

# The Invisible Labour of Informal Care: Parentified, Gendered, and Racialized Caregiving in David Chariandy's *Soucouyant*

## Introduction: Moving Beyond the Metaphorical Valences of Dementia

I first discovered David Chariandy's *Soucouyant* at a book sale at the University of Toronto's Robarts Library many years ago. When I read the novel, I was struck by the parallels its narrative had (and continues to have) with my own experiences. Much like the nameless narrator, I too am the primary caregiver for my mother, who underwent brain surgery when I was in my late teens. Both the surgery and the social infrastructure around my mother left her disabled and unable to work. My brother, much like the narrator's, soon left my mother and me with no warning. I was provided with little guidance by doctors and found it difficult to navigate the bureaucracy of the public healthcare system and insurance companies. This story of mine and my mother's is not unique. Direct funding provided to families who need assistance with caregiving for disabled loved ones is difficult to access. "[O]f the approximately 6,000 people . . . using attendant services in Ontario," only 676 are documented as receiving support from the Direct Funding Program (Kelly 8).<sup>1</sup> Moreover, these figures do not account for those whose primary source of care is informal or who need help with disabilities that are not physical—because people with intellectual disabilities or mental health issues, such as my mother, are ineligible for the program. Eventually, the brain trauma my mother endured because of her surgery led to her developing vascular dementia. As with the narrator of *Soucouyant*, I found it difficult to care for my mother on my own and made provisions for her to be cared for by others when I moved away from our home in Scarborough (where the novel is coincidentally also set) to pursue a master's degree in a different city. Although I did not abandon my mother to the extent the narrator does and remained involved in her life and visited frequently, I still felt guilty for much of the time I was away. Once I returned, however, my mother welcomed me home, and like Adele (the narrator's mother), she did not blame me for needing to leave

for my own mental health. What is often left out of informal caregiving narratives is how caring for another is only possible if you can care for yourself first. In his own account of caring for his mother with Alzheimer's disease, Canadian writer Mike Barnes shares the most illuminating advice he ever received: "You won't be of much help to her if you're dead" (14). The labour of informal caregiving is typically invisible, but it should not be. Novels like *Soucouyant* reveal the suffering endured by both caregivers and those they care for in a public healthcare system that makes it too easy for young carers and their family members to slip through the cracks. Chariandy himself states in an interview with *Canadian Living* that he would like discussions of his novel to include "the psychological toll of dementia on families and caregivers."<sup>2</sup> This essay's goal is to take part in that conversation.

Most scholarship on David Chariandy's novel *Soucouyant* focuses on how the dementia experienced by Adele, the protagonist's mother, represents the preservation of "cultural memory" and the perniciousness of "historical trauma" (Coleman 55; DeFalco 139; Delisle 1; Hellegers and Narayanan 82; Josephs 151). However, by metaphorizing Adele's mental condition, these critics risk treating her dementia as mostly figurative, and they thus elide a more detailed discussion of the literal ramifications of her dementia diagnosis. The work of these scholars is valuable, and they have already done a wonderful and thorough job of exploring the symbolic dimensions of Adele's dementia. My paper's main intervention, then, is to approach Adele's disorder as a literal medical condition and to explore how her caregiving needs affect not only her but also those around her. As Amelia DeFalco notes, the Canadian "national healthcare system remains invisible, unhelpful, unavailable" in the novel (144), and Adele's family and friends must therefore (to varying degrees) provide her with private, informal caregiving.

Scholars including DeFalco remark that informal caregiving is framed through a limited and unrealistic lens within the public imagination; self-help guides for caregivers often sublimate "the more unsettling aspects of care relations" (DeFalco 24). The image of the "saintly caregiver, who goes beyond any expected reaction to illness and becomes a superhuman advocate and nurse," is also pervasive in mainstream media (Levine and Kuerbis 118). *Soucouyant*, however, subverts traditional caregiving narratives by depicting the difficult and typically invisible labour of informal caregiving undertaken by the families and friends of those who

are ill or otherwise disabled. The novel provides a depiction of informal caregiving that is multi-faceted and asks us to question why it is exactly that we place the burden of care on those who are not equipped to handle such pressures instead of putting the onus on the government and the public healthcare system to take care of its most vulnerable members. I will analyze how caregiving in the novel is inflected by age, gender, race, and mental disability. Although the characters are ultimately unable to provide suitable “proper” caregiving, the novel reveals how their limitations are symptomatic of a wider systemic issue within the Canadian healthcare system. Because these characters are unable to access proper public healthcare resources within the community, the burden of care falls upon these characters: the protagonist and his brother, who become *parentified* children (as in they essentially act as parents for their mother); Meera and Mrs. Christopher, who assume but also destabilize the archetypal role of the Black female caregiver (or “mammy”) who goes underacknowledged and unpaid; and the disabled Adele herself. My goal is not to demonize or blame Adele or catastrophize her dementia diagnosis but rather to elucidate the ways in which the novel nuances how we think of informal caregiving. Aging studies scholar Larry Polivka notes that although policymakers often offer “pious expressions of appreciation . . . for the sacrifices caregivers make to keep the system afloat,” governmental support for these caregivers remains inadequate (557). By showcasing the struggles of informal caregivers, Chariandy’s text combats this dangerous and empty political rhetoric.

