with one biting word (Enright 240).

[Hanna] wondered where she could set it down, this hurt that sloshed around inside her [...] The glass [of the front window] was as old as the house. It was her favourite thing, a fragile survivor, slubbed and thickened to gather and distort the light [...] The house was disappearing around her, wall by wall. (Enright 253)

After Rosaleen was found and Christmas had passed, Hanna returned to Ardeevin, with Hugh and the baby, to help list the house on the market. Hugh went about the house with his Polaroid, “silently looking, then the click-whirr-click as the photograph was extruded, another silence as he shook the thing dry and a little piece of her childhood rose to view” (299). Laying in her childhood bed, “she wondered what it was she had wanted, before she had wanted a drink. A life. She had wanted a life [...] thirsted after the great unknown” (300). Here again is an instance that proves the adult’s suspension in childhood, daydreams of youth maintaining Bachelard’s “poetry of the past” (Bachelard 16). Hanna, Constance, Rosaleen - each pained mother painted in the poetry of their past, ensconced in Ardeevin.

Throughout Anne Enright's *The Green Road*, her audience bears witness to the importance and complexity of space. Gaston Bachelard's *The Poetics of Space*, alongside consideration of trauma theory in literature, provides a fruitful avenue for interpretation of this unhealthful and traumatic home. The Madigan home at Ardeevin is filled with ghosts – of bodies dead in the ground and the living Madigan bodies - Rosaleen, Constance, Hanna, all mothers and informal caregivers, each haunted by the duties and methods of caring, each exhibiting embodied experiences of caregiving. This analysis would greatly benefit from consideration of Dan and Emmet as well, as each family member “exhibit(s) some form of affliction and disorientation” (Barros-Del Río 44). The Madigan boys, while not as explicitly trapped in the gap of motherhood, are important figures that deserve to be spatially situated in the grief that soaks through the narrative's pages. Dan found that “the sun rose at the front and set in the back of Ardeevin;” it was his cosmos, his first universe, as Bachelard would call it (Enright 248). Ardeevin is the cosmos for all of the Madigans, whether they still reside under its roof or not. The Madigan family identity is given its frame and location by Ardeevin: the house and family exhibiting “a touch of madness [...] with a strong connection to [the] past” (“A Return to the Western Shore”).

CHAPTER THREE:

“AN UNATTENDED WOUND”:

MOTHERHOOD, LOSS, & CARE

IN TOMMY ORANGE’S *THERE THERE*

The wound that was made when white people came and took all that they took has never healed. *An unattended wound* becomes infected. Becomes a new kind of wound like the history of what actually happened became a new kind of history. *All these stories* that we haven’t been telling all this time, that we haven’t been listening to, are just part of what we need to heal. (Orange 137)

In his debut novel *There There*, Tommy Orange insightfully articulates a pained collective consciousness, an embodied notion and ‘unattended wound’ that is held and shared by each of his characters. As Jennifer Mulson poignantly remarks in her review, “The novel is built around a chorus of voices, each struggling with loss and isolation, yet moving toward connection with one another” (Mulson). This ‘chorus’ may seem disparate initially, composed of many distant and distinct voices and histories, but their paths do cross: in blood, in loss, and in tragedy. One of these intersections occurs via mothers and mothering, or the lack thereof. Many sons and daughters within the pages of *There There* have suffered mentally/psychologically, physically, emotionally, and socially at the failings of their mothers, whether it was due to alcoholism or substance abuse, depression or suicide. These children, now adults with pained perspectives, lack a piece of their own history without their mothers.

Throughout this chapter, I critically engage with the narratives of-and-without care in Tommy Orange’s *There There*. These narratives include the stories of mothers

themselves, whose voices are just as subdued, whose wounds are just as deep, even if their voices and bodies are not present. The implications for analysis of these narratives extend beyond literary studies alone. Examining these narratives of care, or the lack thereof, will lend toward my conversation regarding caregivers, emphasizing that heed be paid to the voices of all caregivers, formal or informal, doctor or nurse, mother or daughter. I turn my attention here to the causes and consequences of a lack of social and material support for caregivers, particularly maternal caregivers, and the epigenetic effect such lack of support creates in future generations.

The mothers of *There There* are all caregivers, informal, not taught how to mother but expected to, even when suffering deeply from trauma or mental illness, even when not yet of age, even when plagued by a lack of mothering from their own mother. All too often throughout history, these kinds of mothers have been deemed inadequate by politicized Western regimes, taken away from their mothers as children, now their children taken away from them. While there is no evidence of government interference in *There There*, the history of such interference hangs over the women of the novel like a threat, swaying from the beams of their consciousness. Barbara Gurr, in her sociological study, *Reproductive Justice*, responds to this history by interrogating “the State and its role in determining the shape and purpose of reproductive health care, particularly in marginalized communities” like those examined here (*Reproductive Justice* 6). Native womens’ bodies have been consistently neglected by the American government and Indian Health Services. How, then, can we expect these mothers, their ‘bodies unattended’, to provide adequate care for their sons and daughters when they are not adequately cared for themselves?

Before first opening the novel's orange cover and turning its first few pages, I had an initial hypothesis for why '*There There*.' "There, there" are the words from a mother's lips, carried by a gentle, tender voice, paired with a hand that sweeps the hair away from a child's tear-streaked face. Mothers, and their caring, are something largely missing from the novel. Those missing mothers are replaced by grandmothers or great-aunts, an original site for fracture and displacement. What further fractures and displaces is the legacy that those mothers leave behind, a legacy of unhealth and unwholeness. For Tony, this is the residual physical and mental effects of fetal alcohol syndrome. For Orvil, this is his mother's addiction and suicide. I am interested in exploring the mothers' health or unhealth, and how it translates to the health or unhealth of their sons and daughters. How does a lack of caring, a lack of "there there's," affect the characters within?

Literary Review

First, meeting with the mothers of *There There* requires conversation with Native scholarship, thus I turn to Paula Gunn Allen's gynosophical and feminist text, *The Sacred Hoop: Recovering the Feminine in American Indian Traditions*, as she attends to the lives and literature of American Indian women. She draws her traditional framework from the Keres Pueblos of the American Southwest, as they are one of the few remaining "Mother-Right peoples," who can thus convey "a clear sense of what gynocratic culture is about" (Gunn Allen 25). Gunn Allen emphasizes the need to return to feminist roots, roots which extend much deeper and farther back than the meetings of suffragettes at Seneca Falls. She emphasizes, "we as feminists must be aware of our history on this continent," reminding us that "the feminist idea of power as it ideally accrues to women stems from tribal sources"

(308, 317). Gunn Allen cites her mother and grandmother as instrumental in defining her own method of feminism, one that is deeply and widely respectful, especially to those bodies/persons and creations that are deemed by colonization to be unworthy. Her grandmother once told her, “Life is a circle, and everything has its place in it” – this is ‘the sacred hoop,’ catching and embracing everything within life’s circle (15). *The Sacred Hoop* thus demonstrates the gynocratic (woman-focused), not patriarchal, history of traditional tribal lifestyles and argues that such an understanding is “essential to all responsible activists who seek life-affirming social change” (16). Gunn Allen does not shy away from a collective Native hesitancy to adopt and assume ‘feminism’ because of its historical ties to nationhood, race, and whiteness. Her gynocentric aesthetic, without marginalizing itself from a white woman’s feminism, permits a wide diversity of people, even, and especially, such mothers herein, honor and respect.

Deeply inspired by Gunn Allen, Luana Ross also articulates a need for a reimagined feminism, one that she specifically labels transnational. Her article, “From the ‘F’ Word to Indigenous/Feminisms,” though brief, tackles the rather unstable bridge between Euroamerican feminists and Native women, asking, “Must women of color renounce feminism in order for racism to be dealt with effectively by white women?” (49). She cites transnational feminism as the necessary form of feminism because it best attends to Native feminine experience, stating, “we are transnational by definition because we are *nations*” (47-48, emphasis added). Even in these terms, transnational feminism does not exclude urban or federally-unrecognized peoples simply because they do not abide with a tribe or on reservation. Transnational feminism captures those persons caught in the borderlands between belonging, thus empowering all communities. Ross notes that her form of

transnational indigenous/feminism “includes female, male, and other genders [... and] privileges storytelling as a way to decolonize and empower our communities [...] work(ing) in ways that challenge prevailing attitudes and rigid institutions” (50).

Ross’s emphasis on storytelling as a way to challenge rigidity relates well to Gayatri Gopinath’s book, *Unruly Visions* (discussed at length throughout other analyses in this study) which calls for a queering of the very rigid, hegemonic, and patriarchal aesthetic that surveils all bodies and persons. Gopinath and her feminist inquiry can lend further perspective to Gunn Allen’s work. While Gopinath argues for a queered optic, Gunn Allen asks for an optic that “Remembers and Re-members,” not suggesting a new kind of aesthetic, but rather a return to an aesthetic that is deeply embedded in Native tradition (Gunn Allen 24). Gopinath and Gunn Allen would agree that these bodies unattended, bodies wounded, have been queered by colonization and “deemed without value in the map of global capital” (Gopinath 5). Those without power, significantly American Indian women, are deemed queer and out of place, savage even, in their unbelonging: “In contemporary times, those who view Indians as hostile savages paint modern Indian people as worthless, alcoholic, and lazy, unwilling to join in the general progressiveness and prosperity that is the final index of the righteousness of the American dream” (Gunn Allen 20). As Gunn Allen calls for an excavation of Native values, so too does Gopinath call for a “queer curation,” an act of caring for and caring about the past, seeking to reveal the “co-implication and radical relationality of seemingly disparate racial formations, geographies, temporalities, and colonial and postcolonial histories of displacement and dwelling” (Gopinath 4).

The above theorists seek attention for Native women's bodies. As I speak to the health of the mothers of *There There*, Lillian Tom-Orme's study, "Native American Women's Health Concerns" from *Health Issues for Women of Color: A Cultural Diversity Perspective*, will prove serviceable. Tom-Orme emphasizes just how lacking bodies of research are concerning American Indian/Alaska Native women. These women have arguably been rendered the least visible bodies, medically, socially, economically, and culturally, in the United States. Native women, "who are considered to be the central caregivers or backbone of the Indian family and kin networks, suffer disproportionately from various health problems that are considered to be preventable," and thus cannot healthfully give care to themselves, let alone their families (Ross 27). Tom-Orme presents visible and actual stakes of her project, asking that women be involved in their personal health care and community-level, culturally competent interventions.

To speak further toward care, I turn to the anthology *Studying Native America: Problems and Prospects*, as it proves particularly useful when engaging with the traumatized stories of *There There*, especially its third chapter: "Native Americans and the Trauma of History," by Bonnie and Edward Duran, and Maria Yellow Horse Brave Heart. This article is the result of a nine-year study of cases from an urban Indian clinic and emerges from a "hope to provide space for reimagining the present" (Duran 62 – decide how to cite, book or article). This reimagination envisions a new kind of care for Native Americans suffering from the psychological void of historical trauma, what the authors name the deepest "soul wound" (64). Orange's "unattended wound" echoes the study's attention to unresolved trauma, which is considered "intergenerationally cumulative, thus compounding the mental health problems of succeeding generations" (64). ...

Many Native American peoples face similar challenges to their physical, spiritual, and psychological health. Alcohol and other drug-related problems are particularly prevalent, contributing to more than 60 percent of the morbidity and mortality among Native American people. Many Native American families are plagued by the symptomology of alcoholism, poverty, learned helplessness and dependence, violence, and the breakdown of values that correlate with healthy living. (61)

Such challenges are only heightened by what Orange names “urbanity.” Urbanity for Native Americans was initially prompted by the Indian Relocation Act of the 1950s, which brought about “a concerted lack of economic and health resources” (63). This problem has persisted throughout the age of ‘Native urbanity’; “While the IHS [Indian Health Services] is responsible for providing health services to tribal and urban communities, Congress has inconsistently provided funds for appropriate levels of functioning” (69). Health resources for urban American Indians and Alaska Natives are significantly lacking, especially with regard to mental health and psychiatric services. This neglect is reprehensible, further contributing to the unresolved wound of historical trauma.

Barbara Gurr, in both her book, *Reproductive Justice: The Politics of Health Care for Native American Women*, and her article, “Mothering in the Borderlands: Policing Native American Women’s Reproductive Healthcare,” speaks more toward the availability of health services for Native Americans, specifically urban Native women. She highlights mothers and their control, or lack of control, in her discussion of families, thus aiding my conclusions here. Motherhood for Native women “has historically been targeted for surveillance, control, and outright removal by the State in its efforts to ensure cultural homogeneity within its borders,” thus surveilling families as a whole as well

(“Mothering...” 69). Contemporary discussions of traditional, and thereby heteronormative and Western, family values, “marginalize all other family forms, re-locating those families outside of the ideological borders of social and political acceptability” (69). In addition to control over families, what can be considered a woman’s emotional bodily framework, control has been asserted over women’s’ physical bodies as well. The ruling apparatus of the State, throughout history, has consistently marginalized Native women and their access to adequate healthcare. Gurr here argues that “the State’s underlying but driving aim is disappearance, either by extermination or through assimilation, into a (fictive) collective ethnicity (which is always already raced, gendered, and sexed)” (*Reproductive Justice* 7).

Bessel Van der Kolk speaks toward such trauma and how it physically and psychologically affects embodiment, in his book *The Body Keeps the Score*. He emphasizes how persons affected by a history of trauma can be mired in that history, “stopped in their growth because they can’t integrate new experiences into their lives” (Van der Kolk 53). A Harvard medical student then trained in psychiatry, Dr. Van der Kolk leaves no scientific explanation untouched. But he pays just as much attention to the emotional narratives of his patients as he does to physiology of the brain. He remembers, while in his residency program, feeling;

...surprised by the dispassionate way patients’ symptoms were discussed and by how much time was spent on trying to manage their suicidal thoughts and self-destructive behaviors, rather than on understanding the possible causes of their despair and helplessness. [He] was also struck by how little attention was paid to their accomplishments and aspirations; whom they **cared for**, loved, or hated; what

motivated and engaged them, what kept them stuck, and what made them feel at peace – the ecology of their lives. (Van der Kolk 24, emphasis added)

His book, while it does not directly speak to Native American experience, reflects on his many patients' embodied experiences of trauma, and thus serves as “both a guide and an invitation - an invitation to dedicate ourselves to facing the reality of trauma, to explore how best to treat it, and to commit ourselves [...] to using every means we have to prevent it” (Van der Kolk 4). Such an attitude toward the treatment and prevention trauma has ties to feminism, especially the transnational feminism that Gunn Allen and Ross are arguing for, one that continues to “challenge prevailing attitudes and rigid institutions,” even and especially those of medicine and caregiving (Ross 50).

