## DECAYED, MISSING, AND FILLED: SUBJECTIVITY AND THE DENTAL SAFETY NET IN CENTRAL APPALACHIA

by

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#### **DEDICATION**

To those underserved patients who are still awaiting dental care in central Appalachia, and to those advocates who are working to provide it.

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#### **ABSTRACT**

Dental caries, popularly known as tooth decay or cavities, is among the world's most common health problems. When caught early, it is also one of the most easily resolvable. Yet, advanced decay is a trenchant marker of social inequality and a major contributor to the maldistribution of physical pain and psychosocial suffering. Why? Access to dental care within the U.S. model of fee-for-service dental private practice follows existing lines of social stratification. Dental disparities, a term that calls attention to the relationships between maldistributed disease and maldistributed care, reflect deep ontological, moral, and political differences about responsibility for the prevention and treatment of dental disease, the quality and distribution of dental care, and even what constitutes health and well-being. What kinds of sociopolitical and moral negotiations constitute and transpire around dental disparities? How do these negotiations shape the experiences of patients and providers, and how do their experiences shape these negotiations? What can an ethnography of the dental safety net – a complex, fragile, and unpredictable network of treatment opportunities for low-income families – tell us about health governance more broadly? These are some of the questions that drive my research.

In this dissertation, I explore how the sociopolitical relations of dental disparities are enacted through the dental safety net. Drawing on fifteen months of ethnographic research in clinical and community settings in central Appalachia, a region that has come to symbolize the dental crisis in the popular imagination, I show how the dental safety net exemplifies health governance in a neoliberal milieu. A fragmented system characterized by a discontinuity that starkly contrasts the model of health care generally advocated in both private and public medical systems, I argue that the dental safety net in far southwest Virginia does not merely fail to relieve the suffering of marginalized people but also can produce it. For example, the constitution of publicly-funded and charitable dental care can serve to routinize and even incentivize excess extractions among low-income adults while exempting preventive or restorative care. In addition to its effects on underserved patients, the dental safety net is a site through the fraught and contradictory relationships of dental providers and the sociopolitical stakes of the pursuit of oral health equity can be understood. For example, the flexible teamwork arrangements prized in private practice, when posited for the dental safety net, are often interpreted by dentists as risks of pluralization and threats to professional hierarchy that must be contained through legislative means. Borrowing from the crude classificatory scheme used to screen teeth quickly, I show how the dental safety net is decayed, as it bears the wear of overuse beyond maintenance; missing, or better described as an absence than a presence; and filled, like a cavitated tooth or a canaled dental root, with manufactured solutions of variable standards and longevity.

#### CHAPTER 1: INTRODUCING AND SITUATING THE RESEARCH

The shutting of a door disturbed me, and, looking up, I found my cousin had departed from the chamber. But from the disordered chamber of my brain, had not, alas! departed, and would not be driven away, the white and ghastly spectrum of the teeth. Not a speck upon their surface — not a shade on their enamel — not a line in their configuration — not an indenture in their edges — but what that period of her smile had sufficed to brand in upon my memory...(I) shuddered as I assigned to them in imagination a sensitive and sentient power, and even when unassisted by the lips, a capability of moral expression. Of Mad'selle Sallé it has been said, "que tous ses pas etoient des sentiments," and of Berenice I more seriously believed que touts ses dents etoient des ideés.<sup>1</sup>

-- Edgar Allan Poe, "Berenice," 1835

"You've *got* to meet Jeff," Whitney called, waving me over on a humid Friday morning in July 2011, "He walked here from Bluefield." It wasn't just recognition of my hometown that compelled Whitney, a dental industry executive and charity care organizer, to introduce us. It was Jeff's mode of travel to the place where we now stood: the Wise County fairground, specifically, the "tent city" set up there for the annual Remote Area Medical/Mission of Mercy free health care fair, henceforth "RAM." For the past decade, over a long weekend each

<sup>&</sup>lt;sup>1</sup> "Que tous ses pas etoient des sentiments" is translated by scholars of Poe as "Her every step was a sentiment." "que touts ses dents etoient des ideés" is translated as "that all her teeth were ideas. Ideas!" (Edgar Allan Poe Society: ND).

<sup>&</sup>lt;sup>2</sup> I use pseudonyms for all individuals who appear in this dissertation. For organizations that are easily recognizable, I use real names, for example Remote Area Medical or, "RAM." RAM is an international medical relief organization headquartered in Knoxville Tennesee. Mission of Mercy or "MOM" is a project of the Virginia Dental Association Foundation, and the primary mechanism through which dental services are provided at RAM events in Virginia and, now, nationwide, as the MOM model originated in Virginia has been replicated in 38 states. The event is organized by a local partner, The Health Wagon, a long-term free mobile medical clinic that was founded by a missionary nurse practitioner working through a local Catholic charitable hospital. This relationship is described in more detail later in this chapter. Throughout this dissertation I refer to the event as the RAM, for two reasons. First, that is the parlance used by most participants in my research. Second, while MOM organizers aim to call attention to their efforts by saying "RAM/MOM," the persistent emphasis on the first acronym serves, to my mind, to call attention to the challenges of attention faced by the problem of dental care inequality: That is, even substantial efforts to increase access to care are subsumed under the idea of a generic health care inequality, which in the U.S. translates to medical inequality.

summer, hundreds of volunteer clinicians and support staff have traveled to Wise from their homes four, eight, twelve hours away, to provide thousands of free medical and dental services to underserved patients, many of whom are the "working poor," whose low-wage employment does not offer benefits such as health insurance, but whose income often makes them ineligible for public health insurance.<sup>3</sup> While patients attend RAM to receive a variety of health services, dental treatments and eye/vision care are, according to both local and national statistical reporting by the organization, the most commonly sought treatments at many of its expeditions.<sup>4</sup>

I recognized Jeff from my volunteer work the day before. He had waited patiently while another volunteer and I set up the registration table at the fairground's entrance. When he saw us pause to await our next assignment, he approached to ask if he could get a "number." "Numbers," or printed tickets in numerical order, were the key to obtaining services at RAM, and they were distributed on a first come, first served basis. The only "eligibility criteria" was waiting, in person, to receive them, often overnight in the fairgrounds' adjacent parking lot, in the sticky summer heat or, sometimes, rain. We explained that tickets would be distributed starting late that night and that Jeff should go to the end of the line of people who had already

<sup>&</sup>lt;sup>3</sup> Virginia has among the nation's most restrictive criteria for public medical insurance. Childless adults in the state are not eligible for Medicaid. Working parents can not qualify for Medicaid if they earn more than 30% of the federal poverty level, or \$5,727/year for a family of three. Elderly and disabled persons' income qualification was 80% of the federal poverty line or, \$15,272/year. Virginia's Family Access to Medical Insurance Security program (FAMIS) extends coverage to children under 18 and pregnant women whose income is up to 200% of the federal poverty level or, \$38,180 for a family of three (Virginia Department of Medical Assistance Services 2014). Dissertation fieldwork was conducted from July 2010 to November 2011, shortly after passage but before implementation of the Patient Protection and Affordable Care Act of 2010 (ACA). At the time of writing, Virginia had not elected to implement Medicaid expansion as part of one strategy of the ACA.

<sup>&</sup>lt;sup>4</sup> For example, at the 2013 RAM at Wise, of the 2244 total patients registered, 56% received dental services valued at \$1,408,292.00 or, 73% of the total value of donated services (The Health Wagon 2014). Thirty-two percent of patients received eye or vision care valued at \$182,808.00. Only a quarter of patients sought general medical care, valued at \$98,333.00, though this financial figure doubles when the value of donated laboratory diagnostic services is taken into account (ibid). As discussed throughout this dissertation, the exclusion of dental benefits from adult public insurance in Virginia, the high cost of dentistry in general, and the challenges faced by families in identifying a dentist who will accept children's dental public benefits, explains this disparity in services sought and provided.

gathered to receive them. When he asked if he could enter the fairground to wash his face and refill his canteen, we said sure. As he walked past us, bearing a large canvas backpack, my co-volunteer, a dental assistant, remarked on how swollen his left lower jaw looked. "Bet I'll be seeing him tomorrow," she said.

That night, around 9pm, I saw Jeff again when I accompanied another volunteer who was driving a golf cart through the parking lot, giving out water and peanut butter crackers donated by a local snack food distributor. By this time, four-and-a-half-rows of approximately thirty vehicles each had filled in the dirt parking lot, and more were entering. Would-be patients passed the time in a variety of ways. Some people had turned the wait into a social occasion, replete with portable grills, lawn chairs, playing cards, laughter, and, in the flatbed of one truck, a TV screen and a Wii gaming system rigged to a generator, so its owners could bowl a couple of frames. Others leaned on their vehicles, reading by flashlight or participating in interviews with journalists from the Washington Post, Newsweek, Al-Jazeera, and other media outlets – or this visiting anthropologist. Many people slept in their vehicles, parents in the reclined front seats and children sprawled out across the back. From within a tent, a young mother tried to soothe her crying baby with a bottle and a wet washcloth while the baby's father stood outside, holding in one hand a magazine to fan fresh air into the tent and, in the other, a dip cup into which he spat tobacco juice. The air smelled of menthol and charcoal, honeysuckle and sweat, and for a moment the scene felt almost like a recreational campground or an outdoor music festival.

As we rounded the far end of the second row of cars, I recognized Jeff. He reclined on a camping pad, using his backpack as a pillow. He waved. I waved back. I thought his jaw looked even more swollen and bruised, though it could have been the effect of a floodlight shining down on him. "I hope you make it in early tomorrow," I called. He grinned, gave me a thumbs up, and

slapped a mosquito on his neck. Seeing the provisions, he put his hands up. I tossed Jeff a bottle of water and a packet of peanut butter crackers, and some for the man beside him, a young-looking guy with shaggy red hair and a four-inch labret spike, who was reading a college geometry textbook.

The next day, after Whitney introduced us, Jeff told me more about his path to RAM. His left lower wisdom tooth started bothering him two years prior, in April 2009, but, as a wage worker on a construction cleanup crew, he didn't have dental benefits or any extra cash, so he didn't get it examined. Plus, as a self-described "natural, outdoorsy" guy, Jeff thought he could prevent infection by adding warm salt water rinses to his daily brushing and flossing routine, and taking Goody's Powder or chewing on a white willow branch to relieve his pain. But over time the pain got worse and, as he remembered reading about "that poor child who died when a dental infection reached his brain," he became scared of the same fate. 5 Jeff saved as much money as he could and, later that year, went to a local dentist to have his teeth evaluated. X-rays revealed that three of his four wisdom teeth were impacted and would need to be removed surgically, but the examination alone cost \$250 – all of his savings. Jeff had also remembered hearing a radio report about RAM, so he started strategizing his attendance. He didn't have a car, and he was mostly a loner so he couldn't ask a friend or family member to drive him the hundred miles from Bluefield to Wise. But he knew that far southwest Virginia's public van could take him within 20 miles of the fairground and that he could walk the rest. Jeff calculated how much money he would need to eat at fast food restaurants along the way, where he could also charge his cell

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<sup>&</sup>lt;sup>5</sup> Jeff was referring to Deamonte Driver, a twelve-year-old boy from Maryland who died in 2007 of a brain infection that resulted from an untreated dental abscess. Driver's mother, a low-income single parent, had attempted to obtain treatment for him but encountered multiple constraints including structural barriers to care and the need to prioritize the dental care of another of her children, whose dental problems she understood to be more urgent (see Otto 2007).

phone, plus the cost of a motel room for the night after the extractions; the other nights, he would sleep under the stars.