My analysis of care relations in *Soucouyant* is a reading that can only be accomplished by traversing the metaphorical and symbolic dimension scholars have thus far ascribed to Adele’s mental disability.<sup>3</sup> Care relations motivate much of the plot, yet analyses about caregiving in the novel are rare, with Amelia DeFalco (2016) and Sally Chivers (2019) producing what are perhaps the only two works broaching this topic. Metaphorical understandings of dementia in *Soucouyant* remain nonetheless useful and do not need to be entirely discarded. I propose the opposite: we must push these readings even further by returning to and putting them in conversation with the literal.<sup>4</sup> Throughout my essay, I argue that the bruises that appear on various characters in the novel can be figuratively attributed to the vampiric-like figure from Caribbean folklore to which the book owes its name. Marlene Goldman writes that the narrator is “haunted not by his mother’s illness” but is instead stalked by the soucouyant, which assumes

the “dreadful otherness” usually reserved for the disease in Canadian dementia narratives (324). My analysis of the novel elaborates upon Goldman’s assertion by arguing that the “true” *soucouyant* is in actuality the draining process of informal caregiving that is instigated by a lack of access to proper public healthcare resources. By using relevant research from the disciplines of disability studies and the health humanities and acknowledging the literal ramifications of having a mental disability, we can foster a deeper understanding of how these disabilities operate within literary texts. Although this paper focuses specifically on dementia and informal caregiving in *Soucouyant*, my intention is to create and model a basic methodology that can (with text-specific modifications) be applied to other works in which mental disability features prominently.

### **All Work and No Play: Parentified Caregiving in *Soucouyant***

For the purposes of this paper, I am primarily interested in what DeFalco terms “para-ordinary” care, which she defines as “experiences of care that often catch participants off guard,” such as “the demands made by a loved one’s sudden illness or impairment” (7), which we see in *Soucouyant* with the rapid and early onset of Adele’s presenile dementia. DeFalco explains that “[s]uch situations are by no means extraordinary—they are common, even ordinary—yet the demands are high and often unpredictable, drawing attention to the ethical difficulty of responding to another’s needs.” This sort of para-ordinary care, DeFalco stresses, occurs largely “outside the healthcare system.” Although informal caregivers (the focus of this paper) are usually family members, the National Family Caregivers Association “advocates for the term *family caregiver* to be defined broadly to include friends and neighbors who assist with care by providing respite, running errands, or a whole host of other tasks that support the caregiver and care recipient” (Crews and Talley 3). Seeing as it is not just Adele’s son who occupies the role of caregiver but also Meera and Mrs. Christopher (who are not technically family members), this definition is the one I use when speaking of informal caregiving in the novel. As Diemut Elisabeth Bubeck notes, “[c]aring’ can refer to an emotional state or to an activity or to a combination of the two” (127). In her theory of care, however, she posits a definition of care as an activity: “Caring for is the meeting of the needs of one person by another person where face-to-face interaction between carer and cared for is a crucial element of the overall activity and where the need is of such a nature

that it cannot possibly be met by the person in need herself" (129).<sup>5</sup> Both DeFalco and Bubeck argue that the labour of care and caregiving have been historically gendered female,<sup>6</sup> a fact that I address in my discussion of the caregiving provided by Meera and Mrs. Christopher.

Caregiving, particularly when it is undertaken by children of ill or disabled parents, can be further divided into two categories: instrumental and emotional caregiving (Chase, "Parentification" 5). Gregory J. Jurkovic explains that "[i]nstrumental role assignments require children to assume responsibility for concrete functional tasks that are necessary for the physical maintenance and support of the family, such as child care, grocery shopping, cooking, nursing an ill or disabled parent, and earning income" (8). In emotional or "expressive" caregiving, "youngsters" must "minister to the family's socioemotional needs through such activities as protecting family members, serving as a confidant, companion, or matelike figure, mediating family conflicts, and providing support, nurturance, and comfort" (8-9). Jurkovic is quick to acknowledge, however, that there is considerable overlap between the two roles: "Instrumental behaviors are not without a psychological-expressive component, just as expressive caretaking activities may have instrumental properties" (9). Accordingly, children often assume both instrumental and emotional roles in caregiving. These young people may become "parentified children" in the sense that they are "parents to their parents, and fulfill this role at the expense of their own developmentally appropriate needs and pursuits" (Chase, Preface x-xi).

The role of young carers in Canada is one that has recently received some attention in scholarship produced by sociologists and social workers. In a 2012 document published by the Vanier Institute of the Family, professors at the School of Social Work at the University of British Columbia explain that in "cases where adults are unable to assume their caregiving role, young family members may be required to take on a range and depth of care-related responsibilities well before they might be otherwise expected or prepared to on a regular basis. These young people are *young carers*" (Charles, Stainton, and Marshall 5). What "differentiates young carers from other young people who contribute to the well-being of their families is that they take on a *primary* caregiving role" (6). Until recently, young carers "have been largely absent from the discussion of family caregiving in Canada" (5). Although the term "young carer" tends to apply to youth eighteen years old or younger (5n1), the "contributions that young carers make to their families typically don't stop once they reach the

age of majority. Rather, most go from being a young carer to being a young adult carer overnight, without any change to their roles or responsibilities” (8). In countries such as Australia, a young carer is thus defined “as anyone in a family caregiving role up to the age of 25 years.” I agree with this assessment and suggest we can use this research on parentified children and young carers to better understand the caregiving role undertaken by the protagonist and his brother in *Soucouyant* and the circumstances that lead to these characters assuming this role.