Mothers of *There There*

There There begins with a flashback, grown-up Tony Loneman returning to his six-year-old self who's just been asked by his friend, “Why's your face look like that?” (Orange 15). At a mere six years of age, Tony is having to confront societal expectations for normative bodies, already deemed as different. He is the first of many bodies in *There There* that are rendered ‘different’ by the world around them. In utero, Tony was diagnosed with fetal alcohol syndrome, his existence defined for him by an addicted mother, he unable to comprehend his difference until it is identified by someone outside himself. The afternoon of that fateful day at elementary school, he is suspended, sent home for fighting, and that is when he notices his reflection in the television, recognizing its difference for the first time: “I tried but couldn't make the face that I found there my own again” (16).

His grandmother tries to assuage him by telling him he is a medicine person; “She said people like me are rare, and that when we come along, people better know we look different because we are different” (17). She is attempting to heal the way he now perceives himself, but it has marked him, split him into pieces. He now labels his face the ‘Drome.’

The Drome is my mom and why she drank, it’s the way history lands on a face, and all the ways I made it so far despite how it has fucked with me since the day I found it there on the TV, staring back at me like a fucking villain.

I’m twenty-one now, which means I can drink if I want. I don’t want to though. The way I see it, I got enough when I was a baby in my mom’s stomach. Getting drunk in there, a drunk fucking baby, a little fucking tadpole thing, hooked up to a cord, floating in a stomach. (Orange 16)

His mother’s history and addiction landed on his face, branding him, his thoughts, his decisions. And she also left Tony – in the care of her mother, Maxine. His grandmother cared for him as a mother, fully and intently, and still cares for him as he lives in her home, reads to her at night, helps her around the house. But Maxine can’t protect him from the world, can’t erase the difference on his face, the product of her daughter’s struggles.

Caught in a web of drug dealers and a plot to rob the Oakland Powwow, with an aging and fragile grandmother, Tony’s ‘tribe’ is, simply put, inadequate. He is the possessor of a “survivor’s child’s complex,” in a unique sense, a “constellation of features resulting from the intergenerational transmission of parental traumatic experiences and responses,” a heritable consciousness which risks the mental health of the recipient child (Duran et al. 65). His mother too, whom we know little else of, was struck with this

complex, plagued by alcoholism, which contributes to sixty percent of morbidity and mortality among Native people, considered one of the many ongoing symptoms of historical trauma (61). His mother, and therefore Tony, shares in the heritable “unattended wound” which rifts through the Native American, specifically urban Native, community (Orange 137). The unresolved trauma that may have contributed to her alcoholism “is intergenerationally cumulative, thus compounding the mental health problems of [her]succeeding generations” (Duran 64). His mother is the victim of addiction and exclusion from the heteronormative society that surrounds her. Due to her predicted socioeconomic status and substance abuse, she did not have nor did she seek adequate access to care, thus Tony is left without proper biological mothering and care, without a whole and healthful family. Tony voices that he only feels truly himself, not the Drome/Tony, when he is dressed in regalia, connected to a social circle (even if it is one with malevolent intentions). This kinship reinvents the family that Tony was denied by his mother’s absence. Tony only very briefly mentions her;

My mom’s in jail. We talk sometimes on the phone, but she’s always saying some shit that makes me wish we didn’t. She told me my dad’s over in New Mexico. That he doesn’t know I exist.

“Then tell that motherfucker I exist,” I said to her.

“Tony, it ain’t simple like that,” she said.

“Don’t call me simple. Don’t fucking call me simple. You fucking did this to me.”

(Orange 19)

Through positioning such a family so early in the novel, Orange is initially presenting us with a mother that achieves what Western modes of authority would expect her to achieve. She has failed, no thanks to the lack of available resources from the State and the State's denial of Native American women's capabilities. And thanks to her decisions, her very visible impact on Tony's life, she has helped transform him into a stereotype, one that Gunn Allen names "the howling savage" (20). Tony frequently gets into fights and is suspended and moved to new schools numerous times. He is mad, so mad that his "face heats up and hardens like it's made of metal, then [he] black(s) out," perpetuating the "view that is most deeply embedded in the American unconscious, where it forms the basis for much of the social oppression of other people of color" (Orange 19; Gunn Allen 21). No matter Maxine's encouragement or his mother's denial, Tony is objectified and othered by society around him. He is queer to society that expects 'normal' faces and even temperaments, that doesn't permit his anger and frustration.

Gunn Allen confronts stories like that of Tony's mother in her chapter, "Angry Women Are Building: Issues and Struggles Facing American Indian Today," crediting the central issue as "survival, *literal survival*, both on a cultural and biological level" (272). Due to a wide array of reasons, biological and political, existing tribes still, five hundred years after contact with colonizers, face the threat of extinction. Researchers estimate that around 25 percent of Native women were sterilized without informed consent, and show that the life-expectancy for a Native person is only 55 years of age, that the infant mortality rate for Native children soars above the national rate (272). The U.S. government continues to curtail resources for tribes, which includes funding for Indian Health Services (IHS). In addition to low federal funding, the IHS continually struggles "to meet all of the health

care needs of its target population” (Williams S43). Due to all of these reasons and more, Native women bear a heavy burden.

Within this geopolitical charnel house, American Indian women struggle on every front for the survival of our children, our people, our self-respect, our value systems, and our way of life. The past five hundred years testify to our skill at waging this struggle: for all the varied weapons of extinction pointed at our heads, we endure [...]

Of course, some, many of us, just give up. Many are alcoholics, many are addicts. Many abandon the children, the old ones. Many commit suicide. Many become violent, go insane. Many go “white” and are never seen or heard from again.

But enough hold onto their traditions and their ways so that even after almost five hundred years, we endure. (Gunn Allen 273-274, emphasis added)

Tony’s mother is one of these that gave up and gave in to the pressures that surrounded her, not able to mother in this hostile ‘charnel’ house that is only really home to those in pursuit of the American dream. In her alcoholism and imprisonment, she has become a mere statistic, one of the 9 in 100,000 Native women who commit suicide, this rate almost twice that of suicide in white women (Tom-Orme 36). And so is Tony, his face evidence of his mother’s alcohol abuse, which is “present in about 85% of neglect cases” (36). Though these numbers are drawn from Tom-Orme’s study on Native women, published in 1995, they echo through time to demonstrate how little had changed in the five hundred years since colonizers first began to change Native lives. And still, not enough has changed since 1995, as bodies like those are still present, represented by the characters of *There*

There. Echoes of her choice reverberate throughout not only Tony's life, but in the other mothers of the novel whose choices are reminiscent of hers.

Orange provides several more examples of mothers beyond Tony's. The most evident narrative of mothering in Orange's *There There* accompanies half-sisters Jacquie Red Feather and Opal Viola Victoria Bear Shield, both of whom have chapters, and thereby space to speak in the novel, unlike Tony Loneman's voiceless, nameless, and absent mother. Their narrative begins in the novel's third chapter, voiced by Opal. Jacquie and Opal's mother, Vicky, passed away when they were just young girls, a victim of cancer. Their mother was also the victim of a series of abusive relationships. Opal recalls one morning, the morning that they would leave their home and move to Alcatraz, being woken hurriedly by her mother, "her face was beat up. She had a brown leather jacket way too big for her draped over her shoulders. Both her top and bottom lips were swollen. Seeing those big lips messed me up" (Orange 45). Their mother's body has become a site of violence and abuse, she another statistic in Tom-Orme's study, a victim of violence that is the cumulative result of "the deterioration of the traditional family structure, alcoholism, and the lingering effects of historical oppression" (Tom-Orme 35). Both of their dads had left their mom, with supposedly no support, no ongoing interest in their daughters' lives. No other appropriate father-figures are present in their lives. Opal asks her mother about their names, why they are different and what they mean, where they could have come from once their dads are out of the picture. That long name has been a source of othering for Opal, "the good thing was, the kids didn't have to do anything to my name to make fun of me, no rhymes or variations. They just said the whole thing and it was funny" (46). Despite her name's distance from her classmates, no matter their white or racial status, her name is a

source of connection for Opal to her history as a Native woman, concretizing her place in a lineage of women, instead of defining her existence by purely paternal status. Her mother tells her, their very distinct names “come from old Indian names. We had our own way of naming before white people came over and spread all those dad names around in order to keep the power with the dads,” and thus she hits firmly on the place where Native identity collides with colonial oppression (46). Opal’s full first name is Opal Viola, the name of her grandmother, her middle name Victoria, her mother’s name, both important in helping Opal place herself within a specifically Native history. Drawing from knowledge of the ancient gynocratic Keres societies, Gunn Allen reminds us that, for Native women, “your mother’s identity is the key to your own identity [...] Naming your own mother (or her equivalent) enables people to place you precisely within the universal web of your life” (30). In giving Opal this name, though it may have othered her from her preteen peers, her name positions her, rooting her to her mothers and thus to the web, or the sacredness, of her life.

Opal’s last name is Bear Shield, which she does not know the origins of, but is certainly curious about, asking – “I didn’t know if Bear Shield meant shields that bears used to protect themselves, or shields people used to protect themselves against bears, or were the shields themselves made out of bears?” (46). While any of these may be true for the meaning behind her surname, I find it more fitting to understand her name as one of action, Bear Shield meaning to carry shield, shore up against any hostile or oppressive forces. This is an apt understanding when met with *The Sacred Hoop*, especially her section entitled “Pushing Up the Sky” in which she presents a feminist understanding of Native women’s issues in the United States. To ‘Bear Shield’ is just what Gunn Allen calls for through her specific kind of feminism, remembering and re-membering the past, both

“recovering our heritage and uncovering the history of colonization” while resisting the “varied weapons of extinction pointed at our heads” in order to endure physically, psychologically, and culturally (Gunn Allen 271, 273). Duran, Duran, and Brave Heart express a similar hope for Native peoples in their article, hoping “to provide space for reimagining the present” and tending appropriately to the trauma, historical and current, that continues to threaten (62).

While Opal’s name does empower her connection to her familial and cultural past, it cannot rescue her, her mother, and her sister from what will occur when they move to Alcatraz. The move is explained as a kind of resistance, a meeting of all Native peoples in the Oakland area gathering together off of the ever-colonial American shores. They hope to be recognized, to simply be cared for in the way that they should be. The morning that they left was the same morning that Opal found her mother fat-lipped and leather-clad – Vicky rushed her girls out of their home taking little with them, leaving their yellow house with its eviction notice plastered to the storm door. Opal understands the move to Alcatraz to be a good thing, asking the only other kid her age, Rocky, “Don’t you think it’s good we’re standing up for something? Trying to make things right for what they done to us all these hundreds of years, since they came?” (Orange 53). Rocky does not seem to agree – “I just wanna go home [...] What’s so good about taking over some stupid place no one wants to be, a place where people been trying to escape from since they made it” (53). Rocky’s perceptions of the island are more realistic – there is not adequate food or living conditions for them thus he cannot view it as home. The physical place is beyond connection to a home; while they hope for federal recognition (i.e. funding, food, et cetera), nothing comes, and instead they are left to sleep on the hard ground of the prison cells

eating watered down stew with bread and butter. Thus the name that Opal is given is not enough, not adequate care on its own. Her mother, in an attempt for greater connection, abandons her daughters, Opal reflecting;

At some point Jacquie had taken our mom's place [...] There was no house or life to go back to, no hope that maybe we would get what we were asking for [...] The men looked more tired and more drunk more often, and there were fewer and fewer women and children around...

"Opal Viola, baby girl," my mom said...

"You have to know that we should never not tell our stories, and that no one is too young to hear. We're all here because of a lie. They been lying to us since they came..."

She told me we could only do what we could do, and that the monster that was the machine that was the government had no intention of slowing itself down for long enough to truly look back to see what happened. (Orange 57-58)

That same afternoon, their last day on Alcatraz, her mother told her she had cancer. Only a full page later in the novel does she slip away and die, "slowly receding into the past like all those sacred and beautiful and forever-lost things" (59). Vicky has been rendered into an inadequate and inattentive mother, but not by her own fault. She has been swept away by the colossal forces of colonialism that continue to surveil Native American bodies, especially women's bodies. She is socially and economically, and ultimately even physiologically, absent – her woman-of-color body withheld from the resources, fiscal and medical, that she needs to mother.

Teresa Evans-Campbell, in her paper “Perceptions of Child Neglect Among Urban American Indian/Alaska Native Parents,” recognizes early on that the majority of research regarding Native issues is reservations-based. This gap in data omits and overlooks an abundance of Native voices and stories, like Vicky and Tony’s mother, as the majority of Native peoples are now urban, and “urban AIAN (American Indian/Alaska Native) families are likely to have substantially different experiences than other AIAN families” (Evans-Campbell 121). The difficulties for urban and reservations-based Natives are significantly different from each other, due in part to “the number of social problems [introduced] to the urban AIAN population including isolation, high rates of unemployment, and a lack of traditional parenting supports” (121). Vicky is lacking each of these, and even her attempt to instantiate her family into a Native community on Alcatraz cannot achieve what she needs. When they move back to the mainland, they move in with Vicky’s adopted brother Ronald, a self-proclaimed medicine man, a man who turns out to be a sexual threat to the girls, she tells Opal and Jacquie that she does not want to abide by doctors’ recommendations, presumably white, hetero- physicians who attend to their patients with sterile, hetero- care. As Gurr explains, both in her book and her article, medicine has historically been shaped to best care for what has colonially and paternally been determined as ‘normative.’ Modern, conventional medicine “continues to rely on a narrow construction of health care in which women of color, women who are economically disadvantaged [...] may not be able to access the care that they need, or may be required to negotiate health-care structures that do not fully recognize their embodied experiences” (*Reproductive Justice* 39). It is this kind of medicine that Vicky is resisting, hoping that a

complete return to her cultural roots will instead take care of the mutated cells that are ravaging her body and return her to right motherhood.