For eleven months Jeff saved money toward his trip. Then, on a Tuesday in mid-July 2011, he boarded the Tazewell County shuttle and rode it as far southwest as it went, then walked across the Russell County line and took that public van to the Wise County border, where he began to hike along the mountainous roads. He got about a third of the way to Wise when night set in, and rain with it, so he slept under a railroad bridge and walked the rest of the way on Wednesday. The trip went mostly as planned, but Jeff fretted a bit when we spoke on Friday morning, as he awaited four surgical extractions plus a filling for a small cavity. He'd spent more on food than anticipated and he'd forgotten to budget an extra day of food for Sunday. The public vans didn't run on Sundays, so his return trip home would be delayed until Monday. He was worried that Sunday's food costs would preclude his planned recovery in a motel room on Friday night, following his procedure, but he was also worried that he wouldn't feel well enough to walk the 20 miles back to take the public van on Monday if he didn't rest well enough following his oral surgery. Making it to the van on Monday was crucial, he told me, so he could go to work on Tuesday. As I listened to him do the calculations I winced, silent in my knowledge that had I met him any other way, I could have helped defray his costs by giving him a \$20 gift card to a local grocery chain to thank him for participating in my research.<sup>6</sup> Jeff was still turning

<sup>&</sup>lt;sup>6</sup> RAM's research site authorization explicitly prohibited me from incentivizing research participants during the three-day event. RAM officials explained this decision two ways, both of which derived from its "no-transaction" environment. First, they claimed that the exchange of resources might appear to violate temporary changes to state practice law that allowed out-of-state clinicians to volunteer at Virginia expeditions which it had recently gotten passed, a tentative and hard-won victory that was increasingly a cornerstone of its national advocacy. Second, they expressed concern that people – both patients awaiting services and "drug dealers" and "junkies" – bought, sold, and utilized illicit substances in their parking lot overnight. RAM organizers felt that utilizing gift cards to thank participants violated these norms, or the perception of them. Moreover, RAM organizers felt that my use of incentives would be overly persuasive and undermine potential participants' ability to decline recruitment, and that participation incentives would create disparities in an environment predicated upon equal access. Barring this important distinction, Jeff and all other participants from whom I collected data at RAM was consented into this

his decision over in his mind when he was called from the waiting area to the procedure area. "I guess I'll see you later," he said, and a volunteer led him to one of a long line of dental chairs in the open air surgical suite.

A few hours later I saw Jeff in the recovery area. He sat on a folding chair backwards, facing a table, his forehead resting on one freckly forearm and his other hand on his backpack, propped up on the ground beside him. Blood-tinged puffs of white gauze burst from his mouth as Jeff raised his head, tried to smile, wearily, and gave me a "thumbs up." I gave him one back, then kept walking to dental triage, where Whitney and Rick, a retired Medicaid administrator and regular event volunteer, beckoned me over. They wanted to know how Jeff was doing. I told them of the thumbs up. They inquired more. Was someone coming to pick him up, or...? Aware of my research obligation to confidentiality, I explained to them – residents of larger metropolitan areas with more extensive and reliable public transportation – broadly, how the region's extremely limited public van service worked. Whitney, formerly a practicing dentist, found Jeff's delayed return home clinically concerning. Rick offered to drive Jeff the 20 miles to the van stop at Russell County, though he knew that wouldn't solve the budget problem of the delay until service resumed on Monday. "We can do better than that," Whitney said, and he held his hands to his mouth to address the dental intake line: "Is anyone here from Bluefield?" he called. "I'm from Tazewell," shouted a man who stood about fortieth in line. Whitney called the man over and asked what services he was waiting to have performed. The man needed to have a crown repaired and a few cavities filled. Did he have room in his vehicle for one more person, Whitney asked. The man said yes. "Congratulations, sir. You are now number one in line for services," Whitney said, pulling out his wallet covertly and continuing, "Here's \$40 for gas. I

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study using a protocol approved by the University of Arizona Institutional Review Board and the RAM Medical Advisory Board.

want you to take another patient home for me." Whitney looked at me: "Now go tell that young man we're getting him home tonight."

#### **Introduction: Dental disparities in the United States**

Jeff's is but one of many stories through which the topic of dental disparities in the United States can be introduced. The precarity of dental care, and the pain and suffering that can inspire such great effort to obtain it, are all too widespread. Why? Dental disease is among the world's most common health problems, specifically dental caries or the disease popularly known as cavities or tooth decay. The World Health Organization estimates that nearly every adult has had at least one cavity in her lifetime (WHO 2013). In the United States, 42% of children have had dental caries in their primary teeth; 59% of adolescents have had them in their permanent teeth (NIDCR 2014). The near-ubiquity of tooth decay owes to its origin in one of the most quotidian – and necessary – processes of life. After a person eats or drinks, naturally occurring oral bacteria metabolize the microscopic bits of food that remain (Colak, et al. 2013).<sup>7</sup> This process produces acid that can break down, or cavitate, a tooth's surface either directly, or through the development of dental plaque. While individual behaviors such as brushing one's teeth or drinking water between meals can help to prevent dental decay by sweeping away these microscopic particles, they are inadequate to address nascent decay or its antecedents, for example the hardened plaque known as dental calculus, once they take hold (Selwitz, et al. 2007). Moreover, many of the other factors to which dental decay's complex etiology can be

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<sup>&</sup>lt;sup>7</sup> Processed foods are often vilified as being disproportionately high in the fermentable carbohydrates that are classified as particularly "cariogenic," or cavity-causing. However, simple sugars that are attractive to oral bacteria also occur in many so-called natural foods, for example cow's milk, human breastmilk and fruit. Much recent research centers on the frequency and duration of exposure to cariogenic substances, and the amount of time between exposures during which saliva and water can "clear" the remnants of these substances.

partially attributed cannot be mitigated by changes to individual behavior, for example: comorbid disease and/or the use of medical treatments which can erode dental enamel, environmental exposures including exposures during gestation, and the mineral composition of dentition, which is in part a product of heredity. Dental caries is also highly amenable to clinical treatment. Procedures to resolve tooth decay are often simple, relatively inexpensive, and capable of preserving both the tooth's structural integrity and its visual appearance. In addition, manual techniques of preventive dental care can also help stave off subsequent decay (Burt and Eklund 2005; Selwitz, et al. 2007).8 Despite the complexity of the etiology of dental caries and the success of technical approaches to its remediation, clinicians, oral health educators, and many dental social scientists tend to disproportionately emphasize the role of individual behavior to prevent disease, a common feature of public health ontology in a neoliberal milieu (Lupton 2007).

Periodic dental decay is common among most people, and its resolution, generally simple. Yet, recurrent, chronic, or advanced dental caries is a trenchant marker of social inequality in the United States and many other countries (NAS 2011, USDHHS 2000, WHO 2015). Eighty percent of cavities diagnosed among U.S. youth are borne by only 25% of children, who are almost invariably from low-income households (Kaste, et al. 1996). U.S. adults who earn less than \$30,000 per year are twice as likely to lose all of their teeth as those who earn more than that (ADA 2014). The distribution of dental treatment follows patterns of social stratification as well. Three times as many U.S. residents are dentally uninsured as those who are

<sup>&</sup>lt;sup>8</sup> For example, topical agents such as topically-applied fluoride can strengthen dental enamel. Thin semipermanent plastic sheathes called sealants can create barriers that disrupt plaque from "sticking." Plaque that has hardened into dental calculus and adhered to teeth's surfaces can be removed manually.

medically uninsured (NADP 2012). Only 48% of employers offer dental plans, as compared to 74% offering medical coverage (BLS, cited by NADP 2012). Meanwhile, dental insurance status tells only part of the story of dental care access. Americans increasingly forego dental procedures, even among the 60% of people who have dental insurance, due to the expense of procedures that are excluded from or only minimally covered by dental insurance plans (Wall, et al. 2012). Over half of Medicaid-insured families can't find a provider who will treat them (Pew Charitable Trusts 2013; see Castañ et al. 2010 for a case example.). Thus, unresolved dental disease represents twin marginalities in the United States: the *presence* of disease and the *absence* of care (Sanders 2012; USDHHS 2000). While dental *treatment* disparities and dental *disease* disparities are, technically, distinct concepts, they are mutually implicated. The advancement of dental disease most commonly occurs among people who lack access to care. Accordingly, in this dissertation I collapse these concepts into the term *dental disparities*.

Dental disparities contribute to the socio-economic stratification of physical suffering. In addition to causing tenderness, swelling, and infection in the mouth, dental decay is also implicated in many other illnesses, from its worsening effects on diabetes, pregnancy, and addiction, to its contribution to death from systemic infection that can begin in the oral cavity (Boggess and Edelstein 2006; Demmer, et al. 2008; Mateos-Moreno, et al. 2013; Nalliah, et al. 2011). Dental disparities also contribute to the stratification of psychosocial pain and suffering

<sup>&</sup>lt;sup>9</sup> This statistic reflects data collected prior to the passage of the Patient Protection and Affordable Care Act of 2010, or the ACA. The implementation of the ACA likely skews this statistic to reflect an even higher disparity, as the medical insurance coverage mandated for adults failed to include dental benefits. Children's dental benefits have been mandated since 1997, though research demonstrates that only half of low-income children nationwide are actually able to utilize those benefits (Ku et al. 2013, Steinmetz et al. 2014)

<sup>&</sup>lt;sup>10</sup> In industry parlance, dental insurance is actually a prepaid dental benefit plan. This rhetorical distinction masks important differences in the constitution of "coverage." Dental benefits are, essentially, pre-payment for a predetermined set of services whose rates are negotiated on a bulk model, rather than a model that operates on pooled risk, as in the case of medical insurance. (Say more here about the % coverage on procedures by offering an example?)

(Locker 2009; Pattussi, et al. 2007). Dental pain factors into school absenteeism among children and work absenteeism among adults, as well as sleeplessness, malnutrition, and depression.

Unresolved dental disease has a particularly profound impact on the lived experience of day-to-day life, as the sensorial markings of dental decay – broken teeth, visible cavities, bad breath – can render its bearers as what Briggs and Mantini-Briggs call "unsanitary subjects" or, people "deemed to be incapable of helping themselves" at home or by terms of seeking clinical care (2004:xvi, see also; Horton and Barker 2009). This dissertation examines how the unsanitary subjectivity of evident dental decay shapes its bearers' everyday experiences, including their interactions with the complex, fragile, and loose network of treatment opportunities for low-income families in the United States known as the dental safety net.

Since it was organized in the early twentieth century, the dental care industry has developed in the model of fee-for-service private practice (Fraundorf 1984; Picard 2009). For those families who do not have private dental insurance, who cannot find a private practice dentist who will accept their public insurance, or who cannot afford dental care, few treatment opportunities exist. Those that do are broadly described as the dental safety net. Highly variable by locale, the dental safety net may include temporary health care events, community health centers, donated services networks, dental public health clinics and outreach events, and, the 20% of private practices that report that they accept Medicaid (Bailit, et al. 1999; Edelstein 2010a; Pew Charitable Trusts 2013). An ideal dental safety net would be virtually indistinguishable from customary private practice dental care in terms of services offered, periodicity of preventive care, and other clinical and management practices. However, this is not

<sup>&</sup>lt;sup>11</sup> While 20% of dental private practices nationwide, and in Virginia, report accepting Medicaid insurance, my fieldwork and a number of other anecdotal sources suggest that this figure is a significant overestimate. Increasingly, hospital emergency rooms are also becoming a de facto dental safety net for patients seeking treatment for dental pain and infection. I describe my fieldsite's dental safety net in Chapter 2.

the case of the dental safety net in much of the United States. Under-resourced, even by comparison to the rest of the social safety net, the dental safety net is tenuous and unpredictable (Bailit, et al. 2006; Bailit, et al. 1999; Burt and Eklund 2005). Clinics routinely experience intractable patient waiting lists, service disruptions, threats to solvency, and staff turnover, particularly when the duration of service among National Health Service Corps dental personnel conclude. Services offered are determined by sociopolitical arrangements such as Medicaid policy – itself, heavily influenced by the dental industry's lobbying of legislative and regulatory bodies – as well as the characteristics of the dental teams who treat patients, for example whether they will reschedule Medicaid insured patients who miss appointments. Together, these qualities often leave patients further excluded from care, their psychosocial needs as well as their clinical ones unmet. They also shape the identities of and relationships among the dentists, dental hygienists, and dental technicians who work or volunteer there.

#### The sociopolitical arrangement of dental disparities and the dental safety net

Dental disparities reflect deep ontological, moral, and political differences in U.S. society about responsibility for the prevention and treatment of dental disease, the quality and distribution of dental care, and even what constitutes health and well-being. What kinds of sociopolitical and moral negotiations constitute and transpire around dental disparities? How do these negotiations shape the experiences of patients like Jeff, and providers like Whitney, and how do their experiences shape these negotiations? What can an ethnography of the dental safety

<sup>&</sup>lt;sup>12</sup> Despite its rhetorical framing as a term that would seem to encompass overall health, "health care" has only addressed problems deemed to be medical since the organization of the health professions in the early twentieth centuries (Picard, Starr). The care of the mouth and oral cavity have been considered as separate since then. Despite multiple attempts in the past to integrate the two discipline, only in the last decade has oral health been generally recognized as part of overall health.

net tell us about health governance more broadly? These are some of the questions that drive my research.