In *Soucouyant*, the unnamed protagonist and his brother become parentified caregivers because their mother is unable to offer them reciprocal support as her condition starts to worsen. “Long ago, she began to forget,” the protagonist says, explaining how he and his brother “were the first to notice” (Chariandy 12). This realization comes as little surprise because, as with other parentified children, they possess “uncanny sensibilities” and “are attuned to their parents’ moods, wishes, vulnerabilities, and nuances” (Chase, “Preface x). The narrator confirms this parentification when he reveals that he and his brother “were young children” when Adele first began to exhibit symptoms of dementia, and that they were thus “naturally alert for the smallest signs of adult weakness” (12). Although they initially take advantage of their mother’s receding memory by eating food when they are not allowed, the protagonist and his brother begin to assume an emotional caregiving role. When his mother accidentally prepares his father’s coffee with salt instead of sugar, the narrator’s brother mediates a potential family conflict by falsely asserting that it is April Fool’s Day, which Adele confirms as her justification, and her husband accepts this reasoning (14-15). Instead of Adele providing her child with comfort and reassurance as a parent should, it is the narrator and his brother who must reassure her by justifying her actions. Accordingly, they are providing her with emotional support. Although this act is not in itself unhealthy, it becomes so because Adele cannot reciprocate by abating their fears. When she questions the narrator about his age and name, he tells her, “Mother . . . I wish . . . I mean, I’m scared sometimes, Mother” (19). His palpable fear affirms that there is an imbalance in their relationship. Nancy D. Chase explains that “[r]esponsiveness to parental need is not inherently problematic” (“Parentification” 4), but it becomes an issue “when there is a lack of acknowledgement and reciprocity between adults and children in terms of the nurturance exchanged” (5). Adele, who (unconvincingly) excuses her own baffling questions to the

narrator by claiming she wants to hear her son “say [his name] *properly*” (19), cannot return the comfort he provides her. The emotional caregiving undertaken by the narrator is perhaps best exemplified in the scene at the buffet. During the week of his fourteenth birthday, the narrator’s family visits a restaurant, but Adele disappears when the others are collecting their food at the buffet. When they eventually find her, she is sitting in a corner with “streaked” makeup and her hands “clasped around her knees” (20). The narrator waits for his now sixteen-year-old brother “to say something reassuring, something appropriate, but he was quiet,” and so the narrator looks to his father to act but he, too, remains “quiet and still.” The responsibility thus falls on the protagonist, barely a teenager, to reach out to his mother, taking her hand. This tactile stimulation reassures her and, although it takes a while, “she smiled” and later tells the protagonist, “I knew you would never leave me.” It is at this point that the fourteen-year-old narrator assumes the role of his mother’s primary caregiver, even lobbying his father to allow his mother to see more doctors, a request the patriarch denies, claiming, “She gone far beyond the help of men, boy” (22).

Of course, we must consider the institutional factors that lead to a fourteen-year-old child and later young adult assuming the primary emotional caregiving role for his mother. While it would perhaps be easy to blame Adele’s husband or even Adele herself for ignoring the protagonist’s plea to seek medical help, the “interpersonal dynamics that arise among individuals with disability and their caregivers are sometimes more accurately attributed to failings in larger system supports rather than to the disability, *per se*” (McDaniel and Pisani 12). The unnamed protagonist and his brother become caregivers largely out of necessity because the public healthcare system does not provide them with adequate support. The narrator explains that they visited “a downtown medical specialist” who diagnosed Adele with dementia but “was puzzled by the many unusual features of Mother’s case” (37). The doctor is struck by how “early the symptoms had appeared, and how slowly and unevenly they had developed.” However, because Adele and Roger (her husband) are reluctant to “agree to any more tests,” the doctor ends “the session by politely stating that . . . there was very little that he could do,” before “handing us some pamphlets.” The Canadian public healthcare system fails Adele and her family. While it is true there is no cure for dementia or Alzheimer’s (and indeed the condition was less understood in the 1980s, when the novel is set, than it is even now), the doctor does not suggest any possible treatment

or medication, offer a prognosis, or even refer Adele and her family to the Alzheimer's Society of Canada or the Alzheimer's Association of Canada, which had both been established by 1980. Adele is well within her rights to refuse to submit to further tests, but surely the doctor could do more than offer pamphlets (that Roger promptly throws away). Moreover, the rationale behind Adele and Roger's declining of further testing is that they "were suspicious about the diagnostic tests which always seemed to presume meanings and circumstances which were never wholly familiar to them in the first place" (39). Adele and Roger are Caribbean-born immigrants, and their reservations towards state-supported healthcare systems are understandable. Sami Schalk contends that "people of color and the poor are more likely to have experiences on the borders or outside of able-bodiedness and able-mindedness due to violence and failures of society to provide access to affordable, quality insurance, housing, and medical care" (10). This point is further echoed by Theri Alyce Pickens, who writes that there is a "historical distrust between medical personnel and Black communities" (51), and by Christina Sharpe, who explains that "medical and other professionals treat Black patients differently: often they don't listen to the concerns of patients and their families; they ration palliative medicine, or deny them access to it altogether" (10).<sup>7</sup> The field of psychiatry has a history of oppressing Black people. Psychiatrists invented diagnoses such as *drapetomania*—"a mental illness causing Black slaves to run away" (Pickens 8). "In the 1960s and 1970s," they invented "protest psychosis" to justify the subjugation, incarceration, and institutionalization of Black people (Clare 114). The reverberation of these racist and dehumanizing medical practices continues to be felt today and provides a contextual backdrop that explains why Adele is hesitant to accept help from state-supported systems of care. The brief interaction with the doctor reveals little was done to lessen the cultural gulf between the doctor and Adele and Roger, and the healthcare system is never mentioned again in the novel. Adele is essentially abandoned by public healthcare institutions, which happens too often with marginalized populations and people in Black communities especially.