Even more than for Opal or for Vicky, Alcatraz most definitively altered the path of Jacquie's life. She spends much of her time on the island drinking on the beach with the other teenagers, one of them Rocky's older brother Harvey. After hearing Jacquie's scream, Opal runs away from Rocky and finds Harvey on the ground, head "swaying – top heavy," Jacquie throwing rocks at him, "Piece of shit" (Orange 55, 57). "What did he do?", Opal asks. "I told him not to. Then he did. I told him to stop [...] It doesn't fucking matter," Jacquie says through suppressed tears (56). Their move to Alcatraz, while hopeful in origins, cannot replace the traditional community. Instead of offering Native young adults proper initiation ceremonies, Alcatraz gives way "to other undifferentiated methods of initiation, conducted away from family and tribe and sometimes involving unhealthy activities. One of the major initiations for Native American youth has involved the use of alcohol, with devastating effects" (Duran et al. 68). That was the night that Jacquie told their mother's place, in body under the blankets on the prison cell floor, and in responsibility, as she tells Opal, significantly, *after* their mother's death that she is pregnant. She is one of the many that Gurr speaks toward in *Reproductive Justice*, contributing to the high rate of unintended pregnancies in Native adolescents. Socioeconomic disadvantage is one of the greatest contributing factors, certainly applicable to Jacquie and her family evident in their many eviction notices and moves from (un)home to (un)home. Though the IHS is not entirely to blame for the high rate and have made some moves toward initiating programs on reservations, including one titled 'Centering Pregnancy' which organizes groups for women of similar gestational age, they

are not attending to adolescent and unintended pregnancy appropriately: “In a recent multicountry study of adolescent pregnancy, Ann Blanc et al. found that adolescents’ success in avoiding pregnancy often depends on having access to contraceptive information, methods, and services” (Gurr 121). The IHS especially does not speak toward contraception for urban Natives, evident in the family’s rootlessness, ultimately the result of Vicky’s relationship or financial status. Jacquie once names home as “a locked station wagon in an empty parking lot. Home was a long ride on a bus. Home was the three of them anywhere safe for the night” – hardly an appropriate home for two young girls (Orange 99). The IHS, and also Vicky as mother and informal caregiver, do not provide appropriate care to the two girls, Native young adults “lost in no-man’s land” and the overwhelming disconnect of the city (Duran et al. 63).

Van der Kolk’s seventh chapter of *The Body Keeps the Score*, “Getting on the Same Wavelength: Attachment and Attunement,” attends to informal caregivers (primarily mothers), and how they shape young children, and thus is relevant to discussion of Vicky. The child’s attachment to caregiver and therefore the place of caregiving provides, in the best-case scenario, him or her with a secure base.

As we grow up, we gradually learn to take care of ourselves, both physically and emotionally, but we get our first lessons in self-care from the way that we are cared *for*. Mastering the skill of self-regulation depends on a large degree on how harmonious our early interactions with our caregivers are. Children whose parents are reliable sources of comfort and strength have a lifetime advantage - a kind of buffer against the worst that fate can hand them (Van der Kolk 112).

Jacquie's ability to care for herself was significantly impacted by her mother's inability to properly care. She witnessed her mother's lack of self-care, her turn from relationship to relationship, and her seeming acceptance of the abuse that her boyfriends dealt her, and finds them a part of the normative experience for Native women. She was not given appropriate guidance through the years of her adolescence and thus turns to alcohol, over and over again in adulthood, for comfort and care, for help dealing with the need "to burn her life down" (Orange 152). Jacquie ultimately bore Harvey's child and gave her up for adoption. She proceeded to have another daughter, Jamie, another child given up for adoption, who died a drug addict, the victim of suicide, shot herself between the eyes. Jamie had three boys of her own, boys that were handed over to Jacquie who, out of shame, gave custody of each of the boys to her sister Opal, who had no children of her own. Jacquie has had a long run with alcoholism, a disease that infiltrated every piece of her life, separated her from her family. Somehow she landed a job as a substance abuse counselor "without ever having achieved any significant sobriety" (106). In the present time of the novel, an attendee at a substance abuse conference titled, "Keep Them From Doing Harm," she is only six months sober, but "that was something. That was not nothing" (152). The conference keynote, with his stories of suicide, made her run to the mini fridge in her hotel room: "In her head she heard her mom say, 'The spider's web is a home and a trap.' [...]" In this case Jacquie was the spider and the minifridge was the web. Home was to drink. To drink was the trap" (101). Jacquie was not set up for success as a caregiver, to her children or to herself, both at the fault of her mother and the health resources made available to her. Ultimately, after an encounter with Harvey at the conference's AA meeting, Jacquie doesn't drink, doesn't reopen her wound. Instead, she throws the bottles from the mini

fridge into the swimming pool, and messages her sister, “*If i come to oakland can i stay?*” (Orange 117). In, finally, trying to return to her family, she is remembering and remembering her trauma, the long lineage of women in her family who have not been treated rightly, who have suffered at the hands of the State and, in turn, the hands of themselves.

As has Jacquie’s, Opal’s perception of motherhood changed after her mother’s death. She takes Jacquie’s grandsons into her home, but, intentionally, chooses not to “teach them anything about being Indian,” much to Orvil’s chagrin (Orange 119). Instead of heeding her mother’s advice on the island, “You have to know that we should never *not* tell our stories,” she hides her regalia and stories away, explaining to Orvil that “learning about your heritage is a privilege. A privilege we don’t have [...] Don’t ever let anyone tell you what being Indian means. Too many of us died to get just a little bit of us here, right now, right in this kitchen. You, me” (58, 119). Orvil doesn’t understand her, thinking to himself as he dreams of dancing: “There was so much he missed. So much he hadn’t been given. Hadn’t been told [...] he knew. He was a part of something. Something you could dance to” (121). He, like his mother, his grandmother(s), is also a victim of inattentive motherhood. Gunn Allen explains, “Failure to know your mother [...] is failure to remember your significance, your reality, your right relationship to earth and society. It is the same as being lost – isolated, abandoned, self-estranged, and alienated from your own life” (301). This loss of connection is a “loss of tradition and memory” at the hands of colonial oppression, in turn leading to “the loss of a positive sense of self” (Gunn Allen 304). Orvil seeks what Gunn Allen calls a “wellspring of identity,” a true sense of self, and thinks he might find that in dancing at the Oakland Powwow (323). At the powwow, he does find connection, but not without cost, the serious consequences that Gunn Allen

alludes to when a person is left without that wellspring of identity. The gang that Tony is a part of robs the powwow, not leaving bodies untouched by bullets, but ravaging innocent persons, Orvil included. Orvil's wound is the site where the family meets together – Opal running to the entrance to only find Orvil's brothers, Jacquie braving the center of the powwow to lift Orvil's still living body from the ground. Looter, one of the brothers, exclaims when Jacquie finds him – “He's *white*,” his history wiped from his face after the shooting, a victim of ongoing trauma, suffering because of the disconnection/lack of proper mothering-and-care felt by those minorities who organized the robbery (Orange 280, emphasis added).

Orvil's body, rushed to the emergency room in the concluding pages of the novel, is just one recipient of the 'unattended wound,' a descendant of a long lineage of narratives of- and without-care. While this study is far from conclusive, having only paid heed to a few of the characters of *There There*, and only portions of their narratives, it is important. Its implications are greater than these mere ~twenty pages. Native women have too long been a part of the fray, bodies queer to the heteronormative hegemonic of a nation still so rooted in colonial authority. Orange tells these stories for a purpose – it is my argument herein that *There There* attends to mothers (informal caregivers), unearthing their stories so that those like them can be properly cared for and attended to, returning them to right motherhood and righting the wrongs of historical trauma on Native women's bodies and the bodies of their sons and daughters.

CHAPTER FOUR:

HEALING THE GLOBAL CITY:

DIASPORIC PHYSICIANS IN KAREN TEI YAMASHITA'S *TROPIC OF ORANGE*
AND STEPHEN FREARS'S *DIRTY PRETTY THINGS*

What does it mean to be transnational, or to be a global citizen? What kind of transnational subject is permitted to be a global citizen? And how does the transnational frame meet with healthcare and caregiving? Transnational texts, such as Karen Tei Yamashita's novel, *Tropic of Orange*, and Stephen Frears's film, *Dirty Pretty Things*, depict transnational subjects, both ex-physicians and former formal caregivers, figured beneath the framework of the global city, and thus also beneath the hegemonic of healthcare and caregiving. Both characters, Yamashita's Manzanar Murakami and Frears's Okwe, are 'othered' by their histories, their bodies, and their spaces in society; they simply "don't exist" (*Dirty Pretty Things*). Their subdued existence, as Sue-Im Lee so poignantly describes in her article on *Tropic of Orange*, serves as a "ringing reminder of the ever-luring horizon of universal human rights" (Lee 522). Lee is here alluding to the UN Universal Declaration of Human Rights, which permits all persons and bodies to "a standard of living adequate for the health and well-being of himself and his family." But both Yamashita's and Frears's subjects seem to be precluded from this right, thus demonstrating the failed promises of the State and the (in)accessibility to health and caregiving for 'othered' global citizens such as themselves.

A thorough review of the literature on both *Tropic of Orange* and *Dirty Pretty Things* reveals that many critics find globalization, what Gayatri Spivak describes as "financialization of the globe," a compelling way to engage with the texts. However, no

critic thus far has encountered both the novel and the film simultaneously. While they are certainly much different texts, *Tropic of Orange* heavily imbued with something akin to magical realism, and *Dirty Pretty Things* with hyperrealism, they are both explicitly transnational texts, occupied by bodies and peoples that do not belong, do not have home, and cannot ‘naturally’ belong to a first world nation, the United States of America or Great Britain respectively. The racial and transnational body in these texts is erased as it tries to enter into these nations, crossing borders illegally. This erasure of bodies, the trade of illegal organs in both texts, and the inability to belong is present for both Manzanar Murakami and Okwe, both ex-physicians, transnationals trying to navigate the global city. Saskia Sassen describes the global city as a “new type of city,” a vast site of production where resources and goods are able to restructure the urban social and economic order (4).

These changes in the functioning of cities have had a massive impact upon both international economic activity and urban form: Cities concentrate control over vast resources, while finance and specialized service industries have restructured the urban social and economic order. (Sassen 4)

Through these two men, Yamashita and Frears provide a distinctive vision for transnational peoples. In telling these stories, they are undertaking a task unfulfilled by science and healthcare, paying attention to bodies shrouded by a neoliberal and hyper-capitalist world. The story of these racialized and disembodied physicians deserves to be told just as much as the story of the racialized and disembodied patient. Through their narratives, Manzanar and Okwe are calling for healing the global city, queer bodies and all. Donald Pease’s article, “How Transnationalism Reconfigured the Field of American Studies: The Transnational/Diaspora Complex,” explains the difference between transnational citizen-

subjects and diasporic subjects, an apt description that pertains well to these two characters. Transnational citizen-subjects are those “who benefit from the transnational rules regulating the movement of goods, finances, and people in the new globalized economic order,” while the diasporic subjects are the “refugees, nomads, indigenous peoples, migrant laborers, stateless peoples, and subalterns who lack such prerogatives” (Pease 41). Pease’s diasporic subject neatly aligns with Gayatri Gopinath’s *Unruly Visions: The Aesthetics of Queer Diaspora*, which advocates for an “alternative cartography,” a remapping of heteronormative spaces to include queer bodies in the aestheticized picture (5). By deferring to Pease’s and Gopinath’s definitions, Manzanar and Okwe are diasporic subjects navigating through the inhospitable landscape of the global city. Their stories illustrate that globalization is a sociopolitical malaise, only able to be healed by these diasporic physicians.

***Tropic of Orange’s* Manzanar Murakami**

Manzanar Murakami is a Japanese American ex-surgeon, music/traffic conductor and composer, a permanent fixture at his concrete podium, an overpass above the ever-congested Los Angeles freeway system. Whether he is noticed or not, with his “lion’s head of white hair” and his silver baton, he continues to create music with the sounds of the city; “The great flow of humanity ran below and beyond his feet in every direction, pumping and pulsating, that blood connection, the great heartbeat of a great city” (Yamashita 35). Though he chose to leave his practice and his patients, his textbooks and his surgical equipment behind for a life on the streets, in essence he still practices care in his own way,

bringing that “great flow of humanity” together in magical and musical composition, now diagnosing the malignancies of the global city, a collective of human bodies, as a whole. The novel is essentially about a great thrombosis in the heart of Los Angeles; a freeway traffic accident erupts into fire, causing drivers to abandon their vehicles, which are soon overcome by the city’s homeless population. The “great heartbeat” that begins on the freeway threads through the lives of Yamashita’s other characters, transcending time, race, ethnicity, gender, socioeconomic status, generation, and geographic location. The tale seamlessly juggles “magical realism, film noir, hip hop, and chicanismo,” allowing Yamashita to portray the aesthetic of friction and collision in an L.A. “where the homeless, gangsters, infant organ entrepreneurs, and Hollywood collide on a stretch of highway struck by disaster.”¹ Manzanar’s story is thus woven closely with the others, especially with Buzzworm, the eccentric spokesman for the L.A. homeless population, and Emi, the young cosmopolitan T.V. executive. Buzzworm is often the omniscient eye for Yamashita’s audience, cluing them and the characters within to greater knowledge. Buzzworm pronounces Manzanar “a kind of witch doctor. He sees and hears things nobody else can. What he’s doing up there is a kind of interpretation;” he embodies the physician-as-storyteller, tending to the bodies, sounds, sights, and smells that go unnoticed by the capitalist city that rushes by (158). His shamanistic perception and his birds’ eye view of the city give him the ability to connect the other narratives to each other. Buzzworm points to Manzanar as the key for understanding the great blood connection between peoples, and thus is a key voice for this thesis. Emi is also very important for an improved understanding

¹ Back Cover, *Tropic of Orange*.

of Manzanar, as the audience comes to find out, she is Manzanar's granddaughter. But she is also part of the problem, a disillusioned city-dweller that does not adequately care for those around her, thus Manzanar must tend to her. Their relationship allows me to further elucidate the need for a transnational voice that transcends difference and 'otherness.'

When considering Manzanar as physician alone, he embodies Pease's definition of a transnational citizen-subject, as he might have been a wealthy American citizen capable of crossing borders. Pease reminds us, "transnational subjects cannot identify with stateless refugees or nomads without forfeiting their identity" (49). This definition alone cannot capture Manzanar's experience, as he was one of the many Japanese Americans interned during World War II. Thus, though he is a physician, his history as an interned Japanese American precludes him the same status and privilege that a white doctor would have access to. He very intimately knew statelessness and nomadism before his medical career, and now finds that he may better care for diasporic persons like him outside of his world as a physician;

Long ago, Manzanar had been a skilled surgeon. His work had entailed careful incisions through layers of living tissue, excising tumors, inserting implants, facilitating transplants. At what point the baton replaced the knife, he could no longer remember. Perhaps the skill had never left his fingers, but the will had [...]

One day, he left a resident to sew up a patient, removed his mask, gloves, and gown [...] to become a statistic under *missing persons*. (Yamashita 56)

Now a statistic, an anomaly for having left a comfortable life, Manzanar's identity as a transnational citizen subject is completely altered. Homeless and subaltern, he is Pease's

diasporic subject. He is looked upon as an outsider, viewed by L.A. as another imperfection, marring the image of Sassen's global city. This global city is "a site of production of specialized services [...] and of financial innovations and the making of markets [...] The things a global city makes are services and financial goods" (Sassen 5). He is no longer a productive member of the global city, not contributing to the services that a global city should offer, thus he does not fit.