In this dissertation, I explore how the sociopolitical relations of dental disparities are enacted through the dental safety net. Drawing on fifteen months of ethnographic research in clinical and community settings in central Appalachia, a region that has come to symbolize the dental crisis in the popular imagination, I show how the dental safety net exemplifies health governance in the neoliberal milieu. A fragmented system characterized by a discontinuity that starkly contrasts the model of health care generally advocated in both private and public medical systems (IOM 2001), I argue that the dental safety net in far southwest Virginia does not merely fail to relieve the suffering of marginalized people but also can produce it. In addition to its effects on underserved patients, I show how the dental safety net also shapes dental providers' identities, or sense of self, and the fraught and often paradoxical relations that characterize dental teams. I explore the real, lived effects of dentally underserved patients' and charitable providers' attempts to navigate a complex and ever-changing system that I describe, borrowing from the crude classificatory scheme used to screen teeth quickly, as decayed, missing, and filled. The dental safety net, I argue, is *decayed* in that it bears the wear of overuse beyond maintenance or, better yet, ongoing replacement or improvement, an especially taxing burden as evermore people depend on it. It is missing, in that the dental safety net is better described as an absence than a presence; there has never, in the history of health care in the United States, been a truly adequate dental safety net or system of accessible dental care. And the dental safety net is *filled*, like a cavitated tooth or a canaled dental root, with manufactured solutions of variable standards and longevity. As a multi-sited community/clinical ethnography, my project investigates these topics through the community health centers, public health clinics and outreach efforts, temporary

charity events, and private practice dentists who accept Medicaid patients or donate services through both official and informal networks by which the dental safety net is constituted.

#### **Theoretical framework**

This dissertation is, at its core, a critique of health inequality in the United States in the tradition of other politicized ethnographies of care (for example, Becker 2007; Horton 2007; Sered and Fernandopulle 2005). I examine the maldistribution of tooth decay and dental care – distinct but related phenomena – among low-income residents of far southwest Virginia. Inspired as well by critical ethnographies that examine the experiences of the people who *deliver* care to marginalized people (for example, Brodwin 2013; Lamphere 2005; Shaw 2012), I also consider how the dental safety net volunteers and employees shape and are shaped by its sociopolitical relations. Accordingly, a political-economic framework guides my analysis; as introduced below, I combine this approach with post-structuralism in the tradition of Michel Foucault.

A number of political economic analyses of health inequality in the United States critique how health care – considered, elsewhere, a public obligation – is enacted through market-based logics and techniques (Boehm 2005; Horton 2006; Lopez 2005; Maskovsky 2000b). This tradition of scholarship often traces the inequitable distribution of care to neoliberal governance, in which the state's sense of responsibility to its citizens is tenuous and non-obligatory, and is often enacted through private or hybridized approaches (Harvey 2005). A major effect of this formulation, which in the United Stated intensified in the second half of the twentieth century, is that most individuals are responsibilized for securing their own health care, typically by participating in an arrangement that confers access vis a vis an insurance benefit such as full-

time salaried employment (Hoffman 2012; Sered and Fernandopulle 2005; Starr 1982).<sup>13</sup> Yet, employer-based medical coverage has not led to an adequate distribution of care (Hoffman 2012; Horton, et al. 2014; Rylko-Bauer and Farmer 2002). Rather, it has institutionalized the social stratification of access and, concomitantly, the inequitable distribution of health problems.

Political-economic critiques of neoliberal health governance are powerful indictments of some of the causes and outcomes of social injustice. However, as a number of scholars point out, they also fail to fully portray the nuanced processes of seeking or providing care. For example, they tend to assume the interminability of neoliberalism, overlook individual's creative attempts to care for themselves, and discount the ways health governance is always emergent, sometimes to unanticipated effect (Mulligan 2014; Shaw 2012). Additionally, political-economic critiques often fail to account for the considerable role of meaning in the construction and governance of health among both individuals and institutions (Bridges 2008; Briggs and Mantini-Briggs 2004; Horton and Barker 2009). For example, in a setting such as the United States, where employerbased insurance and privatized systems of health care are posited as normative, those who are excluded from these systems are often stigmatized as irresponsible, problematic, or otherwise errant (Allen, et al. 2014; Dougherty 2009; Sered and Fernandopulle 2005; Stuber, et al. 2014). In order to address the inability of political-economic approaches to account for the powerful nuances of social processes of health care, many scholars combine them with other intellectual traditions. Accordingly, I follow others' example in turning to post-structuralism in the tradition of Michel Foucault, who galvanized critiques of state-individual relations beyond the market

<sup>&</sup>lt;sup>13</sup> Individuals are also responsibilized for maintaining the resources, including cash resources but also access to credit, to cover expenses above and beyond their employment, benefits, and the salary deduction which covers insurance, These expenses may include co-payments, excluded goods and services, and ancillary items such as cars or other modes of transportation.

focus, and who posited the personal and professional care of the body as a key site for understanding these relations (Foucault 1990).

Foucaultian post-structuralists, like many political economists, also examine contemporary state/subject relations, in particular how interest in and responsibility for the self has been diffused from a central apparatus to the individual (1991; Rabinow and Rose 2006; Rose 2007). Building on Foucault's concept of governmentality, or the "conduct of conduct," these scholars show how configurations of power in late modernity condition individuals to enact social norms through techniques of self-governance (e.g., Dean 2010). Like Foucault, many of them note the primacy of individual and societal bodies in relations of power, from the epidemiology and prevention of disease, to clinician/patient relations, to self-improvement projects that aim to maximize physical and psychosocial well-being (Hogle 2005; Lupton 1995; Martin 2009; Nettleton 1992). In this dissertation I combine political economy and Foucaultian post-structuralism to explore two interrelated topics: (1) the centrality of contradiction in health care in a neoliberal milieu and (2) the roles of morality, affect, and aesthetics in the governance of health.

#### Contradiction as a way of care

Contradiction can be seen in the ways that the intentions, goals, or assumptions of relations of governing often fail to play out and, moreover, may lead to unexpected and often contrary processes. Rather than an exception to many contemporary relations of power, scholars argue, contradiction is, instead, constitutive of them. Here, health and health care are exemplars of this larger dynamic. In the model of health in a neoliberal milieu, individuals are obliged to enact an ever-expanding set of responsibilities for the self which are imagined to occur within a

similarly multiplicative field of possibilities, from the prevention, diagnosis, and treatment of disease to the maximization of wellness (Fox 2005; Lupton 1995; Rajan 2006; Rose 2001). This market-based framework, which increasingly characterizes safety net as well as for-profit care, presupposes the success of consumer relations, in which individuals *seek* goods and services and professionals *deliver* them (Rylko-Bauer and Farmer 2002; Scambler 1987; Starr 1982). The "accomplishment" of care through these relations is considered a logical effect and thus naturalized (Maskovsky 2000; Mol 2008; Mulligan 2014).

Yet, large body of literature demonstrates the failures of this health care imaginary particularly in the resource-constrained environments of the health "safety net," or a combination of public and "third sector" services<sup>14</sup> which arose in light of the failures of private insurance to address the needs of those on the edges of the body politic: public health insurance for low-income children, aging populations, people with disabilities, and other special populations; community clinics that charge on an income-based sliding scale fee; and free clinics, among others (Evers and Laville 2004; Kendall 2000; Salamon 1995). Chronically under-resourced and at perpetual political risk of further constrictions, the health safety net is often impeded from delivering adequate care at the same time that it is ever more burdened by expanding demand due to rising inequality in the U.S, the contraction of workplace benefits, and the soaring costs of medical care (Berlinger, et al. 2014; IOM 2000; Hawkins and Rosenbaum 2005; Sabik 2012). Thus, the safety net emerges not only out of the contradiction of the failure of the health marketplace to accomplish its goal of providing care but, also, re-enacts this contradiction as the increases in need and constraints on resources exist in seemingly perpetual dynamic tension.

<sup>&</sup>lt;sup>14</sup> "Third sector" is a broad term that refers to private, non-governmental organizations (NGOs) that deliver services on a "non-profit" basis. A prolific anthropological literature critically examines the third sector in the United States and elsewhere, as do others in political science, sociology, history, and other fields.

Within the health safety net, patients' material constraints are made evident through the verification of income status in order to qualify for services. Yet in addition to the resource constraints that keep low-income patients from seeking care through the private sector, underserved patients encounter other barriers as well. These barriers constitute threats to the health subjectivities they are trying to enact. For example, the opaque and bureaucratic processes of enrolling in public insurance plans, identifying providers who will accept that insurance, and utilizing such social provisions can "disentitle" (Lopez 2005) individuals from leveraging public entitlements (Castañeda, et al. 2010; Mulligan 2014; Willging 2005). <sup>15</sup> Thus, marginalized people's experience of being stigmatized by the very system that is supposed to serve them can prevent them from accessing needed care (Allen, et al. 2014; Hansen, et al. 2014; Stuber, et al. 2014). The improvisational strategies required by the safety net's deprivation can also result in cross-referral, rationing, deliberate slow-downs, and other strategies deleterious to both providers' needs, as well as patients' (Boehm 2005; Horton 2006; Lopez 2005; Waitzkin, et al. 2002).

From this perspective, the contradictions of stratified care, and their effects on patients and providers, are not merely an unanticipated outcome of health care in a neoliberal framework but, rather, constitutive of it (Becker 2007; Hoffman 2012; Horton 2007; Rylko-Bauer and Farmer 2002). While these contradictions characterizes the market basis that underlies safety net health care, generally, they are particularly magnified in the care of the mouth. Indeed, the exclusion of dental care from the state's definition of essential services, evinces how incomplete the concept of *health* care is.<sup>16</sup> Thus the teeth and mouth – not only a part of the body, but also a

<sup>&</sup>lt;sup>15</sup> A vibrant body of ethnographic research documents the role of bureaucracy in the health and social governance of populations globally. See, for example, Auyero 2012, Gupta 2012, and Hetherington 2011).

<sup>&</sup>lt;sup>16</sup> While the inclusion of a mandatory children's dental benefit in the Children's Health Insurance Program (CHIP) of 1997 is considered a major victory in prioritizing oral health philosophically this benefit continues to suffer from

major source of problems and contributor to other health issues –have been naturalized through the system of care as distinct from and, ultimately, subordinate to the rest of the body. 17 The dynamic tension between ever-expanding responsibilization and ever-constraining structures that characterizes the contradictory quality of market-based care shapes the experiences of dental safety net patients, as well as the dentists, dental hygienists, and dental assistants who work or volunteer there. The insight that the contradictions of neoliberal health governance can, rather than resolving inequality, perpetuate and even expand it (Boehm 2005; Rylko-Bauer and Farmer 2002) guides my examination of patient experiences in the dental safety net. It also provides context for examining the many creative strategies through which patients and providers alike try to obtain and provide care, respectively, despite extraordinary constraints. The vignette which opened this chapter epitomizes this dynamic. The RAM advances a strong rhetoric of equal treatment, in which anyone who waits in line is eligible to receive health care (but, as organizers' rejection of my attempt to distribute research incentives demonstrated, only health care) provided that they have arrived early enough to receive one of the limited number of entry tickets. Yet as exemplified in the special treatment Whitney provided not only to Jeff, but also to the man who would help him get home safely, the emergent characteristics of care in a resource-poor (and fairly frenetic) environment open up possibilities for improvisational moves that can aid in healing as well as highlight microscopic iterations of resource inequality, such as trying to ensure that a patient is transported home expediently following surgery, in direct opposition to how the event envisions itself as working.

inadequate implementability, as 80% of dentists nationwide refuse to treat people insured by Medicaid (NAHP Nd.).

<sup>&</sup>lt;sup>17</sup> This observation is historicized in Chapter 4.

This dissertation argues that contradiction in the dental safety net is, rather than an exception, a routine feature through which safety net care is constituted. This observation moves my discussion to the next major theme that shapes my analysis: the ways in which both governance and (contradictory) enactments of the dental safety net, and health and health care more broadly, are shaped by factors other than relations of power. For example, in Jeff, Whitney identified a patient who appealed to him emotionally, morally, and even aesthetically. In a safety net setting filled with patients whose subjectivity was characterized, tacitly or explicitly, as "unsanitary" (Briggs and Mantini-Briggs 2004), Jeff stood out. His journey to obtain treatment both demanded and demonstrated not only resourcefulness and initiative - traits often associated with "deservingness" (Willen 2012) – but also the ability, physically and otherwise, to carry out his elaborate and burdensome plan. In addition, Jeff's idealization extended beyond the lengths he went to get his clinical needs met. Impacted molars, the dental need he sought to address, are generally interpreted by clinicians as a result of the "bad luck" of physiology rather than the vilified individual behaviors that mark cavitated teeth symbolically as well as clinically (see Horton and Barker 2009). Moreover, his was a case that *could* be resolved tidily, something rare and edifying for dental safety net organizers like Whitney. And then there was Jeff's smile. Even after surgery, his mouth still dulled from surgical anesthesia, Jeff tried to turn up its corners at everyone he met who he perceived as having helped him (myself included), blood-tinged saliva pooling through the small, attractive gap that parted his intact, unblemished front teeth. Even in pain – and he was in acute pain following his surgery – with this attempt at expression Jeff portrayed both a social normativity (Cashdan 1998; Jones 2014; Mehu and Dunbar 2008) and the "proper" gratitude of an underserved patient (see Rivkin-Fish 2011) that eluded many patients who participated in my research. In a field of patients whose attendance at a dental charity clinic

anticipated their "unsanitary subjectivity" of unmet dental needs, made visceral in how they had trained themselves to limit their facial expressions or use their hands to shield their teeth from sight, the freedom with which Jeff comported himself was relatively anomalous, and betrayed the social stakes of dentition.