Moreover, Adele's understanding of her own condition is influenced by the mythology of the *soucouyant* in Caribbean culture.<sup>8</sup> The story Adele tells her son about the traumatic experience of seeing such a creature appears in fragments throughout the novel. In an interview with Kat Tancock, Chariandy says "the meaning of this event or story is only

revealed gradually and perhaps never with absolute clarity.” Picking up on this point, Kit Dobson suggests in another interview with Chariandy that “near the end of the book, you shift towards what we might call a more official tone or discourse of history, although perhaps with anxiety and a sense of irony” (812). We learn the soucouyant Adele saw when she was a child was in fact her mother, whom Adele accidentally set on fire after a soldier emptied a wash bucket on them “filled with oil and tar and solvents” (192). Goldman argues that “the trauma associated with this event contributes to Adele’s dementing illness” (326). From a socio-historical perspective, Goldman also observes how Adele’s “illness was partly instigated and certainly exacerbated by the traumatic dispersal of native Trinidadians during the Second World War and the subsequent scattering of these peoples across North America” (324). Indeed, Adele uses this encounter with the supposed soucouyant as a way to comprehend her condition through a culturally specific lens (in this case, one steeped in Caribbean folklore). This folkloric explanation, however, is no less accurate than “official” historical or medical framing because even these two lenses rely on narrative construction. Diagnosis is, according to critical diagnosis scholar Annemarie Goldstein Jutel, “a narrative in and of itself . . . a story that links in a series of facts or phenomena, and explains their relationship” (163). While often couched in the language of “truth,” diagnosis rests as much on interpretation as fiction. I am *not* suggesting that medical diagnoses are not “real” but instead that they are useful precisely because of the “sense-making” (to use Jutel’s term) they provide both doctors and patients. In the same vein, Adele’s encounter with the alleged soucouyant allows her to grapple with her experience with dementia.

The healthcare system’s fleeting appearance in *Soucouyant* does not mean the failings of Canada’s existing healthcare infrastructure are not among the novel’s primary concerns because the virtual absence of proper governmental support serves as the catalyst for the entire narrative. Adele is even further neglected by other institutional organizations ostensibly designed to protect her. Several years later, when Adele wanders off and her disappearance is brought to the attention of the police, the narrator explains to the officer that Adele “has presenile or early-onset dementia” (65). The officer who arrives writes this information in his notepad, but nothing comes of it. The officer states that he must keep records “[s]o we can know. So we can help.” But help whom exactly? Certainly not Adele, the one with the medical condition, but rather those in the predominantly

white neighbourhood, who the policeman says have been making “complaints” (65). In effect, Adele is failed by the institutions around her that are meant to ensure her health and safety. As a result, the responsibility falls onto her family to provide her with informal care.

The situation only becomes worse for the protagonist and his brother when their father dies in a workplace accident, and the familial caregiving relationship accordingly becomes more complex. His brother takes on “a new role as the working man of the family” (27). Although he is now eighteen, he is still a young carer under the definition I previously provided because he is under the age of twenty-five. Unlike the protagonist, who provides emotional caregiving, his brother assumes an instrumental (as opposed to emotional) caregiving role by providing the household income (since by this point Adele is incapable of working herself). After Adele fails to recognize her older son one evening, he abandons both her and his brother (28). However, Meera, who cares for Adele once the narrator leaves too, later reveals to the protagonist that his brother returned several times during the narrator’s two-year absence. She describes how he would visit and “bring crumpled bills of money” (168) even though his “jeans and sweater had holes, and he smelled” (169). The three of them “ate dinner together,” and Meera noticed “[h]e was famished.” Nonetheless, Adele “acted as if this happened every evening. As if he was still living at home”; she would tell him “to sit up, and he immediately did.” For a time, he would continue to bring “the same crumpled bills of money.” Meera tells the narrator that his brother “was trying his best in circumstances neither of us had chosen” and that she “needed to believe that a belated gesture could matter, if only a little” (169). The brother, having abandoned Adele years before, returns intermittently and continues to fulfill (to a much lesser degree) his instrumental caregiving role by offering Adele money even though it appears that he is now homeless. But the dynamic between him and his mother has changed. By not acknowledging that their having a meal together is no longer a regular occurrence, she is reciprocating his (however minute) instrumental care by providing him with emotional care. She is offering him a sense of normalcy now lacking in his life. The relationship between Adele and her sons reflects the real-life struggles young carers often experience and reveals how the pressures that come with informal caregiving can become too demanding. However, by depicting how Adele herself is sometimes still capable of offering her own form of care, the novel showcases how caregiving relationships can at times

be rewarding despite being complicated and onerous. I want to emphasize the importance of this last point because it is crucial to understand that although informal caregiving can be difficult work, it can nonetheless lead to moments of joy and connection, as we see here in this scene between Adele and her older son.<sup>9</sup>