In "We Are Not The World: Global Village, Universalism, and Karen Tei Yamashita's *Tropic of Orange*," Sue Im-Lee responds to Saskia Sassen's global city. Lee defines the universe as a global village, not distinguishing a single city as global precedent like Sassen does, but invoking a global connection between peoples, prioritizing humanity and hospitality over economic gain. "In its depiction of Los Angeles, too, the novel focuses on extremely disparate socioeconomic positions and emphasizes the growing fissures that run through the global village discourse," Manzanar one of these disparate entities, trying to bridge the fissure between peoples (Sassen 506). His role is now not to dissect and stitch, but to bring together the harmonies of L.A. life and interpret the complex "mapping layers" of humanity. Manzanar is deeply observant, while ordinary persons "never bother to notice, the prehistoric grid of [...] human behavior, nor the historic grid of land usage and property, the great overlays of transport, [...] patterns and connections by every conceivable definition from the distribution of wealth to race" (Yamashita 57). He left his privileged lifestyle to create music out of the mapping layers, layers that include transportation infrastructure, state divisions and boundaries, and racial and economic inequalities and injustices.

To Manzanar, such an "inanimate grid structure" is a physical reminder that we occupy a single structure of existence and that the wires, pipes, cables, and free-ways are all evidence of our bounded-ness, our interconnectedness to each other in the making of a single organism. (Lee 516)

Manzanar may not be a transnational citizen subject, but he is an ideal global 'villager,' constantly working toward connecting those around him to the "great heartbeat" where the global village begins. In his efforts to make music out of these endless layers, Manzanar is caring for transnational peoples as he was unable to as a surgeon.

Manzanar attempts to conduct an alternative mapping of the many layers of Los Angeles, attending to those "micropolitical spaces" and bodies that are subsumed by "successive colonial and nationalist regimes" (Gopinath 5). As he sits up over the city, discerning the many layers, placing "them even delicately and consecutively in a complex grid of pattern, spatial discernment, body politic," Manzanar "imagined himself a kind of recycler. After all he, like other homeless in the city, was a recycler of the last rung. The homeless were the insects and scavengers of society, feeding on leftovers, living in residue, collecting refuse, carting it this way and that" (Yamashita 56). Manzanar is crafting his own kind of queer optic, or queer auditory, rather, that attends to the refuse; "who would use the residue of sounds in the city if Manzanar did not?" (56). These sounds exhibit one of the sites of (un)belonging that Gopinath speaks to. Manzanar successfully employs her queer aesthetic, as he pays heed to "the everyday, the personal, and the discarded that typically fall outside of the purview of official archives," thus recognizing the othered and queered bodies, simultaneously providing us a glimpse into the "violent present" that neglects such bodies, and recognizing the possibility of an alternative future (Gopinath 8).

He chooses a site outside of medicine and the operating room in order to adequately care for these diasporic/queer persons and bodies, like him, also displaced by the hegemonic state.

Diasporic subjects, as opposed to transnational citizen-subjects, do not have the same rights to fair wage, housing, and health care. Homelessness correlates with decreased access to medical care among other resources readily available to American citizens, further separating a homeless person from the rest of society, representing the queer and alt-normative persons that Gopinath illustrates in *Unruly Visions*. The homeless of Los Angeles in Yamashita's narrative qualify as diasporic subjects. Though they may possess American citizenship, they live on the slopes that line the freeway, under overpasses, in back alleys – they are not permitted access to the spaces that American citizens and transnational citizen-subjects have access to. They are only granted attention after the disastrous highway accident, when they descend to occupy the “used car lot” of abandoned vehicles. Manzanar serves as a kind of storyteller for the homeless in *Tropic of Orange*, his music is the “expression of a will to bring the existence of all homeless individuals into the range of perception of the comfortably at-home, and to restore to the homeless themselves a psychic sense of at-homeness” (Sato 128).

Manzanar is intimately familiar with homelessness, thus his need to bring that sense of ‘at-homeness’ to the homeless of his city, those bodies and persons who were beyond the reach of his care when he was in the operating room. Manzanar is definitively one of the thousands of Japanese Americans who was interned during World War II, creating the kind of childhood trauma that gives way to fracture, psychosis even. His internment is not evident upon first reading of *Tropic of Orange* if one is unfamiliar with the history of

internment during the war. Gayle H. Sato, in her essay “Post-Redress Memory: A Personal Reflection on Manzanar Murakami,” addresses this “phantom status of internment studies” both in the novel and in America at large (120).

Tropic of Orange is the first attempt in Asian American writing, and may be the only one still, to reflect on the memory and meaning of internment through a marked, actually hyperbolic, *absence* of references to Japanese American history, culture, and Redress politics. (Sato 127)

Sato reveals how Manzanar “reformulates Japanese American subjectivity from a condition of absent presence in U.S. society to a vital sense of being at home in America that is premised on his ability to carry... an ineradicable painful memory of internment” (121). There is phantomization of Japanese American narratives in Yamashita’s novel, displacing and disembodimenting Japanese Americans within, including Manzanar. He has to live with the “collective memory of internment [which] has always existed distributed across the personal consciousness of each Japanese American who experienced it directly or learned about it secondhand” (121). The collective memory of such trauma lends the experience of intergenerational trauma to descendants of Japanese Americans who were incarcerated. Sato reminds Yamashita’s audience that the only reference to Japanese American history in *Tropic of Orange* lays in Manzanar’s name, the name he shares with one of the ten American internment camps. This “fatal blurring,” as she calls it, of Manzanar’s “generic” name with a distinctly “Jap(anese)” place demonstrates how transferrable his experience is with that of other Japanese Americans, creating in him an ideal spokesperson not only for Nisei and Sansei, but for all suppressed and disembodied diasporic subjects (131). Thus his embodied trauma is connected to how he reads the global

city. The global city is a product of the same State that interned him and his family, displacing him and his sense of healthful home. As he is a direct descendant in a lineage of historical trauma, similar bodies traumatized by Western regimes and the global city are more legible to the queer optic that he has adopted, a way of seeing and legitimizing the experiences of othered persons.

Homeless persons are, and have always been, queer to a neoliberal nation state. They do not meet with the appropriate measure of capitalist productivity or definitions of health and well-being. They are simply ‘other.’ This othering, for Manzanar, is mirrored in his history of internment as a member of the Sansei (third-generation Japanese American). Donna Nagata, in her article “The Japanese American Internment: Exploring the transgenerational consequences of traumatic stress,” describes the unquantifiable impacts that incarceration had both on Nisei and their children, the Sansei. There was a significant “shroud of silence and nonconfirmation of the trauma by the United States itself and society at large” (Nagata 64). Several Sansei that were interviewed “noted that their parents’ internment reminded them of ‘what it means to be a minority in this country...’” while another described that she inherited her father’s “sense of ‘existential anxiety’” (65). As one of the Sansei population, Manzanar embodies and inherits the vulnerability described in Nagata’s study. He left his life in medicine, as he had to leave his childhood home, empty-handed. Emerging out of his turbulent and fractured history as a Japanese American and surgeon – this is Manzanar’s chosen diaspora, out of the normative and stifling and silencing, and into his own notion of queer and accepting existence, thus seeking to intertwine “nonequivalent histories of dispossession and segregation, displacement and dwelling [...] the aesthetic practices of queer diaspora” (Gopinath 31).

Such a queer diaspora is Manzanar's departure from the neoliberal and capitalist world in which he lives. He was forced to be diasporic as a boy, displaced to a camp that did not adequately care for those interned, but now chooses his diaspora, what Gopinath describes as an interruption of the nation-state as it imagines itself. There is another diasporic moment in Yamashita's novel that echoes Manzanar's diaspora, where the homeless of the city overtake the freeway after the thrombotic and incendiary accident. As per his usual, Manzanar is observing the Harbor Freeway at the time of the explosion, when the upended fuel tanks blew up "and the great walls of flames flew up the brush and ivy along the freeway canyon, Manzanar knew instinctively the consequences, knew that his humble encampment... would soon be a pile of ash" (Yamashita 120). He chooses not leave his podium to "save his home," but continues to conduct while "watching the fire engulf the slope... men, women, and children, their dogs and even cats, bedding, and caches of cans and bottles in great green garbage sacks and shopping carts moved into public view, sidling along the lines of abandoned cars..." (120-121). The traffic accident and the great fire that serves as a driving force for Yamashita's narrative exposes the homeless of L.A. to a site of mobility that is typically only accessible to American citizens and transnational citizen subjects with enough wealth to own a car and with the freedom to move through the city, on their way to bigger and better destinations. This narrative moment is about more than just mobility though – it is the moment where the stories and bodies that Manzanar has attended to all along become visible to the whole city. Manzanar's queered optic and auditory allows him to see and hear the stories of the city's homeless and dispossessed, a feat which is not permitted by the hypercapitalist and inattentive global city, a city which threatens the homeless and queer body because it does

not fit into its hypercapitalist and neoliberal agenda. Chiyo Crawford explains, in her article, “From Desert Dust to City Soot: Environmental Justice and Japanese Internment in Karen Tei Yamashita’s *Tropic of Orange*,” “Yamashita presents intricate layers of environmental devastation and environmental racism to expose internment and homelessness as [...] environmental justice issues demanding our attention in the immediate global environmental crisis” (87). These issues are exposed through Manzanar’s queer vision. It is through his eyes that we see the homeless as integral to contemporary L.A., and it is through his conducting that we see the intergenerational trauma and deep collective memory of Japanese internment, and even of homelessness in the United States.

Upon first encountering *Tropic of Orange*, I read Manzanar as potentially schizophrenic, thus one of the many homeless persons that is statistically deemed mentally ill. But such a reading of his character is an instance of othering, a denial of what he is attempting to do for the global city, only reinscribing the modern medical need to diagnose and categorize, neatly fitting his experience into a mold instead of regarding him as he is. Rather than truly and clinically schizophrenic, he is a schizoid and othered body that does not flow with or organically fit into the largely hetero- and hegemonic world that surrounds him. Because his body is sick/queer/different/other, Manzanar both dis- and re-orient the “logic of neoliberal capitalism,” thus exhibiting an alternative mode of being; his ‘queerness’ naming “a state of being out of place and disoriented in the landscape of heteronormativity” (Gopinath 21). Through his alternative and queer optic, not psychotic but only labelled as such because of his *difference*, we see the “mapping layers” that join humanity despite the passage of time and despite technological advances. Sue-Im Lee echoes this sentiment through her definition of a global village.

“[*Tropic of Orange*] postulates another model of global collectivity, a different rationale for a globalist ‘we’ that can express the transnational, transcontinental nature of human existence without imperialist dimensions. Simultaneously, this new model of global collectivity bears the seeds of its own negation, demonstrating the fragility, and indeed the impossibility, of achieving an absolute universalism.”
(Lee 503)

Whether Manzanar’s speculations about the deep-rooted connections between people are elements of psychotic delusion or not does not matter, as he still speaks truths in hope of a better future when privileged peoples, transnational citizen subjects, and diasporic subjects can walk on the same ground. The eyes and ideas of the psychotic, of the homeless, and of diasporic subjects are given a greater voice through this narrative.

There is a brief and singular moment in the novel where Manzanar addresses his past and alludes to his traumatic youth.

The past flooded around him in great murky swirls. For a moment, he saw his childhood in the desert between Lone Pine and Independence, the stubble of the Manzanita and the snow-covered Sierras against azure skies. He remembered his youth, the woman he loved, the family he had, a nine-year-old grandchild he was particularly fond of. He remembered his practice, his patients, his friends. Curiously. He remembered. The past spread out like a great starry fan and then folded in upon itself. (Yamashita 170-171)

The arid landscape he describes is that of Manzanar Internment Camp, the only description of the place in the novel and the only confirmation of his internment apart from his name.

It is coupled with another significant memory, that of his family, another rare narrative occurrence. The two memories are bound up in each other, as are the folds in a fan when it collapses. His generational inheritance did not end with his departure from family life, the consequence evident in Emi's presence and ultimate death. As with any physician, Manzanar is not separate from those he is helping; he is very much linked to their future, implicated in their outcomes. With leaving his family, he left them without a piece of their history, thus Emi is missing her link to the great heartbeat that he feels, that great connection between all peoples. This is evident in Emi's materialism, her desire for a "New Age tan," and her emotional withdrawal from her relationship with Gabriel, her only real connection to "the (inter)net." Buzzworm urges her to go speak with him, hopeful that she can inherit and carry on Manzanar's mission; "Baby sister, the connection begs to be understood," the connection that looks beyond transnational citizen subjects, beyond heteronormative persons, sites, and sounds (Yamashita 237). The only connection that Emi does possess is of her laptop to the world wide web, her deepest relationship (that with Gabriel) achieving its intimacy, sexual and emotional, through her computer. Emi's vision of connectivity to the world around her is thus much different from Manzanar's, as he maps out deep human connections and emphasizes a need for empathic understanding, she abides by a heteronormative and neoliberal optic, not seeing beyond the difference between herself and someone less privileged. As she is hyperconnected, she is distant from the world that surrounds her, afraid even to connect with her grandfather because of his 'queerness.'

Emi is seeking what Gopinath deems "the good life," the life which, within the logic of neoliberal capitalism, "possesses value according to familiar hetero- and

homonormative measurements of success” (Gopinath 21). Manzanar’s vision for remapping operates through an intimacy with queerness/otherness that “allow(s) heterotopic landscapes to come into view” (40). He “dwell(s) in displacement,” a displacement which Emi avoids (40). As Emi instant messages Gabriel, she explains her refusal to interview Manzanar, whom she now knows is her grandfather; “‘*I’m like you,*’ she had typed. ‘*Strictly noir.*’ ‘*But he’s your grandfather.*’ ‘*So I’m in denial, okay?*’” (Yamashita 222). Gabriel reflects, “it just didn’t figure. No two people could be further apart, much less related” (222). Both Gabriel and Emi are resisting intimacy with a nonheteronormative person, despite her and Manzanar’s biological and genealogical intimacy. She self-identifies as “strictly noir,” thus framed by cynicism and moral ambiguity. Emi is Pease’s transnational citizen subject, able to cross borders freely, but the cost of this status is distance from her history and the world around her. While Manzanar stands over the borderlands of the highway, orchestrating music from the babel of the “greatest traffic jam in the world” below his podium, Emi enters these borderlands as a voyeur, in order to cast a news report of the homeless population that has moved in and overtaken the backup of abandoned vehicles (207). Though Buzzworm is there with Emi, urging her to air stories from the homeless persons’ perspectives and to go meet her grandfather, she is instead panning over them and ignoring their embodied existence. As she avoids confronting Manzanar, Emi lays “in a bikini and Ray-Bans stretched out on a beach towel” atop the *NewsNow* van (234). “I do have a California look to maintain,” she tells Buzzworm, while he instead is looking out on “the Harbor Freeway crisis in which every homeless person had for the moment found shelter. Funny how it looked like home” (234).