#### Moral, emotional, and sensory regimes in the neoliberal governance of oral health

Health and health care are sites through which relations between individuals and the state are negotiated. Moreover, health governance extends into social life more generally, for example from notions of cleanliness and the prevention of transmissible disease (Anderson 2006; Bashford 2004; Briggs and Mantini-Briggs 2004) to the constitution of appropriate self-care for existing health issues (Bridges 2008; Carr 2010; Ferzacca 2000) to the construction of well-being as not only the treatment of disease but as the maximization of life satisfaction (Edmonds 2009; Gard 2001; Rajan 2006). Relations of health governance are also exemplary sites for observing the dialectics of some of the most intimate aspects of individuals' lives and the public circulation of ideas. Counterposing Briggs and Mantini-Briggs' concept of "unsanitary subjectivity" (2004, see also, among others Bridges 2008; Horton and Barker 2009), characterized by the failure to take care of one's health either through enacting behaviors or seeking care, the converse, is what Kingfisher and Maskovsky call "proper" personhood (2008): the willing enactment of prescribed notions of personal and clinical bodily care. This dynamic evinces Ann Laura Stoler's observations that the techniques of governance, often claimed to be about the "rule of reason" are, in fact:

(I)ts very opposite: namely, a discursive density around issues of sentiments and their subversive tendencies, around "private" feelings, "public moods," and their political consequences, around

the racial distribution of sensibilities, <sup>18</sup> around assessments of affective dispositions and their beneficent and dangerous political effects (2007:4-5 in Nugent and Vincent.)

Elsewhere, Stoler uses the term "sensory regime" (2002, see also Roth Gordon 2013) to refer to the shaping of sensibilities, tastes, and aesthetics as part of a broader project of the colonial conditioning of bodily comportment. Given that the sensorial is but one of the modes at the intersection of ideology and embodiment through which health is governed, I extend her concept to specify morality and affect as regimes through which health and health care governance is advanced, as well. While morality, the senses, and affect constitute three distinct domains, I examine them together to demonstrate how health governance extends beyond the political.

Scholars theorize intersections among moral, sensorial, and affective governance of a variety of health problems, for example drug addiction (Carr 2010; Zigon 2011), pregnancy and prenatal care (Bridges 2008; Martin 2001), and cancer (Chattoo 2008; Stacey 2009). While some nascent work on the moral, sensorial, and affective governance of oral health (Horton and Barker 2009; Linnemann and Wall 2013; Murakawa 2011) informs my analysis, a more developed scholarly areas informs my perspective: critical studies of obesity. Like dental decay - and unlike more hidden illnesses –obesity has a strong visual and aesthetic component to which critical scholars of this "epidemic" attend. For example, Deborah Lupton argues that the vivid images of obesity prevention campaigns – overweight people eating high calorie foods and coded as slovenly through their dishevelment and flagrant indulgence – is meant to compel populations to adhere to an aspirational self-restraint by confronting them with images that index sensorial and moral disgust (see also Elliott 2007; Kersh 2009; 2015; Thomson 2009). Like obesity, oral health

<sup>&</sup>lt;sup>18</sup> One of the foremost literatures to develop around the roles of affective, moral, and sensory regimes in governance is in the area of race, specifically the malleability of race in both contemporary and historical contexts. I address this literature later in this chapter and in Chapter 2.

offers another example through which we can analyze how the cultural politics of disease and care are shaped by moral, sensorial, and affective regimes.

Teeth are extremely public objects whose sensorial qualities are readily available for interpretation. In Western Europe and the United States the completeness and hue of dentition have, since the eighteenth century, symbolized purity, health, cleanliness, beauty, and prestige (Heneghan 2007; Jones 2014; Paulson 2008). Indeed, in the U.S. the capacity of dental care to "Americanize" immigrants was a key argument in the development and proliferation of dental outreach in elementary schools in the early twentieth century (Picard 2009:35). Since the 1960s, the straightness, size, and whiteness of teeth have been associated with upward social mobility, a connection stoked by dentistry's success at promoting cosmetic techniques as both medically and socially necessary, particularly at moments when the industry was concerned about economic contraction (Fleming, et al. 2008; Hunt 1998; Picard 2009). 19

The aesthetics of dentition are historically and culturally situated, and are only rarely an artifact of impeccable self-care (Geissberger 2013; Kotchemidova 2005). Rather, in the contemporary era, the "perfect smile" commonly results from one's ability to pay for expensive procedures that can align, whiten, enlarge, reduce, or replace teeth that may have been damaged by decay or injury, stained by medications, coffee, or tobacco, or may be considered unfashionable (Celebi 2003; De Jongh, et al. 2008; Fleming, et al. 2008; Stahlnacke, et al. 2007). Thus, the services of aesthetic dentistry confer another benefit to people who can afford them above and beyond the actual treatment: the *appearance* of self-care and, thus, proper

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<sup>&</sup>lt;sup>19</sup> I discuss the history of the dental industry in Chapter 4.

<sup>&</sup>lt;sup>20</sup> Trends in aesthetic dentistry change over time, as well. For example, some of the longer-practicing dental hygienists in my fieldsite, who became my friends, guessed, correctly, my age, based on the straight planing of my teeth. Evenness and uniformity was more in fashion in the 1980s, when I had my orthodonture work, they said, whereas now dentists and patients opt for a more "natural" shape and focus, instead, on whitening.

personhood. Within the interpretive regime of dentition-as-character, good teeth can erase the imperfection of the hereditary and behavioral sources of dental disease and, instead, confer the moral standing of a person who treats her teeth well (Hunt 1998; Thomas 2009). For those for whom cosmetic dentistry is out of reach, so, too, may be proper dental subjectivity. Indeed, the notion of proper dental subjectivity shapes my project as well, as research participants frequently described to me, unsolicited, their excellent care of their teeth.<sup>21</sup>

The converse of proper dental subjectivity is a powerful example of the significance of morality, aesthetics, and affect in health governance. People whose teeth are stained, broken, or missing, or whose teeth bear visible signs of decay, are often believed to be dirty, socially errant, and representative of some specific moral failings: of "good" home hygiene, "good" food choices, and "good" employment that affords access to care (Horton and Barker 2009; Rousseau, et al. 2013; Willis, et al. 2008). Untreated dental disease is a potent symbol that reifies existing categories of marginalization and retrenches their semiotic connections with other harmful and accusatory constructs such as "laziness" or impropriety (Horton and Barker 2009; Hunt 1998; Linnemann and Wall 2013). People with "bad teeth" experience ridicule, abjection, and discrimination in workplaces, homes, and, even health care settings including safety net clinics. Indeed, during my fieldwork, it was not uncommon for clinicians and patients alike to use adjectives like "bombed out" or "rotten," or the phrases "meth(amphetamine) mouth" or "Mountain Dew mouth," terms which presuppose the etiology of decay and, thus, categorize patients before the clinical examination has even commenced. Such rhetoric links the teeth, and by extension their bearers, with notions of destruction, putridity, or vilified behaviors through

<sup>&</sup>lt;sup>21</sup> See Chapter 2.

what Deborah Lupton calls a "pedagogy of disgust" in which individuals are compelled, morally, emotionally and sensorially, to enact the behaviors advanced by health education (2015).

Within the context of the symbolic weight of poor dentition and inadequate access to dental care, the Appalachian setting of my research is particularly fraught.<sup>22</sup> Since its construction in the late 1800s as, simultaneously, a region and a "culture" (Whisnant 2009; Williams 2002), Appalachia(ns) has/have been framed as peripheral and protean, problematic, and nostalgia-laden, an "other" America (Hufford 2002; Mittlefehldt 2013; Satterwhite 2011). Haunting my work since its inception has been my discomfort with the way that Appalachia epitomizes dental disparities in the social imaginary and serves to perpetuate its reputation as a group of people whose physical decline is linked to a moral one. Crucial to understanding this point is attention to the conflation of race and class in the United States, and how Appalachia problematizes it.

Middle-class and elite status the U.S. has long been linked with "whiteness" (Harris 2011; Ladd 2008; Lipsitz 1995). This relationship has been governed, in part, through the shaping of intimate concerns, or "what (can) and (can) not be seen, on visible markers of distinction as well as nonvisible ones, on evaluation of implicit cultural competencies as much as a mastery of publicly recognized norms" (Stoler 2006:5) through practices of bodily care, aesthetic refinement, and even the emotional understanding of one self. As suggested above, the care, beautification, and *portrayal of* the health of the mouth has served to advance class concerns. Given the close connections of class and race, dentition itself has been raced. For example, in the Antebellum south, teeth were objectified, alongside walls, porcelain dishware, and skin, through cleaning rituals meant to extend the aesthetic and moral "purity" of whiteness

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<sup>&</sup>lt;sup>22</sup> My own positionality relative to Appalachia is also fraught. I address it briefly in the last section of this Chapter and in more detail in Chapter 2.

across the domestic sphere (Heneghan 2007). Conversely ,throughout the twentieth century, the teeth of racial minorities have been represented in literature, advertising, and other popular media as being of exaggerated size, hue, distribution, and hygiene – either excessively polished or rampantly decayed – in both the U.S. and elsewhere (Barker 2010; Ciarlo 2011; Most 2000; Wonham 2004; Wu 2003). Within slavery economies of the colonial era, dentition was considered a marker of overall health, and thus a predictor of the strength, vitality, longevity, and overall "quality" of trafficked humans; it contributed to price-setting (Jewell 2012). In addition, as elites' natural dentition was increasingly compromised by the routinization of commodity sugar, slaves' teeth were considered a resource for the fabrication of dentures or early protosurgical implants, whether lost naturally or extracted surgically (Chadwick 2007).

Throughout both history and contemporary iterations, the whiteness that predominates in the construction of central Appalachia, as well as its demographics, is marked by qualifiers of class and their negative connotations: "poor white" (Wilson 1995), "not quite white," (Wray 2006), or "white trash" (Hartigan 2005). Appalachia's "difference" has long been evinced by the documentation of "curious" and problematic practices of bodies individual as well as collective: health and hygiene, sexuality and reproduction, home-keeping and consumption, faith and religion, and work, labor, and the acceptance of social entitlements (Latimer 2006; Massey 2007; Scott 2010). For example, underlying contemporary moral panics about "meth(amphetamine) mouth" and "Mountain Dew Mouth" are the risks they pose to the social status of whiteness (Linnemann and Wall 2013; Murakawa 2011; Raskin 2009). This anxiety is particularly evident in the context of rural, majority-white regions such as Appalachia where the over-consumption of such vilified substances supposedly clusters (Barclay 2013a; Barclay 2013b; Zhang, et al. 2008). Concurrently, notions of how to resolve Appalachia's "problems" reinscribe race and

class hierarchies through the advancement of "benevolent reforms" (Stoler 2006: 5) that date to colonialism; indeed, an "internal colony" framework has inflected scholarly analyses of Appalachia for nearly fifty years (Williams 1979; Williams 2002). I undertake this project cognizant of, sensitive to, and in agreement with many existing critiques of work(ing) on race in an Appalachian context, specifically whiteness.

The insight that "whiteness gains power through its status as an unmarked norm" (Roth-Gordon 2012, drawing on Bucholtz 2011, Frankenberg 1993, Frankenber 1997, Roediger 1998, among others)) begs ethnographic and analytical attention to the diversity within demographic category, a project that is sometimes uncomfortable. For example Emily Satterwhite expresses concern that, in part through her own work, "the places I care about are sometimes appropriated for personal and political projects with which I cannot sympathize" (2011:5) such as a legitimation of self-identified white individuals' feelings of racial superiority or entitlement. Mary Anglin (2004) and Barbara Ellen Smith (2004b) argue, in the same special issue of Journal of Appalachian Studies focused on Whiteness and Racialization in Appalachia, that the trend in whiteness studies of emphasizing "marginal" whites, particularly impoverished white people, risks superceding, erasing, or delegitimizing the structural and literal violence enacted against them. Almost a decade later Jill M. Fraley argues that the systematic exclusion of Appalachians from land and other claims could foment a rights-based legal approach to Appalachians as a protected class that would not necessarily undermine oppressed minorities' legal claims (2013). My perspective follows most closely that of Karissa McCoy who argues, drawing on Toni Morrison's 1992 work Playing in the Dark: Whiteness and the Literary Imagination, that "examining the terms and contingencies upon which definitions of race are founded yields more complex ways of reading the operations of race in...American social structures" (2004:6-7)

(2004:6-7) and Rebecca Aanerud, who argues that viewing whiteness as "a product whose meaning and status must be sustained by a process of reproduction along pre-established lines is crucial to an interruption of whiteness as the status quo" (1997: 43). While a social history of the Appalachian mouth is beyond the scope of this dissertation, my work considers how "good" dentition is naturalized to hegemonic whiteness in the U.S. – inevitably, class-based – by examining the conflation of their opposites, or how poor dentition and dental disparities more broadly are naturalized to low-income, rural white people (see Khaleed and Quinonez 2015).