These moments of reprieve are brief, however, as the caregiving role taken on by Adele's family becomes overwhelmingly burdensome, especially for the protagonist. Echoing other critics, Jennifer Bowering Delisle argues that "Adele herself is at times a kind of *soucouyant*, a strange and terrifying creature . . . a kind of monster, a distortion of the woman she once was" (6). Giselle Liza Anatol similarly infers that Adele comes to embody the traits that define the *soucouyant* (197). Although these readings are compelling, I am hesitant to indulge them because they engage in a literal (although unintentional) demonization of Adele by ascribing to her a set of vampiric traits that implicitly parallel the symptoms of her diagnosis. In her analysis of Chariandy's novel, Sally Chivers discusses how popular media abounds in characterizations of aging and dementia as a "monster under the bed" (108). The mythological figure of the *soucouyant* has a penchant for leaving bruises upon her victims (Alonso 16). It is thus tempting to read the bruises that "mark the characters Adele cares for" (Chivers 116)—and also, I would add, those who care for her—as being directly caused by Adele, who is figuratively acting as a *soucouyant*. I am more swayed, however, by the argument Chivers offers in response to these readings. Alongside other possible interpretations, Chivers observes how the bruises also "signal an encounter with the *soucouyant* who haunts Scarborough" and imply the "fashioning of care relationships" (116). Building off Chivers' argument, I would like to assert that the *soucouyant* that haunts Scarborough is the process of informal caregiving, which leaves its bruises on those embroiled in precarious care relationships.

Chivers notes that the protagonist and his brother have mysterious bruises that connect them to their mother (116). However, these bruises do not simply fade once the brothers have been "freed" of Adele; the day of Adele's funeral, the protagonist awakes with a "mysterious bruise on my forehead" (Chariandy 141), which suggests his exhaustion from caring for Adele continues to affect him even after her passing. In many ways, it is the protagonist himself and *not* Adele who is transformed into a kind of *soucouyant*. In a heated discussion with the narrator, Meera remarks, "Do you realize that you're eternally sad? . . . Do you know what it's like

to be around someone who's eternally sad? It drains you. It sucks your life" (119). Meera reveals here that it is the narrator, and not his mother, who exhibits the vampiric traits of the *soucouyant*. His self-described "melancholy" (194) drains those in the household, including Meera and his mother. This encounter shows that the protagonist, much like his brother, is not equipped to adequately care for Adele and that his relationship with both his mother and Meera becomes strained as a result. But it is important to acknowledge that Meera's mediation is what occasionally restores a semblance of balance to the household, as we see when she has dinner with Adele and her eldest son. Meera, who assumes the role of Adele's primary caregiver for a time, is thus the focus of the next section of my paper.

### **Women's Work: Caregiving as "Feminine"**

Care and, by extension, caregiving have been historically gendered female. DeFalco explains that although "ethics of care philosophers as far back as Nel Noddings and Carol Gilligan have taken pains to stress care as a model for ethical relations that can, and should be adopted by men and women alike, actual care is performed primarily women" (15). Thus, no study of caregiving (including my own) can ignore "the political dimension" of how caregiving largely remains seen as "women's work" (DeFalco 17). Bubeck observes that "[c]aring as an activity, disposition, and attitude forms a central part of probably all cultural conceptions of femininity and is virtually absent from, or even incompatible with, conceptions of masculinity" (160). John E. Crews and Ronda C. Talley claim that "women—mothers, wives, and daughters—provide the bulk of care" in informal caregiving relationships, although Crews and Talley also admit that the gendered division depends largely on specific family dynamics and cannot be overly generalized (4). Yet, as Bubeck asserts, there is indeed a difference in what we perceive to be care relegated to women and care relegated to men:

Now there is a sense of caring that applies specifically to men, namely that of "providing for." Traditionally, men are caring husbands and fathers if they are reliable breadwinners . . . Correspondingly, a caring son would not be expected to care for his frail parent himself, but rather to provide the material resources to pay for care if needed, i.e. if his sister or wife did not agree to, or could not do, the actual caring herself. (162)

Based on Bubeck's formulation, certain forms of instrumental caregiving are coded as "masculine," such as the narrator's brother in *Soucouyant* finding employment and contributing the bulk of the family's household income (at least initially). Other forms of caregiving, then, such as the emotional caregiving provided by the protagonist, are gendered "feminine." However, even the narrator himself absconds these "feminine" duties when he leaves his mother and makes financial provisions on her behalf:

Then my own leaving. I wouldn't just leave her, of course, I'd first alert all of the crucial "people at the bank and the phone and cable companies. I'd arrange for monthly withdrawals from Father's insurance for necessities. I'd contact social services as well as Mother's friend, Mrs. Christopher. I'd make all sorts of provisions for my departure" (Chariandy 28-29).

Overwhelmed by having to provide physical and emotional care for his mother on his own, he shirks this responsibility and leaves her after he contacts "crucial people" and makes "financial provisions," therefore at least ensuring his "masculine" caregiving continues remotely. Yet, once the narrator returns, he makes the effort to engage in more "feminine" aspects of caregiving, such as bathing his mother (83), cooking (11), and completing other housework Meera delegates to him (53). By depicting the narrator taking on these caregiving tasks, the text signals his newfound commitment to his mother.