While Buzzworm subscribes to Manzanar's 'alternative mapping,' Emi disregards it, until it is too late, unwilling to be "disoriented in the landscape of heteronormativity" (Gopinath 21). "Time to put some clothes on and meet another human being. I'm gonna save your life yet," Buzzworm tells her, as he steps down off of her sunny perch (Yamashita 236). Meanwhile Manzanar went on conducting, but "little by little, [he] began to sense a new kind of grid, this one defined not by inanimate structures or other living things but by himself and others like him" (239). Moments later the crack of a gunshot echoes across the freeway, the bullet cracking right through Emi's 'New Age tan,' heightening the colossal damages possible if future generations continue to ignore diasporic and queer bodies that do not 'fit' into the heteronormative framework.

Despite the celebratory nature of Manzanar's great laboring choir, the terror of gunfire ripped across that valley of cars. Manzanar knew it had started with a single shot – the one that had penetrated the soft body of a young woman sunning herself on that news van [...] The sound of the shot penetrated Manzanar's very being with a vengeance he did not understand. The moment repeated itself again and again; he clothed it in desperation each time with pain and more pain. Great shuddering sobs welled from within. (Yamashita 239)

He is painfully aware of the consequences of this war, between the "rising tide of that migration from the South" and the "coordinated might" of every branch of the Armed Forces, with the "motley community of homeless and helpless and well-intentioned" caught between (240). "A rainbow of putrid green gas and red, white, and blue smoke hid the fray from discerning eyes," and Manzanar is truly the only witness, recording "every scream and cry and shudder with dumb incomprehension" (240). The State is shrouding

the *fray*, keeping the knowledge of their innocent bodies away from the greater heteronormative audience of L.A. that surrounds the freeway.

Tropic of Orange thus asserts that America and its heteronormativity is killing off queer diasporic peoples, intending to silence them and bury them underneath the framework of the American dream. Emi is the first casualty in the military attack on the camp of homeless persons on the freeway, her last words “Abort. Retry. Ignore. Fail” (254). As Emi is lifted into the helicopter and Manzanar sees her dying, he thinks, “he hadn’t *meant* to leave her, or anyone else [...] Manzanar had followed an ancient tortoise out into a deep place in his brain and stayed there year after year. Now it had seemed he had surfaced” (257). Manzanar lets his arms drop, with “no need to conduct the music any longer [...] He had seen enough. And he had heard everything” (256 – 257). He and Emi are lifted up above the freeway, “all the airbags in L.A. ruptured forth, unfurled their white powdered wings against the barrage of bullets, and stunned the war to a dead stop. But Manzanar heard nothing” (258). Though Manzanar’s vision of human connectivity wins out for the narrative, his care for othered bodies Yamashita’s achievement in writing of the fragility of the neoliberal and global city, he also suffers a loss. Emi’s vision of neoliberal hyperconnectivity is defeated, wounding Manzanar in the process. No one is precluded from giving care, no one too far above it or too distant from an *other*. Manzanar’s mission ends here, exhausted by his years of creating a melody from the sights, sounds, and smells of the great heartbeat of the city. As he leaves his podium, no longer caring for the city itself but now turning to care for his granddaughter, Yamashita begs for more like him: a healer of the global city and an adequate caregiver for transnational peoples.

Dirty Pretty Things' Okwe

Okwe, from Stephen Frears's critically-acclaimed film, like Manzanar is also an ex-physician. Unlike Manzanar, Okwe did not choose to leave the field of healthcare behind, nor is he a legal citizen as Manzanar is. Okwe was forced to leave his home and family in Nigeria after standing up to political corruption, which was the cause of his wife's murder by government officials. In leaving Nigeria, he left his young daughter, his freedom, and his ability to practice medicine. Now he sleeplessly floats from job to job in the city of London, cab driver by day and desk clerk at the Baltic Hotel by night. Okwe has not left practicing care behind either, though he continues to do so somewhat reluctantly. In one of the first few scenes of the film, Okwe returns from his cab-driving shift and is beckoned to the back office. He goes and is greeted by another of the drivers unbuckling his belt and slipping his pants down to his ankles, displaying a rather unpleasant site. After close examination, Okwe determines that the man has a sexually transmitted disease or genital infection, assuredly from an encounter with one of the city's many prostitutes. He procures antibiotics from Guo Yi, a mortician at the city hospital, and dispenses them to the patient. Not long after this encounter, he is summoned yet again and met by three men with the same symptoms as the first. Okwe chooses to continue to tend to them out of moral obligation, just as he thereafter agrees to help the Somali man who has just had a poorly conducted kidney transplant. His need to help others similarly ostracized from privilege is his perpetual dilemma throughout the narrative.

Okwe displays a deep connection to the other diasporic subjects of the global city, as does Manzanar. The strongest of these connections is with Senay, a Turkish emigrant who is similarly suppressed by London Immigration Services and also works illegally in

the hotel. Another is with Juliette, a prostitute who has frequent customers at the hotel. Okwe first encounters Juliette as she is leaving the hotel. She tells him, “You’d better send someone to check on the room.” He asks, “There is a problem?” And she replies, “How should I know? I don’t exist, remember?” She is another subject that does not belong in the hotel, no one can know that the tip came from her. Okwe goes to check on the toilet, pulling a plastic sack over his hand like a surgical glove, reaching into the bowl as if he is reaching into a body, and he pulls out a human heart. The horror in his eyes forewarns Frears’s audience of the similarly dirty jobs that Okwe will have to take on throughout the remainder of the film. Okwe takes the heart to Señor Juan, the manager of the hotel, who responds with callous disregard: “What the fuck do you know about hearts Okwe?” “Señor Juan, someone is dead.” Señor Juan feigns interest and phones the police, as he dials he questions Okwe, “What is your full name Okwe? Where are you from? Why are you here, in this beautiful country?” Okwe falls silent. “You’ll learn Okwe, hotels are about strangers [...] strangers do dirty things in the night.” Señor Juan’s unspoken threat looms over Okwe – soon he learns Okwe is a trained physician and then tries to coerce him into performing the kidney transplants in the hotel rooms.

The kidney transplants are one of London’s dirtiest secrets in the film, operations run by opportunistic persons like Señor Juan who seek to feed off the low-class diasporic peoples of the global city, furthering Spivak’s financialization of the globe. Such commodification renders diasporic subjects, like the Somali man, even more dispensable. Shital Pravinchandra relates the anonymity of illegal immigrants and displaced bodies to Agamben’s *Homo Sacer*, and in doing so demonstrates the disproportionate allocation of ‘valued life.’ Pravinchandra explains that the Somali man’s “neglected condition certainly

suggests that the death of an undocumented immigrant, like that of the *homo sacer*, is unpunishable. Neither can his kidney extraction be read as a sacrifice, for it is firmly inscribed within the logic of an economic transaction” (45). Pravinchandra proceeds to explain biological hospitality and references medical anthropologist Lawrence Cohen in doing so. Cohen states, “Cyclosporine globalizes.” Cyclosporine is an immunosuppressant that “create(s) a far larger group of potential organ donors... or to put it differently, they render the transplant patient’s body more *hospitable*, immunologically speaking, toward a much larger number of foreign organs” (46-47). Biological hospitality is a very compelling concept when considering Pease’s transnational citizen-subjects and diasporic subjects. The diasporic, asylum-seeking subject is trying to situate himself or herself beyond the limitations of Sue-Im Lee’s Third World villagers. To access the global village, they have to trade an organ for a passport, biological capital in exchange for political/economic. Take Senay, she yearns to leave for New York and never come back, so she too falls for Señor Juan’s promise, and is severely punished. Her price to pay, before he even agrees to the surgery, is her virginity. Her diasporic body is overwritten by the desires of Señor Juan’s transnational and privileged body.

Okwe and Senay, as they exhibit Pease’s diasporic subjects, also are representative of Gopinath’s unruly and queer bodies. They, sharing this with Manzanar of course, are “out of place and disoriented in the landscape of heteronormativity” (Gopinath 21). They are financially and physically commodified, suppressed beneath the aestheticized hegemonic framework, the “normative ways of seeing and knowing that have been so central to the production, containment, and disciplining of [undocumented,] sexual, racial, and gendered bodies” (7). They are Gopinath’s sites of postcolonial fracture. What the film

so successfully conveys is that Okwe and Senay are not the only ones so ignored and belittled by the State. The evidence of the other bodies is present in those Igloo coolers, undocumented kidneys on beds of ice, that are so often passed from the hands of Señor Juan to the suit-wearing, white, supposedly hetero- representative of the State, who upon receiving the ‘goods’ hands over the illegal passports. The film thus provides a glimpse into the “violent present” of the global city, as it pays heed to “the everyday, the personal, and the discarded that typically fall outside the purview of official archives” (8).

Outside of this purview of official archives, paid under the counter, Okwe is essentially homeless, another fate he shares with Manzanar. He may have a roof over his head when he stays in Senay’s flat, or on the sofa in Guo Yi’s dismal hospital quarters, but Frears’s audience never sees him settled. He is either driving the taxicab through London, eyelids heavy with fatigue, manning the desk at The Baltic Hotel, or accompanying Senay. Both he and Senay are working in London without permits, “migrant laborers” and diasporic subjects, as Pease would say. He has no home in London; he cannot make a home in London because he is an illegal immigrant, and he cannot return to his home in Nigeria because of the political unrest, despite his yearning to be with his young daughter. Also like Manzanar, Okwe was a transnational citizen-subject when he lived in Nigeria. He had free mobility as a medical student to study in the United States and he was able to live comfortably, assuming that he’d been able to accrue some wealth since completing medical school. With his flight from his home country, away from his daughter and his medical practice, he becomes a diasporic subject and asylum seeker, displaced and disembodied. Since Okwe is not welcomed and not permitted asylum in the city, it is quite curious that he occupies the spaces that he does, spaces of mobility and hospitality. The taxicabs and

The Baltic Hotel are spaces for transnational citizen-subjects with the mobility and funds to permit them entrance. Sarah Gibson, in her article “‘The Hotel Business is About Strangers:’ Border Politics and Hospitable Spaces in Stephen Frears’s *Dirty Pretty Things*,” engages with the “complex power relations involved in the categorization of others” and analyzes the asylum seeker as opposed to the tourist. Gibson defines the hotel, a fraught space in the film, as a “public, commodified experience of hospitality subject to the logic of an economic exchange,” much different from a house which possesses a “private, personal hospitality” (Gibson 694).

Recall how Manzanar chooses a similar space of mobility, the Los Angeles Harbor Freeway. Manzanar is trying to draw the lines of hospitality from person to person, vehicle to vehicle, creating a melody from the immutable city racket. *Dirty Pretty Things* begins and ends in such a space, the airport. Vicente Rodriguez Ortega writes a detailed analysis of the airport space in his article “Surgical Passports, the EU, and *Dirty Pretty Things*: Rethinking European Identity through Popular Cinema.”

“The juxtaposition of Ryan air and Okwe in the opening scene of the film crystallizes the defining dichotomy that structures the film... Okwe represents the stratum of illegal immigration that sustains the socio-economic foundations of a megalopolis like London... Even if deemed illegal by the institutions that hold the power to define his status, Okwe, like the many Others he stands for, is a necessary component of a society that labels his kind as third-class non-citizens. Ryan Air, conversely, represents the epitome of a borderless world for EU citizens...” (Ortega 24)

Ortega argues that Okwe enters these spaces of hospitality to stand in for the innumerable “Others,” the third-class non-citizens. Okwe is a conductor of such hospitality not through Manzanar’s same willingness but out of necessity, both for financial stability and out of moral obligation.

Okwe is further drawn into the economics of hospitality because of his capabilities as physician. The first economic relationship of this kind is facilitated by his boss who runs the taxicab company when he is solicited to examine several other men, all of whom are minorities and likely diasporic subjects. This relationship leads him to the hospital, another site that is hospitable only for transnational citizen-subjects. We are reminded of this inaccessibility when Okwe helps the nameless Somali immigrant who has just given his kidney for a passport; his family refuses when Okwe urges them to go to the hospital for better care. This transnational transaction would be void if they were to seek help at the hospital. Okwe is in a unique position with the Somali man, with Senay, with Juliette, and with the promiscuous men, because he is offering medical advice, as an asylum-seeking physician, to other asylum-seekers. In the opening scene of the film, Okwe tells the two business men without an arranged driver, “I rescue those who have been let down by the system.” He operates in this manner throughout the rest of the narrative. These diasporic subjects have no other option but to plead with Okwe.

The study by Yvonne Leblanc and her colleagues, “Comparing Approaches to Integrating Refugee and Asylum-Seeking Healthcare Professionals in Canada and the UK,” pays heed to migrant/refugee physicians and nurses and recognizes their “ability to establish economic potential” (Leblanc *et al.* 127). Past research has shown that these men and women can definitely benefit local healthcare systems, but the approaches to

integrating them are not well defined. As Canada and the United Kingdom address this issue, they are taking steps toward a more transnational system. As Okwe is representative of the Others in *Dirty, Pretty Things*, he also represents the large and unrecognized population of immigrant health professionals. Leblanc's study also addresses the difficulty with granting refugee healthcare professionals' status. One response voices the injustice in granting refugee physicians an advantage, which would heighten the competition between refugees for the already scarce resources. Okwe initially denied Sr. Juan's offer to perform these transplant surgeries, as he did not want to take part in the dishonest manipulation of diasporic subjects. But once Senay decides to have the surgery, Okwe takes initiative and the tables turn; he extracts one of Sr. Juan's kidneys to earn their economic freedom. In one of the final scenes of the film, the camera shows Okwe standing with Senay and Juliette, not apart from them, as he hands the Styrofoam cooler with Sr. Juan's kidney to the British man in exchange for the passports. The man asks them why he has never seen them before, and Okwe responds, "Because we are the ones you do not see. We drive your cars, we clean your rooms, we suck your cocks." In doing so, he "speaks in the name of all the invisible people who labor in London's informal service economies" (Pravinchandra 55). Okwe does not take advantage of the invisible laborers as Sr. Juan does, but teams with them. Despite being neglected by the power structures that be, as Manzanar is neglected in his homelessness, his disability, and his history as Japanese American, Okwe responds as Manzanar does and tries to stitch together humanity, bringing us closer to the horizon of universal human rights.

Global Prescriptions

Both of these works, *Tropic of Orange* and *Dirty Pretty Things*, employ ex-physicians as their main characters. In doing so, the novel and the film pay heed to subdued, diasporic peoples, as Manzanar and Okwe both fight to heal their respective global cities and unite minorities around them who are denied place and the ability to cross borders. The moment that most closely relates *Tropic of Orange* and *Dirty Pretty Things* is when both Manzanar and Okwe identify the disembodied human hearts.