The sensory, aesthetic, and moral regimes of health governance shape the lives of lowincome people who need to obtain dental care. They also shape providers. In this dissertation, I am particularly interested in these effects on providers who work or volunteer in safety net, charity, or other relief settings. As Didier Fassin argues, the politics of humanitarianism is a contemporary politics through which the provider's sense of compassion – an experience at the intersection of morality and feeling -- is paramount (Fassin 2011). Following his genealogy of humanitarianism as a concept that encompasses, beyond the traditional international relief framework, all sites of depravation in which care is administered, I extend his observations to the dental safety net in the United States. Yet this emotional-moral politics is the site of much contradiction as well, for example as providers' moral obligations are sated through merely the actions of providing care in the clinical encounter, their attention diverted from action to reform of the structural conditions which underlie inequality. This dynamic is evinced in professional formation as well, particularly as the dental safety net becomes a site of training. In one of the few critical investigations of dental professionalization, Rivkin-Fish demonstrates how "community-engaged" dental education shapes the moral stances of dental students. Volunteering at a community health fair seems to lead students to evaluate patients in terms of

their social mores, for example the proper demonstration of gratitude, rather than to sympathize with the structural inequalities through which American dental care is produced (Rivkin-Fish 2011).

As these and other scholars show, the patient and provider identities produced through the sociopolitical, moral, and sensorial governance of the contemporary health safety net exemplify the contradictions of market-based care as they contribute to the development of tiered or exclusionary deliveries of care. One of the major paradoxes of neoliberal health governance is how it rhetorically demands that patients act and even feel like consumers despite the reality that, for many, their healthcare "choices" are highly constrained. Thus, there is a fraught relationship between, on the one hand, a health social imaginary that imagines an ever-expanding set of possibilities through which patients can enact their socio-politically-constructed responsibility and, on the other hand, the real conditions of constraint that limit opportunities. In the case of patients in the dental safety net, this tension between their responsibilization for their oral health and their restriction from achieving it, is a particularly potent example of how the moral, sensory, and affective regimes of neoliberal health governance shapes their subjectivity. Put plainly, patients who bear the physical pain and stigma of advanced dental caries are made to want to have them resolved and are then excluded from doing so, in a recursive pattern that reminds them of their errancy from proper personhood, and the insult they present to the rest of humanity. For providers, these tensions are felt in how organized dentistry abrogates its social obligation by attempting to shut out structural reform and, instead, obligates clinicians to individualizing models of charity.

## Morality and contradiction in two sites of care

In Chapter 2, I describe in detail the broader setting of my fieldwork, as well as the study population, methods of data collection, and my experience of conducting this research. Here, I describe two clinical settings that comprised primary sites of ongoing data collection for this project. I pay close attention to how they are each constituted, as sites of moral governance, through contradiction. The RAM, introduced in the opening of this chapter, served as a primary site of data collection, as well as frequent topic of conversation during fieldwork. Another site served this function as well: a public health pilot project that provided preventive dental care to within the elementary schools they attended.

Introduced earlier in this chapter, the Remote Area Medical "health expedition" (in RAM terminology) is an annual three-day health care event that occurs each July on the Wise County Fairgrounds. Every year, over 2000 patients receive approximately \$2Mil in free dental, medical, and eye care (The Health Wagon 2014) in a temporary "tent city": rows of private temporary patient rooms powered (and cooled, in the July heat) by generators; massive vehicles outfitted with mobile screening and diagnostic equipment, for example mammography and sigmoidoscopy; two hundred dental chairs set up side by side, shielded from the elements by ventilated tenting and tarping but otherwise fully public. Services include an array of screening, diagnostic, preventive, and treatment medical, as well as eyeglasses and select pharmacy services. On the dental side, extractions are the most ubiquitous procedures, averaging in the range of 5000 individual teeth extracted per RAM. The most popular procedure on the dental side is the provision of customized dentures, of which approximately 100 are distributed each year to a group of patients selected at random from a "denture lottery." Access to services is distributed as equitably as possible, with tickets given out on a "first come, first served" basis, beginning at 3am on the first day of the event; patients line up in the parking lot beginning up to

36 hours in advance, when the parking lot gates are opened. While similar events occur elsewhere in the region, namely Grundy, Virginia and Bristol, on the Virginia/ Tennessee border, as well as elsewhere throughout the country and the world, the RAM at Wise is one of the organization's oldest annual events in the U.S., largest, and most well-publicized through a vociferous media presence. It has also been a galvanizing force for political critique, as the event serves as a lens through which the persistence of unequal access to health care in the United States can capture public attention.

Remote Area Medical was founded in the mid-1980s by British expatriate Stan Brock. Brock lived with the Wapishana in Guyana, where his father had been a British civil servant, throughout his adolescence and early adulthood in the mid-twentieth century (Brock 1999). He later starred in a number of adventure films and television programs, most notably Mutual of Omaha's Wild Kingdom. Having suffered an advanced injury while working at a large cattle ranch that was a twenty-six day walk from the closest medical facility, Brock later founded RAM to bring biomedicine, as well as dental and veterinary care, to similarly inaccessible settings worldwide (Remote Area Medical 2015).<sup>23</sup> The RAM at Wise was first initiated in 2000 by Sister Bernadette Kenny, a certified nurse practitioner with the Order of Medical Missionaries of Mary. She had been running a mobile medical unit, The Health Wagon, in the region since 1978, and,

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<sup>&</sup>lt;sup>23</sup> The "remoteness" of RAM's locations, and the exoticism implied, has long figured in RAM's narrative, both self-directed and that produced through journalistic and other accounts (see, for example Angell 2014). Brock reports that his decision to host the first domestic RAM, in eastern Tennessee, was a response to a local community's request. Ninety percent of RAM expeditions are now domestic. While Brock's earliest celebrity had to do with his displays of daring in film and on television, his contemporary enigmatism has not only to do with the charitability and politicization exemplified by RAM – he uses the RAM platform to advocate, among other things, a single payer system in U.S. healthcare and cross-state recognition of clinical licensing for medical humanitarianism – but also his asceticism. For example, he lived from the early 1980s until 2012 in an abandoned schoolhouse in Knoxville Tennessee that doubled as RAM headquarters, where he slept on a woven mat, took bucket showers outdoors, and refused to have the HVAC system repaired (Angell 2014). Brock wears, every day, a personalized uniform that derives from British military khaki drills, and features personally-designed RAM insignia patches. He flies himself and a few other key staff – who also wear the khaki uniform – to every RAM in a C-47 cargo aircraft that flew support for the D-Day invasion of 1944.

after volunteering at an event in Tennessee, invited RAM to host an event in far southwest Virginia. "Sister Bernie's" inauguration of RAM planning coincided with the early development of the Mission of Mercy project of the Virginia Dental Association Foundation, a similar outreach model developed by the Executive Director of the Virginia Dental Association (VDA) to galvanize efforts among private practice dentists to increase their provisions to dentally underserved patients.<sup>24</sup> The two efforts were quickly combined in order to provide dental as well as medical care.

In the intervening decade between the first RAM/MOM co-event in 2000 and my fieldwork there in 2008, 2010, and 2011, and in the subsequent years since, the organization of the event has changed a number of times in response to both internal and extrinsic factors. The event's first four years, in particular, were a period of growth and refinement, particularly around administration and governance. The national organization requires local partnership to execute its events, but the enormity of the Wise event quickly demanded an infrastructure beyond the immediate capacity of The Health Wagon, or even the region's hospitals and health care systems. Partnerships were expanded to meet the enormous patient demand and infrastructure needs, bringing in, for example, a number of non-local entities: the University of Virginia Health System, Virginia Lion's Club, Virginia chapter of the National Guard, Virginia Department of Health, and Appalachian College of Pharmacy to direct, respectively, medical care; vision services and on-site volunteer logistical support; security; research requests, data collection, prevention education, and social services coordination; and on-site medication services. The Health Wagon, now under the leadership of two local doctoral-level nurse practitioner mentored by Sister Bernie, coordinates all donations and sponsorship, media relations, and relationships

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<sup>&</sup>lt;sup>24</sup> See Footnote 2, page 1, for a discussion of why I refer to the event, in this manuscript, as the RAM.

with RAM headquarters and local practitioners who provide follow-on care. Governance is conducted by a board comprised of representatives of most of these organizations, as well as strategic partners throughout the state.

While these changes have been necessary, in order to respond to patient demand, they also reflect tensions in the event, now into its second decade, and how negotiations must be made in healthcare even when its economics are moderated the provision of free care. The popularity of and state, national, and international attention paid to the RAM at Wise, among both patients and volunteers, has been one of its greatest areas of flux. Volunteerism among local private practice dentists has declined significantly, as many early supporters have observed what they reported to me as a problematic pattern at the event: the shift of leadership and governance from local control to Virginia's power centers in its central and northern cities namely its capitol, Richmond. Many local clinicians also take umbrage at the national organization's refusal to screen patients inclusion along the lines of specific criteria – that is to determine "need," vis a vis income requirements and/or "belonging," for example documentation of national citizenship. Too often former volunteers found themselves, they told me, treating former patients for free they believed to be "too cheap" to pay copayments or "too biased" toward the care provided by clinicians visiting from urban centers. Many resented how RAM perpetuated the narrative that Appalachians needed to be "saved" by the beneficence of urban elites, a theme I also heard among some community health workers and medical clinicians I knew socially. Some of them scoffed at the discontinuity of care provided by the RAM – that some of the procedures performed "on the fly," such as fillings or dental restorations, did not hold up, in quality, leaving them little choice but to repair the failed apparatus, for free, shortly after the event. For many local dentists, who told me they already donated free care through their church's outreach

ministry or other means, the RAM was a sore spot. "Give me a break," one told me, rolling his eyes at the thought that his urban colleagues were more skilled and more charitable than he was, "I RAM it every day."<sup>25</sup>

Critiques of the popularity of the RAM, and how it may undermine what locals perceived as RAM's mission to serve their community, inflect many underserved patients' analyses of the event as well. Numerous patient participants who I met through other venues told me that they, or someone they knew, had waited in line at RAM for up to 48 hours, only to be turned away at the close of the event, their "spot taken" by someone who had insurance, or who wasn't a resident of the subregion, the state or Appalachian region, or the country. News coverage of the event only seemed to bolster this reputation, with its orientation toward the RAM's most dramatic aspects: the long lines of patients sleeping in their cars, or interviews with the "most unusual" patient cases including, in 2010, a man I had met who told me that he had traveled there from Haiti. Indeed, the reputation of the event as being overly-saturated with people in need of treatment seemed to have a negative effect during my third year collecting data there, in 2011.

While the numbers of patients and services reported post-facto were consistent with prior years,

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<sup>&</sup>lt;sup>25</sup> The networked governance and popularity of RAM-Wise also affected my research in unanticipated ways. As I discuss on page 6, footnote 6, the mechanisms by which I conducted data collection were highly circumscribed by the national organization. As I found out eight months into fieldwork, there was, technically, a research protocol approval board within the RAM-Wise's Medical Board to which the national organization should have referred me, as it was supposed to refer all research requests. Led by experienced clinician-researchers from University of Virginia and the Virginia Department of Health, my request to conduct data collection at RAM-Wise a second time during fieldwork was approved easily. This negotiation over authority to approve research is but one of many ongoing struggles between the national organization and local leadership. A handful of local/state leaders have remarked to me of their desire to loosen their relationship from the national RAM organization, due to such struggles, but that to do so at a moment with RAM is so internationally renowned would be politically and logistically injurious. Relatedly, the popularity of RAM – Wise has also led to the development of what I might call an enormous *narrative* infrastructure, in which journalists, filmmakers, politicians, comedians, and researchers including but not limited to myself, find themselves in something of competition for the attention of both volunteers and participants, so as to capture the breadth, depth, and variability of stories, particularly the "best" ones such as Jeff's.