Meera's intervention affords the protagonist and his brother the luxury of choosing when to return home and begin caring for their mother again. The narrator (and, by extension, likely the reader) assumes Meera is Adele's nurse (10). We cannot exactly fault him for believing this stranger is a nurse specializing in "palliative care" (55) because, by his own admission, he *did* notify social services he was leaving. Strikingly, however, there is no mention of social services elsewhere in the novel; instead, the reader can only assume Adele has somehow (but not surprisingly) fallen through the cracks of the system, which has made it possible for a complete stranger to move in with her under the guise of being her nurse. Nonetheless, Meera is the one who has been caring for Adele in the protagonist's absence, and when he discovers she is "not a qualified nurse at all" (124), she angrily retorts, "I never once said I was a nurse. That was you. Your own convenient belief. Your own guilty story" (125). Meera is correct, but she is also using Adele to assuage her guilt. When the narrator abdicated his

“feminine” role as caregiver for his mother, he assumed she would be cared for by the public healthcare system. But this presumption was obviously incorrect; the responsibility has instead fallen once more to an informal caregiver, Meera, whom we discover is a former neighbour who once cruelly prank-called Adele and lied about how Adele’s entire family were victims of a horrific accident.

But why is it Meera—and not any of her schoolmates who also bullied Adele—who must assume the role of *de facto* caregiver for her? In her important chapter on caregiving in Chariandy’s novel, DeFalco offers the following as a potential answer to this question:

Meera’s care suggests an awakening to responsibility, to the relational identity she strove to disavow with prank phone calls and cruel jokes. Despite having a mother with the same ethnic background as Adele, or rather because of this similarity, Meera studiously avoided contact with the narrator and his brother in an attempt to avoid the same ostracism they suffered from their classmates. Indeed, to avoid victimization Meera became the victimizer, mocking the narrator and his family. (144)

Consequently, in a scene that parallels her prank call, Meera phones Adele again. After Adele reveals on the phone that she is “feeling a little bit lonely,” Meera suggests a visit, even though Adele does not recognize to whom she is speaking (Chariandy 168). Examining this scene in more detail, it is possible to push further DeFalco’s claim that Meera’s decision to care for Adele serves as some sort of “awakening to responsibility.” Meera primarily decides to care for Adele *out of guilt*—although Meera’s sense of responsibility also plays an important role. The morning after she prank-calls Adele, Meera sees “the bruises that were caused when she had pressed the receiver of that phone so unforgivingly against herself,” and she begins to weep “for what seemed to be the first time in her life” (166). The bruises symbolize how the pain she causes Adele also causes *her* pain, leaving an indelible impression on her, both physically and emotionally. Like the protagonist and his brother, Meera is literally “marked” by her relationship with Adele.

Notably, Meera also possesses a birthmark that becomes more prominent when she becomes Adele’s caregiver. This birthmark, which “looks a bit like one of those symbols on a weather map” (34), implies that Meera has an inherent affinity for Adele. In fact, this “mark on her

neck" (10) is one of the first physical attributes the narrator notices when he returns home and discovers Meera has been caring for his mother. Initially, Meera attempts to cover her birthmark with her hand, suggesting she longs to hide her connection to Adele. This attempt to conceal her physical link to Adele is similar to how, years before, she attempted to reject all association with Adele's family. Moreover, the fact that she has a birthmark and not a temporary bruise reveals that her connection to Adele is innate. Rather than bind the protagonist and Meera together, however, their shared experience of caring for Adele initially serves to drive them apart. I have already explored how informal care is like a *soucouyant* in that it drains those enmeshed in such relationships. During a moment of tension, the narrator describes Meera to himself as an "inscrutable bitch with a stupid smear of a birthmark" before asserting, "I know these sorts of things [about Adele] . . . because I've lived with her for a lifetime . . . she's not just some goddamned patient of yours, she's my *mother!*" (82). The narrator's need to attest to his understanding of Adele betrays his own insecurity over having abandoned her, suggesting he longs to bury the fact that he is and has been an imperfect caregiver. But as I explained, Meera is similarly flawed. In part, she decides to become Adele's caregiver to atone for her past behaviour and to ease her conscience, which are the same reasons why the narrator returns after abandoning his mother for years. I am not making a value judgment here. This novel appropriately depicts how caregivers are not always "saintly" (Levine and Kuerbis 118) and altruistic in their motivations, which is merely a fact of life. Adele is *not* "officially" Meera's responsibility, although it is laudable she cares for her at all. The text's intimation that Meera has any sort of responsibility to Adele is due in part to an apparent solidarity spurred by their shared gender and race, a connection displayed both figuratively and literally on Meera's skin. Although I have suggested that Meera and the narrator are motivated partly by guilt, I want to clearly state that DeFalco's argument about an "awakening to responsibility" still stands. It is not altogether uncommon, as Pickens emphasizes, for disability to "be taken care of within [Black] families or local enclaves" because of the discrimination Black people have faced from the medical-industrial complex (51). Building on Pickens' point, then, we must remain critical of the systems in place that result in informal caregiving being the "norm" in Black communities while at the same time acknowledging that racialized forms of care are no less legitimate than "formal" alternatives, especially when these latter include "state-imposed

regimes of surveillance” (Sharpe 20) and violence towards Black people that are “carried out under the rubric of care” (139n28).