Manzanar opened the cooler, pulled a drawstring bag from the melted ice and opened it. Inside [...] was a tiny purple slimy thing padded tenderly by what was now called tepid refrigeration. “Newborn,” he said without battin’ an eye. “Human heart’s consistently the size of your fist. In this case, a newborn’s fist... How did you get this?” Manzanar asked. “I imagine it was harvested for transplant.”
(Yamashita 216-7)

Okwe similarly pulls a heart from its hiding place, not an Igloo cooler but a toilet bowl in a room at the Baltic Hotel. The hearts belong to the queer and disembodied diasporic citizens who cannot exist as fully human, barred as they are from basic human rights. One heart is that of a child, the other of a grown refugee who was hoping for improved economic and political status. Both men see these hearts, and the people that they belonged to, as casualties of the global city and globalization. They do not turn a blind eye, as do the L.A. passersby and Señor Juan, but seek to repair the borders that obstruct the global village. They both ask the question that concludes *Tropic of Orange*, “What are these goddamn lines anyway? What do they connect? What do they divide?” (270). Manzanar and Okwe

were castaways of the global city and the new economic order; their narratives, and those of the people that they helped, serve to inspire a modern audience to look beyond the dividing lines of the global city and to give voice to those diasporic subjects, caring for those deemed queer by the neoliberal nation-state.

CHAPTER FIVE:

QUERYING & QUEERING CAREGIVING:
 READING BODIES OTHERED BY ILLNESS
 VIA POROCHISTA KHAKPOUR'S *SICK: A MEMOIR*

Ever since I can remember, I dreamed of escaping.

Escaping *what* was always the question... (Khakpour 39)

The word diaspora is often reductively defined as an escape, ‘the dispersion of any people from their original homeland.’ Leah Lakshmi Piepzna-Samarasinha’s poem, “diaspora,” from her volume *Bodymap*, names diaspora differently: “to be in diaspora, maybe you are always a ghost always missing something...”. Through my experience with diaspora and transnational studies, especially thanks to Gayatri Gopinath, I have come to define diaspora much more broadly, something more akin to the “ghost always missing something” that Lakshmi describes. Gopinath expresses a “dissatisfaction with standard formations of diaspora that inevitably foreground the nation as the primary point of reference,” and thus proposes an alternative cartography (Gopinath 4). This new kind of theoretical mapping “rejects dominant cartographies that either privilege the nation-state or cast into shadow all those spaces, and gender and sexual formations, deemed without value in the map of global capital” (4). This mapping extends to queered, othered, and alternative bodies and formations (physical and psychological), including those othered by illness and disability. For Gopinath, and for the purposes of this study, “‘queerness’ here names a state of being out of place and disoriented in the landscape of heteronormativity” (21). This notion of disorientation is often expressed by individuals

with ‘unruly’ bodies, bodies that defy the heteronormative definitions of health and wellness and refuse to be disciplined into normative ways of ‘well-being’. One such voice is evident in Porochista Khakpour’s 2018 memoir, *Sick*, labelled on the back cover her “grueling, emotional journey” as a woman, an Iranian American, a writer, and as a chronically ill person. The memoir thus navigates her queer diaspora: her attempted escape from the hegemonic constructs that define her existence as a disabled-and-suffering woman of color.

Khakpour’s *Sick* is a brutally honest depiction of “escaping” from home, from the place, space, and body already prescribed. Her memoir conveys her long battle with illness which ultimately results, after \$140,00+ spent on medical bills, in a diagnosis of late-state Lyme disease. The narrative relies heavily on the movement from place to place, chronicling her family’s flight from Tehran and the Iran-Iraq War, to “Tehrangeles,” an Iranian community in Los Angeles, then to the dreamlike New York City, Santa Fe, small-town Pennsylvania, Germany, et cetera. Throughout it all, she navigates a search for self, a becoming, or alternatively, an escape from the heteronormative body/space/place she cannot fully occupy. The memoir intimately describes the physical and psychological symptoms of Lyme, in addition to her addiction patterns and other encounters with illness, in order to confront the misconstrued notion that bodies are faultless and flawless houses for our beings. Susan Wendell, in her article “Toward a Feminist Theory of Disability,” asserts, “disability is not a biological given; like gender, it is socially constructed from biological reality. Our culture idealizes the body and demands that we control it. Thus, although most people will be disabled at some time in their lives, the disabled are made ‘the other’” (Wendell 104). Wendell argues that chronic illness be recognized as a

disability, and so too does Khakpour. Her narrative describes Lyme disease as one “that many in the medical profession, unless they specialize in it, find too controversial, too full of unknowns, to fully buy it as legitimate,” othering her because of her biological reality (Khakpour 21). Thus, though she is the accumulation of her own (dis)embodied experiences, she is denied full inhabitation of her body, over and over again, because of caregivers’ hesitancy in assigning a diagnosis of Lyme, or for that matter, any diagnosis at all.

Even long before Khakpour’s official diagnosis, and her endlessly repeated hospital stays, she felt a discomfort in her body. When her body met with chronic illness and disability, she “grew to feel at home” (6). The cover image depicts Khakpour herself, laying down, eyes wide but fixed and sure, mouth closed, nasal cannula hooked in place behind her ears, thick black hair fanning around her head. In this image, and in the memoir itself, she is confronting her audience with this stare and with the spill of pills that border her name and existence and the title of the book, challenging caregivers’ denial of her ‘othered’ body and creating a space for herself via the health humanities. Early on in the memoir, Khakpour voices, “I am a foreigner, but in ways that go much deeper... under the epidermis and into the blood cells” (Khakpour 6). Her body is “foreign,” strange, as it resists heteronormative modes and diagnoses. In a *New Yorker* review of *Sick*, Lidija Haas writes that “pain and disease are what they are—they resist meaning and the narratives that make it. Other people’s sicknesses, as bodily phenomena, must be imagined or taken on trust, since they can never quite be transmitted across the gap” (13). So many bodies and persons fall into this gap because they are queer, queer to their friends and family and queer to caregivers and healthcare providers. This ‘gap’ deserves to be explored, in order to pay

attention to the persons and queer bodies that have fallen into its cavernous mouth, and to be bridged, by establishing a framework, or a transnational net rather, of adequate caregiving. Such a framework can draw from Gopinath's vision for a queer optic, which "brings into focus and into the realm of the present the energy of those nonnormative desires, practices, bodies, and affiliations concealed within dominant historical narratives" (Gopinath 4). Why is it that nonnormative bodies such as Khakpour's are consistently denied existence by the Western and hegemonic optic, in other words, the heteronormative way that providers *see* patients? She experiences so many different symptoms, and attempts treatments with an array of formal practitioners and intimacy with a number of informal caregivers. But despite her attempts, she is largely ineffectively cared for, due to her 'queer' existence as a woman of color navigating chronic unhealth, and her insufficient care for herself. Through this study, I hope to name the "*what*" that Khakpour is escaping from, to shed light on her and other patients' experiences of 'queering' via disease and healthcare, and to analyze and critique caregivers' perceptions of queer bodies, thus querying (or queering) caregiving for 'others.'

Articulating a Framework for 'Querying & Queering'

Performing an aestheticized practice of queer diaspora in Khakpour's memoir demands that we look at illness as queering, especially for a young woman like Khakpour. Michele Lent Hirsch's book, *Invisible: How Young Women with Serious Health Issues Navigate Work, Relationships, and the Pressure to Seem Just Fine*, greatly contributes to this notion of queered embodied experiences. Hirsch herself shares commonalities with

Khakpour; she too was diagnosed with Lyme disease, in addition to thyroid cancer and mast-cell activation syndrome, among other health difficulties. Also, like Khakpour, she uses the pages of her book to explore the intersection of gender and health, between femininity and illness/disease/disability. While *Sick* is a memoir, *Invisible* is an accumulation of personal health narratives, Hirsch's included, interviews, and research studies. Hirsch seeks to answer the following question: how are women shaped by disease, and how do they shape the disease to fit their otherwise maligned bodies? She notes, "disability is largely about the world's failure to make space for you," articulating the same kind of disembodied disgust that Khakpour speaks toward. The Kirkus review of *Invisible* states, "At a moment when women's experiences in the workplace have come to the fore, Hirsch's eye-opening study of gender-based disparity surrounding illness will hopefully help spawn a similar reckoning for women's health" ("Kirkus Review"). Khakpour's *Sick* also calls for this reckoning, but broadens it, confronting caregivers with non-normative, non-masculine bodies such as hers and Hirsch's.

Engaging with Khakpour, and Hirsch supplementally, points to the gendered experience of illness, disease, and disability, and thus is intimately and intricately linked to feminist theory and phenomenology at large. Wendell, as mentioned above, is one of the early writers on the intersection between feminism and disability. She speaks at length toward the ongoing difficulty that othered/queered/disabled bodies have in placing themselves in the heteronormative world around them, ultimately arguing that feminist theory can free the disabled other from the stricture of Disability and the social constructs that surround it. Gopinath's argument for the queer body is similar to Wendell's plea – both are grounded in the need for body equality. Wendell also fell ill due to a disabling

chronic illness, so she and Khakpour share the same ‘othered’ ground. In her much-later study, “Unhealthy Disabled: Treating Chronic Illnesses as Disabilities,” she continues to explore terms of definition for ‘disability’ and disabled persons. Here Wendell begs the question, are illness and disability necessarily always *evil*? Western medicine tends to paint ill and disabled bodies in this way, as if the way to reckon with those bodies is to overwrite the illness, ‘healing’ them of their otherness. The solution, she says, is not so black and white. Rather, ill and disabled persons should be met where they are, recognized as human even in the light of suffering. Her argument converges with Gopinath’s: as the aesthetic practice of queer diaspora “provides us with a critical model of engaging with difference: a model that does not see past difference, but opens the possibility of forging alliances in and through it” (Gopinath 29).

Queer diaspora problematizes prescriptions of ‘normative’ embodiment, as does feminist phenomenology, thus this analysis requires engaging with Lisa Folkmarson Käll and Kristin Zeiler’s anthology *Feminist Phenomenology and Medicine*. The text is compiled of essays from many different perspectives that each speak toward different medicalized modes of being. Abby Wilkerson, one of the essayists, best describes what it means to apply phenomenology to medicine.

Because phenomenology addresses meaning “at the level of the life-world” and contextualizes this lived experience in the interactions of “embodiment and culture,” it opens up a critical space for assessing the life impact of medicalization through attention both to how normality and its boundaries are defined and to the nature of subsequent interventions into departures from normality. (Käll & Zeiler 156)

These ‘departures from normality’ is what I am interested in. Khakpour’s diasporic body and narrative departs from normality, thus it is ‘queer’ and ‘other’ to the medicalized and heteronormative optic. The stakes of *Feminist Phenomenology and Medicine* are such: “to advance more comprehensive analyses of issues such as bodily self-experience, normality and deviance, self-alienation and objectification” (Käll & Zeiler 2). Käll and Zeiler, and each of the chapters therein, thus speak directly toward Khakpour’s ‘bodily self-experience;’ she is a feminist and woman of color trying to navigate the hegemonic of American healthcare, all the while feeling distanced from her own body, without a home. While dealing with issues of embodiment and situatedness, the book also “examines normative cultural practices and structures of meaning that situate different bodies in different ways and with different conditions, and seek to lay bare the constitutive conditions of experience” (Käll & Zeiler 2). This study also seeks to investigate areas that are not typically deemed ‘medical’ – sexuality, bodily appearance, and norms of beauty – each of which factor heavily into Khakpour’s othered and queer narrative.

Sick offers a painstakingly personal portrayal of just what it means to be ‘sick,’ and what all accompanies that label. There are two specific essays within *Feminist Phenomenology and Medicine* that are serviceable in this query, Linda Fisher’s “The Illness Experience” and Wilkerson’s “Wandering in the Unhomelike: Chronic Depression, Inequality, and the Recovery Imperative.” Fisher voices the need for a phenomenological approach in studies on illness, especially in studies on *the experience* of illness. Fisher deems that the illness experience, purportedly subjective, is “heavily colored by the reception, construal, and treatment of the individual in the wider social context” (Käll & Zeiler 39-40). *Sick* provides us with exactly that, as the care and attention she is given by

others, caregiver or not, restructures her own experience with illness. Her self-perception is so greatly based upon how she is received and perceived by others, especially those she trusts with the knowledge of her body and illness(es). Fisher queries why illness is framed “not just as the compromise but the negation of health [...] In this manner, health is defined in opposition to illness, as the absence of or resistance to this ever-threatening Other, the negative foregrounding and delineating the positive” (31). Khakpour does not just have a disease, she *is* ill; her body becomes what Fisher calls this ‘ever-threatening Other.’ While her illness experience does not draw significantly from the actual voices and writings of an outsider, what Fisher calls ‘a view from without,’ her experience is fractured and framed by the care given to her mind and body, or the lack thereof, what Fisher calls ‘a view from within.’ *Sick* provides us with this view from within, not only relating her sense of self to her bodily experience but entrenching that experience within the broader sociocultural context. This analysis inherits the kind of phenomenological approach that Fisher elucidates, explaining how Khakpour’s memoir portrays ‘a view from within,’ thereby commenting on society at large.

Wilkerson’s “Wandering in the Unhomelike,” as the essay title conveys, speaks to this unsettling ‘othering’ as well, specifically in the context of depression. Through frequent use of bodily metaphors drawing from Delmore Schwartz’s poem, “The Heavy Bear Who Goes With Me,” she conceptualizes the illness experience of depression, focusing her argument with a Marxist lens to demonstrate the how depression meets with “broader social power dynamics” (Käll & Zeiler 155). She employs Heidegger to construct a Marxist framework, and Fredrik Svenaus for grounding her phenomenology-meets-medicine argument. Heidegger’s concept of “being-in-the-world, in which objects’

meanings depend on their role in human projects,” speaks directly toward an experience of depression (156). Heidegger points to boredom and anxiety, which Svenaeus notes, are symptoms of depression, as “unhomelike phenomena,” in which “the world resists meaningfulness” (156).

For Heidegger, unhomelikeness is a necessary tool in the quest for authenticity; however, as Svenaeus notes, when it is not “balanced by homelikeness [...] we fall into a bottomless pit of darkness.” In depression, unhomelikeness suffuses embodiment, illustrated well by the bear, lumbering and slow yet always capable of annihilation, a creature whose presence would seem to render home itself unhomelike. (Käll & Zeiler 156)

Wilkerson’s application of ‘the unhomelike’ is evident in Khakpour’s embodied discomfort that she voices throughout *Sick*. Her uncanny disembodiment is certainly multifaceted, but is ultimately rooted in her illness and dis-ease: “Every part of my body felt like its wiring was all wrong, I felt like a foreigner in a hostile country, never adjusting or accepting that this was what it had all come to” (Khakpour 108). At several points throughout the narrative, she voices a kind of lost and home-less feeling, not knowing if she was “depressed, addicted, messed up from [a car] wreck, or something else;” she feels foreign to her own self, not just to those around her, thus she partially others herself because of her experience with disembodiment (63). Her body is unhomelike, not just for her, but for friends and family, and even for healthcare providers too – her body’s deviance from health into illness, what Fisher calls “the ever-threatening Other,” is uncanny and unhomelike, even to readers like me and you (Käll & Zeiler 31).