<sup>&</sup>lt;sup>26</sup> The man's family had read about the RAM-Wise in a widely-circulated essay by former health insurance industry executive turned whistleblower Wendell Potter (see Potter 2009), and brought him there.

something just seemed to have...shifted...as I noticed the medical bays unoccupied, and the medical waiting area fully empty on Saturday afternoon. For sure, a new intake process had helped the flow of people become more orderly but I couldn't help but wonder if there was another explanation – that local residents, scared (or tired) of being turned away simply did not attend the event. Looking back to the dental tent served to correct my thesis: beyond the dental waiting area, where every chair was filled, patients stood nearby or sat in an area that had been turned into makeshift overflow seating. while the medical area remained sparsely populated.<sup>27</sup>

For as deliberately "free-for-all" as the RAM both envisioned and executed its approach to care, the other site where I collected data, a school-based dental public health pilot project, was an entirely different approach. "The pilot," as I call it hereaver, aimed to provide a limited number of preventive services to a specified population: elementary-age schoolchildren. Children's dental public health services in Virginia had traditionally depended upon staff dentists and dental hygienists providing preventive and basic treatment services to elementary school children from out of a Virginia Department of Health mobile unit. The sustainability of this arrangement, previously effective in terms of minimizing the risk of missed appointments by eliminating parents' burden of travel to the public health district dental clinic and, thus, maximizing patient encounters per hour, was waning. The aging mobile unit and equipment needed repairs or replacements that would not be possible under a state public health budget forecast to contract due to the national recession on the state's income was increasingly realized.

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<sup>&</sup>lt;sup>27</sup> One local public health administrator and clinician has long argued that the reason that medical services at RAM – Wise are comparatively underutilized by local residents is that the area has a particularly high rate of Medicaid coverage, as high as 2/3 of residents in one county (County Health Maps Nd.). While residents bear a disproportionate burden of disease, those diseases that are covered by Medicaid for medical management render RAM's medical services less desirable for patients who also need dental work. In other words, in the time-limited environment of the RAM, patients who have Medicaid or some degree of confidence that they can access the free services provided by the Health Wagon year round opt to wait in line to obtain those services – dentistry – that are far less dependably available to them, even if their medical need "feels" greater vis a vis pain or other indicators.

Medicaid dental reimbursement rates had stagnated, while the cost of fuel escalated. The expense of the staff dentist's salary relative to workdays in which much of his time was spent on the unreimburseable task of travel could no longer be justified. Staffing, itself, was also unsustainable, as a previously stable source of public health dentists – dentists who, at retirement age, sought to give up the responsibility of owning a private practice but wanted to maintain an income stream - dwindled, as private practice dentists were anticipated to keep working, to recoup projected to be income lost to recession-era patient declines.

Anticipating these threats to the continuity of dental public health services, a regional director in southwest Virginia researched other states' models of children's dental public health care. One, which had been implemented in approximately half of states<sup>28</sup> and evaluated as safe, cost-effective, and otherwise beneficial, caught her attention: teams of semi-autonomous public health dental hygienists and assistants providing a limited set of preventive services to "safety net" patients (often, in "institutional" settings such as public schools and nursing homes) under a reconfigured supervision structure, typically provided remotely by an offsite public health dentist. Part of a larger trend in health care to expand access to basic care by permitting multiple types of providers to practice "to the tops of their licenses" (IOM 2011)—in medicine, for example, the authorization of increasing levels of autonomy among nurse practitioners or

<sup>&</sup>lt;sup>28</sup> As of the time of writing this dissertation in 2015, thirty-seven (37) states have licensed "Direct Access" dental hygienists – meaning, the ability of some dental hygienists to provide a limited set of preventive services to patients without prior authorization of a dentist - though statutes vary by state. Commonly Direct Access dental hygienists must meet certain criteria such as advanced training obligations, and are subject to performing an extremely limited set of duties such as prophylactic cleanings. In only one state, Colorado, is Direct Access permitted in both public health/safety net and private practice settings; in every other state, Direct Access is limited to public health/safety net settings, though the specifics of this limitation – for example, public institutions versus private community health centers - varies by state. In all but eight (8) states, patients in all public health/safety net settings can be treated by a dental hygienist working under "general" supervision, or indirect supervision by a dentist who examines the patient either before or after duties performed by a dental hygienist. In Virginia, approval for Direct Access remains in the pilot phase, not yet permanently enshrined by practice law. See ADHA 2015b and ADHA 2015c.

physicians assistants, as well as the recognition of pluralistic medical pedagogies such as osteopathy and naturopathy – held additional appeal, as maximizing the work of the allied dental professions was also a focus area of a federal workforce grant to increase access to preventive services, namely dental sealants (described below), or in Dental Health Professional Shortage Areas (DHPSAs)<sup>29</sup> like southwest Virginia, which could offset some program costs.

The regional director proposed that Virginia implement in two regions in far southwest (and one other underserved region) a pilot project in which teams of public health dental hygienists and dental assistants would effectively continue, under the remote supervision of a public health dentist located in the Virginia Department of Health (VDH) central office, the preventive tasks that Virginia Department of Health dental staff had performed to that point: distributing educational materials and toothbrushes; performing prophylactic cleanings or "prophies;" applying fluoride varnish and dental sealants, or thin semi-permanent plastic sheathes that help keep the antecedents to decay (such as sugars) from sitting on their teeth; and making referrals, as appropriate, to local dentists. The remote clinical supervisor would provide quality assurance and field treatment and referral decision-making processes through routine telecommunication and periodic on-site spot-checks. Importantly, dental public health hygienists would only be able to screen children's teeth for general indicators of decay, using non-invasive procedures such a visual inspection and gentle probing of dental surfaces. Those children whose screenings indicated possible decay would be referred by the public health dental hygienists to local private practice dentists, who could then perform a full examination, <sup>30</sup> perform procedures

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<sup>&</sup>lt;sup>29</sup> See http://datawarehouse.hrsa.gov/topics/shortageAreas.aspx The workforce grant was available through the Health Resources and Service Administration, or HRSA.

<sup>&</sup>lt;sup>30</sup> Neither dental scopes of practice nor dental billing codes are standardized across states. Consequently, each state defines screening and examination (and a new category, assessment) differently, typically based on the level of invasiveness of technique and of sophistication of diagnostic imagery, such as radiograph or intra-oral digital imaging. Most states permit dental hygienists to perform screenings, which typically utilize behavioral assessments

such as drilling and filling cavities or encapsulating teeth and, theoretically, provide long-term dental "homes."

The proposal was attractive to public administrators because it addressed persistent threats to the sustainability of public health dentistry in the region, while also advancing VDH's revised stance on toward oral health, which emphasized prevention education and offloaded responsibility for treatment to patients and the private sector, a model, as described above, increasingly common for public health in a neoliberal milieu. The proposal also appealed to administrators for its leveraging of "cultural recognition" (Shaw 2005). It was anticipated that pilot staff dental hygienists and assistants would be locally "born and bred," and thus able to draw on their deep local knowledge and assumed relatability to meet evaluation goals both explicit and implied, from patient recruitment and successful referrals to dental homes, to family-level behavior change intensified through home visits to those children with the worst clinical measures. Achieving implementation of the pilot, however, required one more accomplishment: changing the regulation of practice, a feat which required buy-in from both policy makers and the dental industry.

The health care practice climate in Virginia is among the country's most conservative, oriented toward assuring a strict professional hierarchy and limiting the competition and other effects of pluralization.<sup>31</sup> For example, the practice of licensed nurse practitioners in Virginia is restricted under the regulatory and clinical supervision of medical doctors, in contrast to the thirty-nine (39) other states where the profession enjoys somewhere between the partial and full self-governance and independent practice (AANP 2015). For example, the independent practice

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and cursory clinical assessments, under indirect supervision, in which a dentist is not present in the room. In most states annual examinations, which use advance clinical techniques and diagnostic tools, must be completed by dentists.

<sup>&</sup>lt;sup>31</sup> As noted on page 2, Footnote 3, Virginia also has extremely conservative Medicaid statutes.

of physical therapists in Virginia was recently limited to those who have obtained doctoral-level degrees (2015). Efforts persist to limit the use of the word "physician" to those holding the degree "Medical Doctor," thus excluding doctoral-level practitioners of osteopathy, Chinese Medicine, naturopathy, nurse midwifery, and other medical disciplines (Virginia 2010). Dentistry in Virginia is enacted similarly. The practice of dental hygiene and dental assisting are, like dentistry, governed by the Virginia Board of Dentistry, on whose board there are only two seats for licensed dental hygienists, as compared with seven seats for licensed dentists (Professions 2015). Proposals to expand the functions of trained dental "midlevels" and reform conservative approaches to supervision have long been viewed with skepticism, and repeatedly shot down (Dentistry 2015 see meeting minutes). Thus, because the pilot depended upon practice reform, it also depended on approval for practice reform among representatives of the dental establishment, as well as the legislators and public administrators they influence. In order to accomplish this feat, the VDH convened a special group of stakeholders to negotiate the precise terms of the practice changes, ranging from the tasks approved for remote supervision to the training requirements and number of practice hours logged, to the duration of time after which time the changes would expire. The stakeholder group comprised representatives of the Virginia Department of Health, Virginia Board of Dentistry, and Virginia Dental Association; importantly, it did not include representatives from the hygienists or assistants' professional associations.

As this background demonstrates, the pilot was implemented through contradiction under which lay a strong orientation toward the governance of morality from its very inception. As examined in Ch.4, the pilot depended on the willingness of private practice dentists to take referrals of low-income children who needed treatment, in anticipation of the ongoing closure of

all public health dentistry clinical services. Yet most private practice dentists in the region were — like their skepticism regarding charity care organized outside of their immediate social networks — skeptical of treating publicly-insured patients and, moreover, of the dental pilot as a beacon of a larger loosening of restrictions over the practice of dental hygienists and other mid-levels. Thus, the assurance of one of the pilot's foremost goals — helping low-income families secure "dental homes" — was tenuous from the outset. The perpetuation of an individualizing model of care, in which patients were responsibilized for the prevention of decay, *even if they already had it*, was ensured and, as one of the few outcome measures over which staff had absolute control, venerated through statistics on number of patients educated or number of toothbrushes distributed.

My own entry into the pilot was, like these dynamics, an exemplar of the tension that surrounds the dental safety net in far southwest Virginia. I first heard of the pilot during a formative interview with one of the area's regional health directors, Dr. P., though I (mis)understood it to comprise one of the more liberal approaches to dental team reform that caused anxiety among dentists in the area (see Chapters 4 and 5 for a discussion of these models). We met in summer 2008 at the time when funding and statutes were being negotiated, and he was eager to involve anthropological methods to round out nascent evaluation efforts. By the time I arrived in July 2010, funding and practice law obligations had been met and the pilot was being implemented. Dr. P proposed to embed me in the project. As I would find out, while Dr. P. took a lot of ownership over the project, and the pilot intervention itself was run through his health district and an adjacent one, it was actually <u>administered</u> at the level of the state. Therefore, permissions for my involvement had to be run through the Virginia Department of Health, including an administrative supervisor and clinical dentistry supervisor stationed at

headquarters in Richmond, who would supervise the field teams of dental hygienists and assistants in southwest Virginia remotely, as well as coordinate with some other subcontracting agencies. I found myself disinvited from the project by these supervisors, neither of whom had heard of my research proposal nor expressed interest in having me provide a qualitative component to its evaluation efforts, and both of whom were troubled by Dr. P.'s ongoing incursions into the state's established bureaucracy. While the central public health office did not take to me very well because of Dr. P.'s assertiveness, local staff were equally reluctant to involve me too closely in their efforts as they seemed to feel – understandably – that I, a non-clinician and an inexplicable presence, was there to monitor their work efforts.

In my first few months of fieldwork, I spent much of my time carefully negotiating relationships among Dr. P.'s enthusiasm for my work, public health headquarters' staff's permission to include me (or, at times, exclusion), and other dynamics, such as gaining the trust of the local subcontractors tasked with implementing specific aspects of the project. I developed an entirely separate set of project materials in the public health language with which they were comfortable, obtained approval from the Virginia Department of Health's Institutional Review Board for my Disclosure Form, and eventually was allowed to participate in most aspects of the project. Concurrently, I also applied for (and received) my own research funding. I approached local project staff from a chastened perspective, acknowledging the ways in which my presence had aroused feelings of suspicion or defense and seeking, sincerely, to make amends. Through my conversations with these women, who went on to become some of my most helpful key informants and, moreover, trusted friends in the field. Eventually they offered me full access to their work on the project as well as thoughtful reflections on their experiences in private practice and other setting. Moreover, they often helped facilitate snowball sampling of private practice

dental staff, which proved key when my direct attempts failed. They introduced me to some private practice dental hygienists and assistants and, in turn, some of these potential participants introduced me to others.