### **Race, Mental Disability, and the Politics of Care: The “Mammy” Figure and Disabled Caregiving**

The “mammy” archetype is pernicious and pervasive. She is an enslaved Black woman who is the “maid of all work, caring for the children, washing, ironing, cooking, cleaning” (Parkhurst 351). Although the “mammy” is typically associated with the southern United States, this figure was also dominant in Canadian advertising during the early twentieth century (Kinahan 188) and still exists in contemporary Canadian popular culture and media (Nelson 66). Interpretations of the “mammy” by Black Canadian writers (including Chariandy) are also informed by the experiences of Black women from the British Caribbean who immigrated to Canada in the 1950s and 1960s through the Domestic Worker Scheme (Beckford 122-23).<sup>10</sup> Chariandy’s novel rebukes this stereotype in its depiction of Meera and Mrs. Christopher, both of whom are Black caregivers. The former, as I have discussed, has decidedly complex motivations and remains an active agent in her desire to care for Adele (rather than having this responsibility forced upon her).

Mrs. Christopher, moreover, becomes an informal caregiver for Adele once the narrator notifies Mrs. Christopher of his decision to leave Adele, but Mrs. Christopher ultimately demands recognition in the form of payment once Adele dies. When Mrs. Christopher visits Adele for the first time since the narrator’s return, she enters with her own key, has a sustained conversation with Adele, and is clearly familiar with Meera (Chariandy 86-87), all of which suggests she has been a frequent presence in Adele’s life while the narrator has been gone. After Adele’s death, the narrator quickly sells the house for \$50,000 and offers \$10,000 to Mrs. Christopher because she has spent two years caring for Adele (147). He is stunned, however, when she tells him, “It not enough . . . For *me*, I talking. It not enough for *me*.” She has been keeping meticulous track of the wages she should have earned as a domestic worker, ultimately totalling somewhere between \$100,344.10 and \$345,033.48 (148). The narrator is infuriated by her reaction and angrily says, “For god’s sake, she was your *friend!*” She responds, “That not at all the point. You check the math yourself. Is all right and proper.” The narrator thinks to himself, “I don’t know what angers me the most, the demand itself or the fact that I expected gratitude, just

simple gratitude, from this woman” (148), but he furiously and reluctantly writes her a cheque for the entire proceeds of the house (150). The novel rejects the “mammy” archetype by having Mrs. Christopher (rightfully) request remuneration for the informal caregiving she has been providing Adele (caregiving, I might add, he specifically asked of her when he left). Regardless of whether she was Adele’s friend or not, a mere “thanks” (which the narrator later sarcastically offers once he has paid her) is not enough. This scene functions as a moment of empowerment for Mrs. Christopher, who advocates for the value of her labour. Invisible caregiving is arduous work, and the math Mrs. Christopher shows the narrator reveals it has a monetary value that is almost never reimbursed by the government.

The “mammy” archetype is also further nuanced by Adele herself taking on an informal caregiving role for Bohdan, an autistic child of Eastern European descent. At Adele’s funeral, Bohdan’s mother tells the narrator that Adele often cared for him because “I was working all the time” and that Adele “never take any money for this” (140). After stating that Adele “was a lesson to us all,” Bohdan’s mother ponders, “Imagine everyone house, everyone community and nation so open.” However, the idea that Adele is capable of caring for anyone else, much less a child, runs counter to the narrator’s earlier revelation that she “steadily lost jobs” because her dementia gradually impeded her from properly caring for children (13). We have already learned Adele cannot be a responsible enough caregiver even though she appears to have assumed this role for Bohdan. Although Adele embodies the characteristics of the “mammy” figure in the sense that she is a Black woman who cares for a white child out of the apparent goodness of her heart, the novel invites us to question her suitability for this role because Adele is an imperfect caregiver. How is it, then, that the responsibility of caring for any child at all is thrust upon her?<sup>11</sup>

Whereas the novel depicts Adele and Meera sharing a connection based on their gender and race, it implies Bohdan and Adele share a connection based on the exclusion they face as a result of their struggles with mental disability. Bohdan’s mother reveals that although “some children are so cruel” to Bohdan and tease him because he is autistic, Adele never passed any judgment (139). Their bond is apparent in their idiosyncratic use of the word “eyestache.” The protagonist details how Bohdan traces “my eyebrows . . . with his thumb” and how he describes

them as an “eyestache” (143-144). This moment mirrors an earlier scene in the novel in which Adele performs a similar action and also describes the protagonist’s eyebrows with the word “eyestache” (92). We know this word is a construction of Adele’s because Meera (who never speaks with Bohdan directly) also uses it at the end of the novel (196). This word signals the connection Adele has with Meera but also the special bond—as Bohdan’s mother attests—Adele had with Bohdan. In her conversation with the protagonist, Bohdan’s mother posits a utopian vision in which all those with mental disabilities are able to care for each other. However, it is the government and the healthcare system that should help provide adequate patient-centred care for those who are disabled and lack the financial means to pay for private care if needed.