The Medicalized Aesthetic: Seeking Formal Care

Khakpour's illness experience was significantly shaped by what I am calling the medicalized aesthetic, in other words, the optic employed by formal caregivers and healthcare providers. When she is, perhaps, at her lowest point, symptoms of every kind ravaging her body and mind, she admits;

I became someone whose main job was trying out medications and going to the doctor. It was like shopping in a way [...] I tried out antidepressants with names like sci-fi wizard goddesses, Paxil and Celexa [...] I tried acupuncture, I tried an ayurvedic center, I tried multiple healers, I tried nutritionists. At one point I was seeing three different sleep specialists who all seemed fairly invested in hiding how stumped they felt. I spent every penny I had searching for the energy to keep seeking. (Khakpour 104)

This section will evidently speak toward the many healthcare providers that Khakpour sees and seeks. Her experiences of formal caregivers and the care that they give inform her illness experience and her sense of selfhood and identity. Even as she states, "*I think there is something wrong with me physically,*" the providers she sees are confounded by the cacophony of her symptoms and thus fail to truly listen to her narrative (Khakpour 104). There are several specifically Iranian American physicians who care (or fail to care) for Khakpour. One, Firoozeh, a female nurse practitioner tries relentlessly to dissect the root of Khakpour's ill health, while others, all male physicians, do not attend to her body and disease effectively. While their experiences of Gopinath's region and cultural

(un)belonging may be similar, gender and societal seat and illness interrupt the intimacy available to them.

Western medicine operates under a strictly heteronormative optic, permitting illness, of course, but largely for the purpose of restoring health, turning illness ‘off.’ Nearly all of Khakpour’s formal caregivers subscribe to this optic, the standard way of *seeing* patients, not finding validity in her story and symptoms because they “fall outside of the purview of official archives” (Gopinath 8). Both Linda Fisher and Susan Wendell speak toward this rendering of illness, especially by those situated within the medical hegemonic. Fisher notes, “whether such negative social framings of illness are latent or on the surface, whether mild or strong, they serve to constitute illness and the ill person as Other” (Käll & Zeiler 31). Illness thus “serves the normative function of designating what counts as normality and the desirable status quo” (31). Disability is identified similarly, as it is largely socially-constructed. Illness and disability are even further complicated by gender – it is ill and disabled women who “struggle with both the oppressions of being women in male-dominated societies and the oppressions of being [ill or] disabled in societies dominated by the able-bodied” (“Toward a Feminist Theory of Disability” 105). As femininity has historically implied a lack of power, both these terms, illness and disability, connote weakness. Feminine, ill, and disabled bodies are evidently less *visible*, even to such caregivers as these. Consider again the cover of Khakpour’s memoir - her gaze commands the space of the narrative as her eyes and expression are challenging the medicalized optic that would dare pin her body down as something to be pointed at, defying with a look all those who’ve labelled her as ‘sick.’ I also invite us to consider the cover of Hirsch’s *Invisible*, pictured here. This image very fittingly demonstrates the diminished

visibility of women with chronic illness. In the medicine cabinet, split by the opened door of the mirror, half of a woman's face looks back at us. Her face already obscured by shadow, the mirror of the medicine cabinet (representing the medicalized optic that I've been speaking toward), fractures her sense of self. And behind the mirror are three plastic pill bottles, with their indistinct prescription labels, trying to return her unruly body to a



normative existence. This medicalized mirror alters the way that a young and chronically ill woman sees herself; her identity has changed because of what physicians and providers have diagnosed and prescribed. Hirsch's *Invisible* and Khakpour's *Sick* present the oft-obscured eyes and perspectives of those on the other side of the normative optic, giving identity and body and emotion to those patients that only serve as statistics, to those 'real' persons acting their way through commercials for prescriptions.

The optic for chronic illness, especially those illnesses that are muddled by difficult or unreliable methods of diagnosis, is even more debilitating. Chronic Fatigue Syndrome, Somatization Disorder, Chronic Depression, Chronic Lyme Disease – each of these illnesses functions beneath the *knowing-ness* of medicine. When Khakpour is first pulled into sickness, experiencing a tumult of symptoms simultaneously, she tells her editor, “*Chronic fatigue [...] that's what they are saying*. But no one was saying it and there was no ‘they’” (Khakpour 107). The ‘they’ is a signifier for some greater body of knowledge that has the ability to name, and thereby signify, what Khakpour is experiencing. The ‘they’ conjures up an image of a presumably wise group of medical experts, all hetero, white, and

male, physicians and researchers gathered around her very ‘other’ body, pointing to a cold collective of data and statistics that implicates her body into a gendered and complex diagnosis. The ‘they’ would not understand Khakpour’s body, that she “doesn’t look like what [they] might expect. That [she’s] a brown Middle Eastern woman” instead of privileged and white like the bodies that fill their studies (129). She finds illness turns her body, literally and imaginatively, “white – thin and pale to the point where everyone congratulates me at my sickest as I transform to a white woman in appearance [...] Every part of me in illness becomes the white woman of their dreams” (129). This is how ‘they’ and their medicalized aesthetic frames Khakpour and woman like her. This is the typical narrative of Chronic Fatigue Syndrome, among other chronic illnesses, and Khakpour, in her confused scramble for a diagnosis, defers to what the ‘they’ might be saying, thereby subscribing to the medicalized aesthetic that surveils ill bodies and minds.

In their 2009 study for the *Journal of Women’s Health*, “Implications of Gender in Chronic Lyme Disease,” Gary Wormser and Eugene Shapiro identify one of the difficulties in their study as the “relatively small number of patients with post-Lyme disease who were available to be *analyzed*. This is likely because very few patients actually develop significant long-term functional impairment after a true episode of Lyme disease” (833, emphasis added). Their study ends with the following conclusion: “This finding suggests that illnesses with a female preponderance, such as fibromyalgia, chronic fatigue syndrome, or depression, may be misdiagnosed as chronic Lyme disease” (Wormser & Shapiro 831). Instead of attending to the narrative to the persons within this study, Wormser and Shapiro take to the normative optic and diagnose and *analyze* based upon statistics and probabilities. Similarly, in the article, “The Overdiagnosis of Lyme Disease,”

the authors write, “the greatest diagnostic problem demonstrated in this study was distinguishing Lyme arthritis, encephalopathy, or polyneuropathy from chronic fatigue syndrome or fibromyalgia” (1815). Khakpour speaks to these kind of studies in her essay, “On Place”: “It is no coincidence then that doctors and patients and the entire Lyme community report – anecdotally of course as there is still a frustrating scarcity of good data on anything Lyme-related – that women suffer the most from Lyme” (166). In her own theorizing and through her narrative voice, she highlights the ‘normality’ of chronic illness for women, and how that chronic illness is often mistaken for mental illness because “women simply aren’t allowed to be physically sick until they are mentally sick, too, and then it is by some miracle or accident that the two can be separated for proper diagnosis” (166). Due to the nature of these studies on Lyme, and of their field in general, they subscribe to the medicalized aesthetic that traps othered and ill, thereby queer, bodies beneath the framework of medical diagnostics and statistics, a trap that has persisted for decades upon decades. The medical rhetoric for physicians and practitioners and researchers rests on the history of hysteria, a history in which women who were physically ill, especially those chronically physically ill, were deemed to have poor mental health as well. This mindset persists even today, in these kinds of studies, and thereby in the minds of women like Hirsch and Khakpour, because they are at the hands of these physicians and practitioners and researchers who continue to ascribe to a hysteric kind of rhetoric.

Consider Samira, who Hirsch introduces as a “twenty-nine-year-old woman of color/femmedrogynous person of color” who was diagnosed first with polycystic ovarian syndrome (PCOS), then post-traumatic stress disorder, then hypothyroid, then severe irritable bowel syndrome, then insulin-resistance due to complications of PCOS (Hirsch

130). Her body and medical chart are the cumulative results of her illnesses, not able to be separated from the illness experience;

Despite this combination of serious – and diagnosed – health issues, Samira cannot get doctors to listen.

“I live with chronic pain,” she writes, “but am refused any form of reprieve from my practitioners. They don’t see the pain, exhaustion, anxiety, or depression that have become a part of my conditions [...] I’ve dealt with homophobia and misdiagnosis” – and, it seems, the common belief that her pain isn’t worth treating or even real.

The history of ignoring or disbelieving women’s pain is centuries old. The problem is so vast that it’s almost too unwieldy, too pervasive throughout history, to summarize briefly. (Hirsch 130-131).

Unwieldy – this is what by-the-book practitioners use to describe bodies like Samira and Khakpour’s. They are unruly and slippery and too risky to listen to, so caregivers that ascribe to the medicalized aesthetic choose to be ignorant, or rather, subscribe to the stony incomprehension that chooses only to listen to medical journals and texts, without the patient narratives necessary for fostering empathy and understanding. Gopinath asserts that an ‘unruly vision’ is essential for inclusive accommodation and thus to proper care for queered and othered persons.

One of the most othering symptoms, according to Khakpour and the women of Hirsch’s *Invisible*, is fatigue and all that accompanies it. Wendell, in her study “Unhealthy Disabled: Treating Chronic Illnesses as Disabilities,” reminds us, “fatigue is one of the

most common and misunderstood impairments of chronic illness” (24). Fatigue resists the typical categorization that other symptoms fall easily into; “it is more debilitating, it lasts longer, and it is less predictable [...] Reasonable precautions may help prevent it, but it resists control” (“Unhealthy Disabled” 24-25). The normative medicalized aesthetic depends upon control, so a symptom like fierce and unyielding fatigue unsettles even the most scrupulous of physicians/providers. Khakpour frequently mentions ‘Dr. E,’ an infectious disease specialist, one of the few physicians she sees regularly. He is one, due to his specialty in ‘unruly’ diseases, that has a grasp on the ‘impossibilities’ of Lyme disease. When she started experiencing such fatigue, he warns her that “almost always, as the spirochetes multiply and infiltrate the body, the Lyme sufferer loses the ability to sleep. *It’s usually a particular type of insomnia, he said, the kind that really ruins people. It’s not the type of insomnia the general public can begin to fathom*” (Khakpour 101). Fatigue renders already strange bodies *unfathomable*, especially in the light of a neoliberal and hyperproductive capitalist era. Fatigued persons cannot be appropriately productive, thus they are inherently worth less, compared to ‘healthy’ colleagues and coworkers, ‘productive’ neighbors, family members, and friends.

As Khakpour navigates doctor’s office after doctor’s office, seeking some kind of diagnosis or reprieve, one provider she trusts is a nurse practitioner who “was an expert in women’s health,” Firoozeh, who also, “by strange coincidence, happened to be Iranian” (Khakpour 149). Khakpour in this instance of meeting Firoozeh is diminishing her own symptoms, asking, “‘Why do you think there is something definitely wrong?’ [...] She looked at me like I was crazy” (149). Firoozeh eventually named her diagnosis as something very near to ‘Diabetes 1.5,’ not a true diagnosis, but something outside of and

beyond diagnostic criteria, beyond what I've called the *knowingness* of medicine. While descriptions of Khakpour's relationship with Firoozeh are limited, I am interested in exploring it because she attends to Khakpour's body much more intimately and frequently than do any of her other formal caregivers. She and Khakpour, in their existence outside of the white/hetero West as Iranian Americans, share what Gopinath calls a region of (un)belonging. Firoozeh is also a woman of color who had to navigate very masculine and medicalized spaces, attempting to situate herself in a landscape that is largely hostile to women, especially to women of color, and even more so to women of Middle Eastern descent. Firoozeh's body is also queer to society around her because of her origins, personal or familial, another victim of the disorientation that is "the by-product of dominant constructions of national and communal (un)belonging" (Gopinath 8). While she did not fully grasp the root of Khakpour's difficulties with unhealth, she took her seriously, believing in her story and her symptoms and her body as other formal caregivers had not. Most of her other healthcare providers, Iranian or not, did not grant her the concerned care that Firoozeh did. In Khakpour's words, after having moved back to New York, her other healthcare providers "seemed as clueless as I was, my body a mystery they couldn't solve. I started to feel rejected by them, sensing their dread when they'd greet me, feeling the frustration in their bodies as they pored over yet another batch of bloodwork" (Khakpour 174). Their dread arises out of the normative optic that deems Khakpour's body and bloodwork queer, that optic that hopes to see a body that can be tactfully replaced into a healthy and normative state of being.

Instead of subscribing to the normative medicalized aesthetic, illness narratives like Khakpour's are advocating for a queer optic, a way of seeing- and caring for patients that

does not belittle their experiences with its rigid constructions of health. This revitalized optic queers its own way of seeing. Gopinath identifies the goal of her study as the creation of “a shared queer visual aesthetic that mobilizes new ways of seeing both regions and archives, and that puts into play, through an affective register, an intimate relation between the two” (4). Patients, as persons, emerge out of a personal region and archive, thus their illness experiences are embedded both in where they come from, where they find home, and their archive of memories, what *beyond* illness shaped their body and mind.

Finding Home in the Other: Relationships Of- and Without-Care

In addition to the ‘they’ that diagnose and prescribe and surveil over bodies like Khakpour’s, there is another ‘they’ present in *Sick*, those unlicensed and supposedly supportive voices of her informal caregivers. It is important to thus engage not only with the formal caregivers in her narrative, but with the relationships she carries throughout as well. While formal caregivers and healthcare providers can validate one’s illness via diagnosis, family, friends, and lovers are those who validate one’s sense of being. Such people have both the ability to affirm one’s sense of self even in the midst of a debilitating diagnosis, like Chronic Lyme Disease, and the potential to further fracture and further Other. *Sick* is thus muddled by many informal caregivers, including a long list of boyfriends, friends who flit in and out of Khakpour’s life, and her parents back in Los Angeles. Khakpour reflects on these relationships, saying, “The deal with so many chronic illnesses is that most people won’t want to believe you... you make them uncomfortable. Your existence is evidence of death, and no one needs to keep seeing that – especially not

the people who gave birth to you” (Khakpour 82). Even fathers and mothers and friends can other their kin in an instance of illness. They are hopeful in the expectation that illness will soon dissolve, and the son/daughter/friend will return to health and ‘normality.’ Chronic illness defies these borders and boundaries set for bodies, thus making us as friends, parents, boyfriends, and girlfriends, uncomfortable. Every phase of Khakpour’s health “seemed to have had a [person] attached to it [...] they serve as echoes of [her] memory, as witnesses, as invisible testimony” (139). This portion of my chapter attends to those partners and persons, exploring her many attempts to find home in the other. Made into a ghost by illness, she is trying to find that “something always missing” in *someone* (Lakshmi).