### **Outline of Chapters**

In the chapters that follow, I examine the politics and meanings of oral health and the dental safety net in far southwest Virginia. I investigate how ideas about the mouth and the distribution and quality of care shape and are shaped by underserved patients and the providers who endeavor to serve them. For patients, these dynamics have primarily to do with clinical exclusion and social marginalization. Patients must navigate ever-shifting care opportunities, accept an extremely limited set of treatments, and bear the awareness that their poor dentition makes them vulnerable to interpretation – both outside the clinic and within it – as irresponsible, unclean, and immoral. For providers, these dynamics have to do with professional negotiations, as well as moral ones. Employees and volunteer clinicians must navigate situations in which the resource-constrained and improvisational character of the dental safety net generates tension among professional norms such as team hierarchies, personal ethics and emotions, and adherence to practice statutes.

In the remainder of this chapter, I outline the chapters which follow. I opened this chapter with the story of Jeff, whose case was unusual among those I collected both at the RAM and beyond it. Yet the fact of its anomolousness is crucial to my understanding of the dental safety net in far southwest Virginia, and how it is experienced by providers as well as patients.<sup>32</sup> More common are the stories of the patients who didn't smile – who trained themselves not to smile –

<sup>32</sup> For a discussion of the selection of the case studies presented here, see Chapter 2.

or who used their hands to shield their mouths. This distinction is important as I turn to the body of this manuscript because, as I will show, while Jeff is precisely the patient who the dental safety net is able to serve – who the safety net *envisions* itself as serving – his story renders visible the safety net's inadequacy to address the much more complicated needs and limited abilities of the people who seek care there. Far more common are the stories of people whose needs cannot be met by the dental safety net as it currently exists.

Chapter 2 describes my fieldsite and situates it within the dental safety net in far southwest Virginia. I present an overview of the groups and individuals comprising my study sample, and outline my data collection methods and analysis. In this chapter, I also reflect on my experience as an ethnographer who has both a strong emotional connection to the region and is also – as marked through my teeth, as well as other indices – not "of" it. How did I come to do this research? What was my positionality in the field and what has it been since fieldwork? What challenges and opportunities did I encounter in my work, and how have they informed my analysis?

In Chapter 3, I examine the experiences of residents of far southwest Virginia who suffer from untreated dental disease. Following from classical ethnographies of illness, this chapter seeks to describe research participants' everyday experiences dealing with unresolved dental disease and their attempts to seek care. I introduce three case studies in order to examine the relationship between existing or evident dental decay and patients' perpetual exclusions from the kind of dental care that would address a variety of oral and psychosocial needs: Tonya, whose advanced dental decay indexes feelings of worthlessness that tie to her history of drug addiction; Renata, whose identity as someone who takes care of herself is undermined when her attempts at treatment-seeking are limited by the variety and quality of treatments offered her; and Janie,

whose story demonstrates the complex, laborious, and often demoralizing processes by which parents attempt to obtain dental care for their children. Drawing on medical anthropology's theorization of the major themes of stigma and suffering, this chapter investigates three underserved patients' experiences not only as physical or psychosocial suffering broadly conceived, but the specific suffering of feeling stigmatized by the poor dentition that results from their failed attempts to access care. I build on arguments about the contradictions of neoliberal approaches to the health safety net in order to show how the suffering of untreated dental disease is compounded through it, in part by the ways that the dental safety net compels underserved patients to attempt to seek treatment of which it cannot actually guarantee delivery. In addition to contributing to an understanding of dental suffering, this chapter provides ethnographic evidence of how even reference to untreated dental disease places patients into vilified and vulnerable subject positions in which their morality is open to question. Thematically, these stories also move the chapter to a discussion about the individualization of responsibility for dental care in late modernity, and the paradoxes that exist therein, specifically, the societal expectation of patient persistence despite evidence indicating the unlikelihood of their success.

In Chapter 4, I examine the experiences of dental safety net providers in order to understand how they navigate the personal and professional quandaries that occur therein.

Provider engagement with the dental safety net in the region tends to take on two major forms – employment and volunteerism – that often overlaps. Dental hygienists and technician employed by the public health pilot tend to have previously worked in private practice and must engage private practice dentists to take referrals, for example. Private practice providers tend to allocate some portion of their practice to safety net service, whether by accepting Medicaid-enrolled clients, volunteering at the RAM, or donating some services for free through personal referral

networks. I describe the efforts of providers who exemplify each of these trajectories in order to understand how entanglements of public/charitable dental services and private practice carve deep professional, ethical, and emotional chasms that impact not only patient care, but also providers' identities. I show how the care that clinicians deliver in the dental safety net depends upon their ability to improvise in ways that often contradict professional norms, such as the distribution of tasks or management of time. In this chapter I focus on how expertise, in particular, has become a flashpoint through which dental safety net provider subjectivities are negotiated in ways that exemplify the paradoxical aspects of health professionalism in late modernity. Through this analysis I reveal how it is through contestations over professionalism that the stakes of the debate over access to dental care – what Steven Epstein calls the unique "cultural authority" (1995) of the health professions, in this case, to shape the narrative of dentistry and the resolution of oral health inequality in America – are revealed.

Chapter 5 aims to offer practical, productive, and actionable critiques of efforts to improve access to dental care in far southwest Virginia, and the US more broadly. Drawing on case examples from other states I review some major efforts to reform the dental safety net, including Medicaid reform focused on the expansion of dental benefits among adults; dental team reform, specifically the institutionalization of semi-autonomous mid-level providers called Dental Therapists; and dental practice reform, specifically the utilization of large group practices. I examine the influence that organized dentistry has long maintained over the dental safety net, by which it has simultaneously abrogated its institutional responsibility, attempted to eclipse structural reform, and obligated clinicians to an individualizing altruism. I also examine how other forces are increasingly influencing dental safety net reform, such as political pressure in favor of Medicaid expansion and dental professional expansion. Still, many of these proposed

reforms perpetuate models that exemplify contradictory aspects of the neoliberal governance of health, for example the strong emphasis on individual patient behavior as an effective mechanism for preventing disease or the proliferation of regulation concomitant to the expansion of professional roles. I argue that the inhibition of structural reform in the dental safety net fundamentally contradicts the (cl)aims of advocates, as well as the actual work enacted there as documented in Chapter 4.

In Chapter 6, my dissertation's conclusion, I review how the patient and provider identities produced through the sociopolitical, moral, and affective governance of the dental safety net exemplify the contradictions of market-based care. For patients, these contradictions have to do with both the outcomes of care and the processes through which they are imagined to occur. By continuing to exclude patients and by failing to address clinical or social needs adequately, the dental safety net becomes a site through which underserved patients' suffering can be, rather than reduced, compounded. Some of the most devastatingly contradictory aspects of the dental safety net's shaping of patient identities occur beyond the clinic, however, as patients are obligated to a neoliberal model of consumerism that projects the outcome of trying to obtain care as a *fait accompli*, rather than – as patients' own experience suggests – unpredictable or even unlikely. For clinicians, the contradictory aspects of dental safety net provider subjectivity have to do with the quandaries through which their personal and professional allegiances, ethics, and feelings are challenged, often directly. Private practice dentists continue to do charitable volunteer work that focuses on a lower standard of clinical care, and fail to support professional reform that would merely codify the actions like dental team renegotiations that they are already doing improvisationally, even as they admonish that solution as inadequate.

# **CHAPTER 2: SETTING AND METHODS**

#### Introduction

Every anthropologist has a reason for a population or region of interest, oftentimes one that is deeply personal. My work on the dental safety net in far southwest Virginia is no exception. My family moved to a small town in southern West Virginia in 1981, when I was seven years old, so that my father could work as the lead radiologist at a local community hospital. While we wanted – and tried – to integrate ourselves into the community as much as possible, our status as outsiders was indelible. My father's advanced education and profession differentiated us as elites in a town whose major industries, and identity, were oriented toward physical labor, primarily coal mining and industrial railroad. Our difference was furthermore evident in our frequent travel to my mother and his' families in the suburbs of New York City and Washington DC and our position as practicing Jews in a majority evangelical Christian area. Moreover, my father's profession and my mother's volunteerism in a free clinic she co-founded with a nurse-practitioner and paid employment managing my father's and other physicians' billing, put them in another position through which their privilege was highlighted. Not only did they provide medical care for neighbors, everyday contacts, and the extended families of my classmates, but through their work they also gained intimate knowledge about the increasingly dire economic circumstances that shaped and reshaped residents' engagement with medical care over time.

The 1980s were a turbulent time in central Appalachia. Many lifetime employees of coal and the railroads were laid off. Concurrently, my family's relationships in the community were

deepening and, with it, our understanding of the violence of the coal industry,<sup>33</sup> for example how the break-ups of the state's formerly strong unions left former miners without pension support or other resources to address the physical and psychosocial tolls of a lifetime of hard manual labor. While my parents never betrayed the confidence of specific patients, many of whom my sister and I would have known from our day-to-day interactions, they routinely portrayed their observations on the increasing challenges faced by many people we knew and cared for. My parents drew on their progressive political orientation, cultivated through student activism in the 1960s, to explain to my sister and me the effects of deindustrialization as a social justice problem, and to encourage us in their traditions of critique, action, and empathy.

Even after I moved away from Appalachia, first to pursue undergraduate education, then employment, then graduate school, I continued to carry it close in my heart. After my family moved away, and most of my friends who completed four-year undergraduate degrees as well as many who found employment elsewhere, my visits home began to wane. During my doctoral training, as my research interests turned toward questions about health disparities, access to health care, and representations of disease and illness, I found myself thinking more and more about the region of my youth, and what a dissertation research project there might look like.

### Engagement as a research foundation

As I contemplated research topics for my dissertation, I sought to find one that would allow me to, in the words of Mark Nichter's explication of engaged anthropology, "engage in

<sup>&</sup>lt;sup>33</sup> The coal industry has a history of physical violence and intimidation against miners, specifically those who invoked their right to unionize (Scott 2010, Williams 2002). Scholars have also argued that the coal industry advances symbolic, structural, and environmental violence against not only workers but also the communities whose resources they extract, and nearby communities, more broadly (Mittlefehldt 2013, Satterwhite 2011, Whisnant 2009).

real-world problem solving *and* maintain a critical perspective" (2008: xi FN3, emphasis mine). I strengthened my understanding of social theory so as to deepen my work in public health, and learned how to use ethnographic methods as a way to dissect larger social problems, and – hopefully – identify novel solutions. Although I had gained experience, through my prior public health work in other settings on HIV/AIDS, women's reproductive health, and intimate partner and youth violence, I wasn't sure that any of these topics would be salient, desirable, or plausible in the central Appalachian context. I decided, instead, to conduct formative research – a kind of research needs assessment – to explore possible dissertation topics. In summer 2008 I took a two week driving trip to determine, together, the location and topic of my research.

I started in Blacksburg, Virginia, headquarters of the Virginia Rural Health Association, then drove in a large circle that crossed the areas of four states that intersect right near the Cumberland Gap, or the southeastern third of central Appalachia: Virginia, Tennessee, Kentucky, and West Virginia. At each stop I met with people with whom I'd made appointments in advance – health department directors, safety net clinicians, economic development professionals, professors, preachers – to ask what health topics were most important for the region, but the least understood. At each informal stop, for example when getting gas or renting a motel room, I'd try to engage people I met in discussion of health research topics, as well. Responses fell into four general categories: prescription drug abuse; obesity, diabetes, and metabolic syndrome; prenatal care and delivery; and oral health and access to dental care.

People I spoke with advocated strongly for the last topic. Emergency room staff told me about people showing up for treatment of toothaches and abscesses. Policy makers told me about the twin "epidemics" of "meth mouth" and "Mountain Dew mouth." The director of a free clinic

invited me to observe dental operations at the RAM that, fortuitously, coincided with my visit.<sup>34</sup> Everyone with whom I spoke reported that no one else was studying social or behavioral aspects of oral health in the region, and that it urgently needed research. One key informant, the regional public health director who I introduce in Chapter 1 as Dr. P., made a particularly compelling proposal, as described in Chapter 1: that I embed in the pilot. Upon returning home from my formative research trip, I examined a number of literatures, including medical anthropology, the anthropology of Appalachia, the social and behavioral sciences of oral health, and an emerging literature on the use of dental mid-level professionals to expand the dental safety net and determined that ethnographic research might address lacunae in each.