Regardless, it is not surprising for racialized people living with disabilities (such as Adele) to eschew state-supported care because, as disability justice advocate Leah Lakshmi Piepzna-Samarasinha passionately attests, “the state was built on racist, colonialist ableism and will not save us, because it was created to kill us” (15). Care collectives comprised of disabled people and their loved ones are able to thrive. As Piepzna-Samarasinha acknowledges, however, “community’ is not a magic unicorn, a one-stop shop that always helps us” (23). Moreover, “there aren’t a million collectives for low-income Black and brown autistic, physically disabled, or chronically ill people in Toronto” (46).<sup>12</sup> This last point is particularly relevant to Adele, who lacks access to this kind of community because the area in which she lives is largely white and non-disabled. Thus, her relationship with Bohdan gestures towards what could be accomplished if Adele were able to access these community-based supports, although she is ultimately unable to make use of this form of interdependent care.<sup>13</sup>

### **Conclusion: Towards a Better Understanding of Informal Caregiving**

I would like to conclude this essay by returning to the story I shared in my introduction. As a non-Black racialized person who both cares for a mother with a disability and has a disability of my own, I found David Chariandy’s novel to be a gift that has helped me grapple with my own experiences with informal caregiving. *Soucouyant* reveals the gaps in public policy and law by showcasing how marginalized communities must rely on each other just to *survive*. The government and the public healthcare system have shirked their responsibility of ensuring and tending to the well-being

of the population; pressure should be placed on those in powerful positions in the government to create changes in policy and law that would lead to better supports for minoritized communities, including people of colour and people with disabilities. Moreover, the forms of informal care that arise among these groups must be acknowledged and legitimized as appropriate alternatives but should not be seen as the only solution. *Soucouyant* offers us a glimpse into the process of informal caregiving that is messy and authentic and, perhaps most importantly, challenges us to rethink how we conceptualize care.

#### Notes

1. The full name of this program is the Self-Managed Attendant Services in Ontario Direct Funding Program. My sincerest thanks to Professor Anne McGuire for suggesting I read Christine Kelly's *Disability Politics and Care*.
2. Many thanks to peer-review reader A for drawing my attention to this interview.
3. In this paper, I consider Adele's dementia a mental disability. Within disability studies, there has been a wide-ranging debate about how to label and categorize impairments and disabilities that are mental rather than physical and how to better incorporate these conditions into the disability rights movement. I agree with Margaret Price, who suggests that the label "mental disability" is productive and inclusive because "this term can include not only madness, but also cognitive and intellectual dis/abilities of various kinds," as well as "physical illnesses accompanied by mental effects" (19). Price acknowledges Cynthia Lewiecki-Wilson's essay "Rethinking Rhetoric through Mental Disabilities" as important to her formulation of these claims. My deepest thanks to Professor Katherine Schaap Williams for introducing me to Price's work.
4. It goes without saying that much of my thinking in this essay is indebted both to Susan Sontag's landmark essay "Illness as Metaphor," which addresses the figurative language used to discuss illness, and to David T. Mitchell and Sharon L. Snyder's *Narrative Prosthesis*, which explores how physical disability is often used as a narrative and discursive device in literature. For those interested in learning more about methods of non-figurative reading, see Schmitt, "Tidal Conrad (Literally)," and Freedgood and Schmitt, "Denotatively, Technically, Literally."
5. For further elucidation of Bubeck's concept of care, which both extends and tends to the limitations of this definition, see pp. 129-37 of *Care, Gender, and Justice*.
6. See especially Bubeck's section on "The Gendered Nature of Care" (159-70) and DeFalco's section on "Moral Dilemmas and the Gender of Ethics" (9-17).
7. Many thanks to peer-review reader B for suggesting Christina Sharpe's illuminating monograph *In the Wake*.
8. María Alonso Alonso explains that "a *soucouyant* is a Caribbean folkloric figure": It usually represents marginal women as it is commonly considered to be a female who looks like an old person and lives an apparently ordinary life in the outskirts of a city or a village. But at night, this woman turns into a ball of fire and travels across the sky to suck the blood of her victims while they sleep. It is supposed that the best way to identify a *soucouyant* is to look for an old

neighbor that appears the next morning with bruises all over her body as if she had been beaten up the night before. (16)

The *soucouyant* figure thus at once creates bruises on her victims and endures bruises of her own from the fire that engulfs her.

9. I cannot recommend enough Leah Lakshmi Piepzna-Samarasinha's groundbreaking book *Care Work*, which provides more insight into the nuances of informal disabled caregiving, including both its rewards and shortcomings.
10. Again, many thanks to reader A for suggesting this article. I encourage readers to consult Beckford's paper for a more thorough exploration of how the "mammy" and "domestic" figures have evolved over time in Canadian society and literature.
11. The capability of people with disabilities as caregivers has received significant attention in disability studies. For a detailed discussion of this debate, see Deborah Marks' *Disability* (95-113), as well as Piepzna-Samarasinha's *Care Work*. Although I certainly agree that those with disabilities can be responsible caregivers, I am suggesting that the novel itself depicts Adele as not being among this group because she cannot by this point care for her own children and the children of others.
12. It is also important to note that disability studies and disability justice movements are typically youth-oriented (Goldman 344n10), which further explains why Adele, who is older, may not have access to these communities.
13. By contrast, Chariandy's equally brilliant second novel *Brother* offers a depiction of community care that is successful.

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