Sick is very self-aware, sure of its sorrows and confusions and even contradictions. Khakpour thus admits to her heavy, and often unhealthy, reliance on relationships, her most notable reflection on this just after she ends a near-abusive relationship with Ryan;

I realized that for years now, every stage of my life had been calibrated by romantic relationships – including the measurements of health and wellness. Being alone suddenly, at this point in my life, made me feel especially unanchored [...] As much as I didn’t want to admit to that dependence, it felt like I had lost a soul mate and needed a placeholder. (Khakpour 137)

She very quickly turns to a colleague, Jacob, after the breakup, a man whom Ryan had always been suspicious of for his ‘eye’ for Khakpour, deepening her friendship with him until it, very quickly, reaches sexual and emotional intimacy. Out of earnestness, Jacob asks her to move in with that very fall, so that they could “practice,” Khakpour very sure

of what he meant. She describes this as the “most Adult relationship” of her life, full of great hope and the promise of a ‘real life’ (Khakpour 140). Ryan became the “Bad Boyfriend” while Jacob very readily became the “Good Boyfriend,” the new informal caregiver in a long lineage of informal carers who, each time, Khakpour thought was the one who could care best (140). Jacob was the most serious of Khakpour’s carers and lovers, thus why I take particular interest in his role in the narrative.

Hirsch, in her personal reflections in *Invisible*, as opposed to the stories she draws from other voices, accentuates the very danger of vulnerability in the illness experience. Jacob proposes to Khakpour and their engagement persists through a series of long-distance stints, but ultimately falters due to his alcoholism; his vulnerability prohibits caring for Khakpour in her vulnerability. In a way, Jacob idealized Khakpour’s sick body, and had since the beginning of their friendship, with him driving her to appointments when Ryan was no longer there to do so. He idealized her for her bodily dependency/despondency, and she him for his method of caring and his dreaming of her in his future. They failed each other because they did not properly confront the queer innate in both of their bodies. Jacob was too distanced, as had been each of her lovers, their relationships founded on need instead of want; Khakpour finds it unclear if all of those men “were caretakers or protectors of additional stressors when life would hand me its trials, trials these men couldn’t access as they were primarily trials of the body” (152). Khakpour here identifies her distinct challenge in heterosexual relationships – the men, primarily white, with whom she assumes intimacy are unfamiliar with her queerness, as a woman, an Iranian American, and a sick person.

Hirsch also explains such distancing in relationships well, evident in her personal narrative and in her stories from other women. While not exclusive to hetero-relationships, “there seems to be more of a precedent for cisgender men rejecting women for their health [...] those deep cultural forces and beauty standards and gender roles were still there in the relationship, pinning [women] down” (Hirsch 12, 11). Queer and ‘sick’ bodies are often Othered, even in very intimate relationships beyond the misogyny of medicine. Thus there lays a kind of danger in dating.

You’re a woman who’s barely out of high school or college, or you’re thirty and supposedly at your sexual peak. You’re in pain [...] or your immune system is weak, or it’s overly strong, or there’s a tumor or a faulty valve [...]. You are strange to your ‘healthy’ friends, who perhaps want to understand, but can’t. You are strange to the older women you meet – women who cluck and say, ‘Too young.’

And on top of that, what you keep hearing whether you’re single or partnered is that you’re already in danger of being ditched. (Hirsch, back cover)

Hirsch says she herself is ‘more gay than straight,’ having had several relationships with women, but she does not expound on these, does not offer how these women attended to or cared for her body. And neither does Khakpour, who also identifies as gender queer. In her brief but notable chapter, “On Lovers Lost and Found,” she asserts her queerness but doesn’t fully claim it: “(... Because I am afforded heterosexual privilege in dating men so often, I tend not to rush to mark that box (the LGBTQ ‘box’). Perhaps it’s also because I feel overwhelmed by all my marginal identifiers. But I question that omission; to leave that out would be disingenuous too)” (Khakpour 239). Despite her three notable relationships

with women, she writes of her queerness in parentheses, not even claiming her writing as words that deserve a rightful place in the narrative. In doing so, she is othering herself and her alt-sexual body, in order to comply with what is deemed heteronormative, in order to not be further othered.

There are other relationships within *Sick* that demonstrate informal caregiving beyond lovers and boyfriends, best evident in Khakpour's mother and father. As she begins the memoir, she admits there is one thing she has always known: "I have been sick my whole life. I don't remember a time when I wasn't in some sort of physical or mental pain" (27). Part of this mental sickness emerged in her childhood and her family's flight from Iran amidst the tumult of the Islamic Revolution. Her parents, members of the "educated, progressive, Western-friendly upper class," could not have lasted there (27). Khakpour describes her first memories are from this time of flight, memories of pure anxiety from seeing her parents so panicked. She cites storytelling as her method of survival, "furiously she told stories to distract" and pull them out of their trauma (27). These memories are what Gopinath calls one's archive, the collective of memories that continue to shape one's future no matter their distance from the present. Khakpour's archive is marred by the traumatic transplant from Tehran to Tehrangeles. What I find even more curious – her earliest memory of storytelling demonstrates caregiving. She attempted to care for her parents while they were in deep grief over the move far away from home to a place where they became victims of Gopinath's regional (un)belonging. As her childhood begins with caregiving, the rest of her life as we see it leans heavily on that thread. Several providers diagnose her with PTSD throughout her narrative, citing this early experience as one that could cause significant psychological repercussions later in life. Khakpour was the one

providing care, denied an attentive and appropriate home and care from her parents, thus she seeks home and attentive care throughout her illness experience, in largely unhealthy ways.

Khakpour's mother is evidently no longer an unattentive mother. She scoops her daughter out of Chicago and out of Germany in the midst of severe relapses to bring her back home to Los Angeles. But she is not a perfectly healthy mother either. She too is bound by what Khakpour calls her "Western-friendly" vision, the optic that Others and distances her daughter's illness experience. Already displaced and disposed in her existence as an Iranian woman living in the United States, she cannot fully empathize, or other herself further, to meet with her daughter's queer symptoms. Khakpour explains that her mother validated her illness only once, saying she looked truly sick – "To be seen, to be heard, to exist wholly, whether in beauty or in ugliness [...] felt like another big step to wellness" (Khakpour 82). This recognition is a form of love for Khakpour, the kind she felt she never received as a child navigating a new (and unhomelike) home. America was not homelike to her parents either, as her illness greatly distorted their vision for what an American life might be like.

They were supposed to have money, I was supposed to have health, and all of that was supposed to be tied up in the same bundle. Health and wealth. I think the only thing that consoles them is the fact that it seems like a big chunk of Americans are also without those things. All my life, I've heard my parents and relatives say *America is a sick country*, in every meaning of the sentence possible. (Khakpour 83)

America has denied them of the American dream, that hopeful promise that is most readily available to heteronormative and white persons. A hope not so readily available to Iranian Americans in a post-9/11 and hypervigilant West. It is not that they are poor, but members of a fragile middle class where substantial health difficulties can lead to bankruptcy. They do not expect America to be a country that lacks adequate and accessible healthcare, finding it unbelievable that illness cannot be easily and seamlessly ‘fixed’. Khakpour’s parents are, in part, assigning their daughter blame for her otherness. They are shocked, nearly disappointed, when she seeks admission to the hospital’s psychiatric unit near her home in California, appalled that she would choose to publicize her already queered, woman-of-color, body as something *sick*. Her parents are not the only ones to accuse her in such a way. In the midst of crippling poverty, she sold a few family heirlooms to a pawn shop owned by an elderly Iranian man. As he takes her things, he tells her, “my boy in medical university; my girl, married and with baby. Your fault for being a starve of an artist, daughter” (Khakpour 121). In their “Western-friendly” vision, her parents, and this Iranian man of their generation, subscribe the heteronormative optic that Gopinath warns against, the optic that expects persons and bodies no matter their origins or health to be neatly categorized and subsumed into American perceptions of normality. They are thus negatively contributing to Khakpour’s illness experience. Fisher reminds us that there are many instances “where the ill person is seen as not only responsible but morally blameworthy for their illness, the illness seen as their fault, even as deserved” (Käll & Zeiler 30-31). Even when such blame is not assigned, “there is still frequently an overriding moral negativity and anxiety about illness, a negativity and anxiety, once again, that can extend to the ill person herself, even if unwittingly” (31). The Othering of a person, who is

queer in gender or of body or of mind, can truly fracture, cracking through the sense of one's self. The informal caregivers of *Sick*, even beyond those that I have discussed here, are just as essential and informative to Khakpour's illness experience as are her informal caregivers. Her friends, boyfriends and lovers, and parents all "can at least tell you I existed. They might not have thought of me much, but they can tell you I was real. Sometimes too real" (Khakpour 239).

Caring for the Self

"I sometimes wonder if I would have been less sick if I had a home." (Khakpour 168)

The above reflection from *Sick* captures Khakpour's embodied and emotional longing for place. This analysis begins with her dream of escaping, and this thought articulates what she is escaping from and where she hopes to escape to: she yearns to leave physical and psychological troubles of the body behind and find some a kind of home, a body that is more homelike. Thus this third analytical portion of my chapter regards the care that Khakpour affords herself. Her method of caring is via region, as she seems to think that a new location (whether New York or Northern California or Santa Fe, what she longingly names the "Land of Enchantment"), a new physical home, will help ease her body away from discomfort (Khakpour 145). She structures her novel around place, naming each chapter after the locale in which the chapter's happenings *happen*. She begins the novel with the question, *what?*, but moves into the novel to ask, *where?* Where can she

find her home, her sense of herself, and her health, or alternatively, the absence of Lyme relapses?

Gopinath writes of region in *Unruly Visions*, stating, “A turn to the regional is quite often a turn to the personal and the autobiographical. Evocations of the region often take the form of deeply affective, personal explorations of regional belonging or alienation” (6). Khakpour is navigating this very personal search and escape for a regional belonging, as she is alienated and othered in every place that she has sought home: “When the body feels out of place it will cling to anything that looks like life. Cities. Homes. Peoples. Lovers. Love is the only good way many of us know how to feel alive” (Khakpour 239). This is why she continues to ‘escape’ from every place that she settles into, only keeping hope alive for New York and returning there repeatedly despite the harshness of the city, the lack of intimacy in its busy streets. The city is not any kinder to her than the polluted cloud over L.A. or the arid desert of New Mexico, she is still rendered vulnerable even when hiding in the ever-buoyant city of the American Dream, the dream that her body precludes her from.

Her formal and informal caregivers do not privilege her voice or her body to be vulnerable, and that is what Alondra Nelson, the Columbia University’s Dean of Social Science, cites as problematic in one’s attempts to achieve wellness;

What’s especially challenging, Nelson says, is that human suffering, human vulnerability, is usually what we turn to when we want to find the universal thread that unites human beings. [...] When that very vulnerability, and that very sense of

suffering, is put into question, it makes it very difficult, I think, for people to get well. (Hirsch 130)

Khakpour thus finds herself foreign and without belonging in every place (and in every person) that she escapes into: “There was never a home for me [...] Only recently do I wonder if that has to do with being considered ‘foreign’ [...] How could I recognize myself if no one else could?” (Khakpour 167). Her body and illness(es) are unrecognizable to informal caregivers and undefinable to her healthcare providers, thus she is distanced from her own sense of self and made further vulnerable through their perception of her and her illness(es). Her archive is not one that felt homelike, therefore she is exactly the queer diasporic body that Gopinath describes. For many such persons, “the region as ‘the place where you’re from’ is an ambivalent site, where one’s queerness is both formed and nurtured but also disciplined and repudiated” (Gopinath 12). Khakpour articulates feeling foreign and ‘queer’ as a young girl, out of place in her body and in her home. Her original region, rooted in the archive of her family’s flight from Tehran, othered her from the beginning, and continues to do so, as her embodied queerness is disciplined and contained by her parents and the city of L.A. itself.

All of this points to her failure to fully care for herself. She admits, “I am not a poster girl for wellness. I am a sick girl. I know sickness. I live with it, in some ways, I keep myself sick” (Khakpour 229). Her history of inattentive caregivers has turned her body into “the ever threatening Other” even to herself, keeping her from self-care and the “space to suspect” her symptoms, rendering in her “a sort of dazzling indifference, a mute button almost creating a lovely white noise, its antipresence so very present like another hole in [her] life” (Käll & Zeiler 31; Khakpour 98). Her queer diaspora seeks escape from

this antipresence, begging for a queered aesthetic that allows her body to be *present*, even in illness. Wilkerson's "Wandering Through the Unhomelike" asks for this as well, that disability be permitted to be "central to the human condition, rather than a departure from it" (Käll & Zeiler 162).

While Khakpour has difficulty adequately caring for her body through region and through the hands of others, her writing is an act of care in itself. Her memoir places a mirror in front of the medicalized aesthetic, asking for a reframing of the aestheticized picture that figures sick and disabled persons. She writes a queer diaspora out of the hegemonic optic and into a new kind of "archival practice that excavate(s)" stories like hers from the fray (Gopinath 6). Though "language is a sticky thing, especially when we try to capture what's happening in our bodies and in our culture," Khakpour commands her language, not withholding any detail of her illness experience but fully exposing it, disorienting her audience with every thought and action, even if aberrant or shocking (Hirsch ix). Even if caregivers and onlookers can deny her body, they cannot deny the reality of her words. Her memoir begs the questions, "Whose bodies count? Whose bodies do we systematically inconvenience or overlook?," thus demanding that her pain 'count' (Hirsch ix). The difficulty of pain, and therefore also of any illness, disease, or disability, especially one that is so unequivocally Othered, lays in its unsharability. Pain is at risk of inexpressibility, its triumph what Elaine Scarry names "the absolute split between one's sense of one's own reality and the reality of other persons (4). Though Khakpour's memoir is still subject to this unsharability of pain, it greatly diminishes that space between a pained person's reality and the reality of those around her. Her narrative of body and its space and its symptoms functions as the bridge between pain and the imagination of the other, in this

case, the caregiver. *Sick* is thus realizing and legitimizing the experience of a chronically ill person, with all of her physical and psychological and social suffering, imparting just what it is to be 'sick' in the eyes of healthcare providers and informal caregivers, and even to oneself. Though Khakpour continues to navigate chronic illness, something that caregivers often define as without hope and without healing, her memoir is hopeful – hopeful that other bodies such as hers do not have to navigate such unwelcome, such diaspora, as she had to, that such persons like Glory and Rosaleen, Jacquie and Opal, Manzanar and Okwe, are not erased into ghosts by the unsharability of their pain.

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