### Critically examining the Appalachian mouth as an emergent research goal

My formative research trip and subsequent reading left me feeling eager to address a topic that was meaningful to residents of my fieldsite as well as to contribute to medical anthropology, and dental public health policy and practice. One additional experience compelled me to study oral health and dental care in the region. Throughout the rest of summer 2008 I discovered, to my surprise, the extent of national and international media attention to RAM, specifically to the dental care provided there.<sup>35</sup> Taking a human interest journalistic approach, the numerous portrayals of charity dental care in the region seemed well-meaning, aimed at bringing public attention to the problem of dental suffering. But they also tended to individualize patients'

<sup>&</sup>lt;sup>34</sup> My visit during formative fieldwork in 2008 also coincided with an explosion of media coverage on the RAM, set in action by an article, the prior year, by Mary Otto, the Washington Post reporter who became interested in dental disparities due to her coverage of Deamonte Driver's death (see Otto 2007). Otto has gone on to be one of the foremost observers of dental disparities, nationally.

<sup>&</sup>lt;sup>35</sup> The timing of my trip only allowed me to visit the site the day before the health fair began. During this visit, I encountered one reporter for a national news outlet. I had no idea how frequent, extensive, or routine was the coverage of the event. Media coverage of the RAM has continued throughout fieldwork, analysis, and write-up. Content has been, generally, consistent with that examined here.

experiences as an unfortunate outcome of happenstance rather than trace the structural causes of dental disease, namely low-income adults' persistent exclusion from dental care. In focusing on the individual aspects of patients' stories, they also sensationalized the experience of receiving care in the large public outdoor setting of the county fair – commonly describing the circumstance as "third world" health care in a "first world" setting<sup>36</sup> – rather than examining the societal circumstances through which such care was necessitated. News coverage also tended to



Figure 1: "Rural Medical Camp Tackles Health Care Gaps," Howard Berkes, NPR, July 27, 2009 perpetuate stereotypes that have, since the colonial era, posited Appalachians as problematic, complicit in their own suffering, and desperate for rescue by outsiders. Photographs showed

<sup>36</sup> Attention to clinical set-ups stationed in livestock stalls is a frequently used trope.

obese adults smoking cigarettes and drinking Mountain Dew from two-liter bottles while dirty-faced and saggy-diapered children played just beyond their view. Interviews featured patients who disregarded the negative impact of tobacco on their dentition, and praised volunteer clinicians for their compassion and generosity. Politicians and event organizers, too, emphasized the altruism of volunteers, eliding subjects such as how the employer-driven, market-based health care model that is ubiquitous in the United States created these needs in the first place, or how Virginia's Medicaid dental benefit for adults only offered extraction, rather than the routine preventive and basic care that might allow patients to save their teeth.<sup>37</sup>



Figure 2: File Image. Caption reads "WISE, VA - JULY 20: Women wait for various medical procedures outside a barn during the Remote Area Medical (RAM) clinic July 20, 2007 at the Wise County Fairground in Wise, Virginia."

<sup>37</sup> As discussed throughout this dissertation, RAM and its representatives took a politicized turn during fieldwork. Many of their public campaigns and quotations in media coverage call explicit attention to this injustice.

In covering the RAM this way, the media perpetuated the image of Appalachia calcified in the social imagination, one that pathologizes residents and divorces their experiences from broader social and structural contexts. Appalachians have long been vilified as people who fail to fulfill ideals that have been advanced as laudatory or normative, specifically self-restraint and propriety. In particular, Appalachians are routinely portrayed as degraded with regard to the intimate comportments by which the body is cared for and managed: hygiene and disease prevention, reproduction and kinship arrangements, and consumption in its many forms, from eating and drinking to consumerism (Harkins 2005; Satterwhite 2011; Stewart 1996; Wray 2006). Coded as aberrant, these behaviors are taken to evince errant subjectivities. For example, the region's comparatively high utilization of social entitlements is often framed as evincing the laziness of its residents, rather than the neoliberal governance through which the region has been exploited, its resources literally and metaphorically extracted, and an inadequate infrastructure – for example, the dental safety net that I characterize as decayed, missing, and filled – left in its wake (Latimer 2006; Whisnant 2009; Williams 2002).

Throughout popular narratives that posit Appalachian bodies as synecdoches of moral decay, the teeth have long figured prominently. Charles Dudley Warner, writing in 1889, commented that Appalachian girls "marry young, bear many children, work like galley-slaves and at the time when women should be at their best they fade, lose their teeth, become ugly, and look old" (1889:271). Poor dentition is iconic to villains in the film sub-genre known as "hillbilly horror" (Bell 1997)<sup>38</sup> and its parodic progeny, such as "incest teeth," a costume prosthetic modeled on the dentition of sexually violent and social-norm-violating locals in James Dickey's novel Deliverance, and the movie based upon it. In the popular Netflix series *Orange is the New* 

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<sup>&</sup>lt;sup>38</sup> I thank Emily Satterwhite for pointing me to this observation.

*Black*, antagonist Tiffany 'Pennsatucky' Doggett is coded as Appalachian not only through her dialect and flashback scenes that specify her geographic origin, but also through her teeth, whose

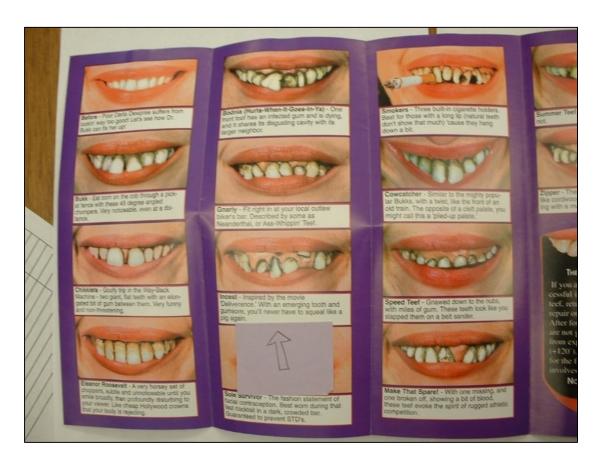


Figure 3: "Incest teeth," advertisement circa 1980s from the James Dickey archives, Atlanta GA..

ravages have been a focal point of both dialogue within the show and commentary on it.<sup>39</sup> While the trope of Appalachian dental immorality is prevalent in fiction, the notion that untended teeth are, in the words of cultural critic Carol J. Clover, a "little incivility" that are actually a "surface symptom (of)…larger uncivility" (1993:126) extends to other media as well. Oral health education campaigns, for example, construct a narrative in which the decay itself, as well as the

<sup>&</sup>lt;sup>39</sup> Much popular attention to Pennsatucky has centered on her teeth, from how they serve as a metaphor through which the program's class concerns are made evident to actress Taryn Manning's level of commitment to her role, that she would allow herself to be made so physically and morally unattractive. See Sered 2014, Weber 2013.

behaviors and values presumed to underlie it, are framed as uncivil and "disgusting" in the words of Deborah Lupton (2015).<sup>40</sup> So, have I observed since summer 2008, reading coverage of the RAM, did journalism as well.

Since I first observed it in 2008, and routinely ever since, media coverage of the RAM has become part of the semiotic chain through which Appalachians are interpellated into a degraded subject position based on their presumed failures to comply with idealized norms of bodily comportment, whether brushing one's teeth, drinking water instead of Mountain Dew, or maintaining a job with an employer who offers dental benefits. Framed through the verbiage of "internal" medical missionarism and humanitarianism meant to address the moral needs of America's "third world," as well as its clinical ones, charitable and public health interventions on dental disparities in central Appalachia often have the effect of recreating hierarchies at the intersection of race and class, in which local populations play supplicants to extra-regional agendas, at best benevolent but misguided and, at worse, re-entrenching of the harmful stereotypes through which the region's marginality was originally constructed. Though this "social fact" is not limited to Appalachia, to my mind, a particularly rich place to examine the

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<sup>&</sup>lt;sup>40</sup> In his analysis of the film "District 9," Mocke Jansen van Veuren refers to the loss of teeth as a "bodily disaster" (2012).

<sup>&</sup>lt;sup>41</sup> Some Appalachian scholars, like other scholars (c.f. Bridges) argue the value of the "strategic use of positivist essentialism in a scrupulously visible political interest" (Spivak 1985: 342-343, 345, cited in Anglin 2002) as it has to do with Appalachia, for example to cultivate political outrage over the structural violence enacted through Appalachia's export economy. My awareness of these competing stances has informed my research since its conception and, I imagine, will continue do so for the duration of my career. Indeed, like many anthropologists involved in humanitarian agendas (see Fassin) I aim to critique the stereotypes that underlie the figure of the Appalachian mouth even as I must traffic in its representation in order to draw attention, and contribute to the cultivation of efforts to increase access to dental care.

<sup>&</sup>lt;sup>42</sup> Some essayists' recent works evince this point particularly well. See, for example Hitchins, Thomas 2009, Smarsh 2014.

construction of this stereotype, and to examine critically the broader structural, community, and clinical forces that underlie it.

The role of Appalachian's poor dentition in the social imaginary intersects with another long-standing research interest of mine: the roles of race and class in the construction of Appalachia. As described in Chapter 1, teeth are a key site through which ideas about the not just body as its own topic, but the body as an indicator of morality are portrayed.

# **Research setting**

I conducted fifteen months of multisited ethnographic data collection in a large area of Virginia known as "far southwest." Encompassing approximately 3500 acres, the region is bounded to the east and south by a valley bisected by U.S.-460/19 and the Tennessee state border, respectively. It extends westward into a "tail" in the Cumberland Gap, where the state line follows a northeastwardly trajectory along the borders of Kentucky and West Virginia.

The landscape is a juxtaposition of a vast pristine environment and the extensive industrialization of natural resources, with communities ranging from fewer than 100 people to townships of 5000 people throughout. For thirteen consecutive months (July 2010-August 2011) I lived in Big Stone Gap, one of the region's larger towns [population: 5643 (2010 Census)] whose centrality in terms of major roads, if not "as the crow flies," served as an ideal base from which to travel throughout the region, or to meet participants who were traveling to this hub or nearby Wise or Norton<sup>43</sup> and were willing to meet me while there. I also conducted seven other

<sup>43</sup> Big Stone Gap is a 20 minute drive from another of the region's larger towns, Wise, with a third larger town, Norton, sitting in between. Together, the three-town micropolitan area has a total population of nearly 13,000 people, not including the seasonal variations of residential college students at UVA-Wise.

non-consecutive weeks of data collection throughout the region on subsequent visits.



Figure 4 Map of fieldsite, highlighted in grey. Credit: Randy Haas

I initially defined this fieldsite – admittedly, a large space for one person to cover in one year – based on its definition as a federally designated Dental Health Professionals Shortage Area, or a region that had fewer than 1 dentist per 5,000 residents (HRSA Nd.). I thought it might be valuable to recruit study participants from each of the seven counties in order to analyze data comparatively based on proximity to centers of dental private practice and dental safety net settings. Dental practices, whether private practice or safety net, tended to cluster around a few main towns: Wise, Norton, and Big Stone Gap in the center of the region, Tazewell

and Bluefield in the northeast, and Bristol in the southeast.<sup>44</sup> While I elected, ultimately, not to use geographic distinction in analyzing data, the enormity of the area from which I recruited participants did inform my thinking in another way: Traveling those roads routinely, sometimes up to four-and-a-half hours per day, and tracking mileage for the sake of my research grant, I gained firsthand experience of the necessity of resources – financial, time, and, of course, having a car – to fulfill needs across the region. In my case, those needs were data collection. In the case of my participants, those needs were health care, as well as work, shopping, and socializing, among others.

# Fieldsite and population overview

The intensifier "far" in the phrase "far southwest Virginia" reflects both geopolitical characteristics and semiotic ones. The Commonwealth of Virginia aggregates or splits locales and their inhabitants into planning districts for the purposes of governance, for example economic development, social services, and public health. The drawing of districts is also entangled with population criteria, and districts come to be known for their personalities or "cultures," especially in relation to larger narratives of the state. Far southwest Virginia<sup>45</sup> comprises two planning districts, Lenowisco and Cumberland Plateau, which together encompass seven counties and one independent city. The counties' classification by the federal and state government, and by local residents, as "central Appalachian" echoes through discussions in, about, and "for" the region, culminating in the routine claim that far southwest

<sup>44</sup>Moreover, residents of these regional border areas, as well as the area in the northwest part of the state, often had access to dental practices in nearby micropolitans, for example Pikeville, Kentucky or Kingsport, Tennessee. <sup>45</sup> I am unable to trace the origin of the phrase "far southwest Virginia." While more of a folk designation than institutional category, it is routinely used in institutional settings with regard to state functions such as planning and development. My great thanks to Lauren Penney calling my attention to the blending of the official and unofficial uses of this term.

Virginia is "culturally" more like its neighbors in adjacent counties in Kentucky, Tennessee, and West Virginia, than it is like the rest of Virginia. He Indeed, oftentimes when I described the location of my fieldsite to someone from northern or central Virginia, I would use geographical referents to denote just how "far" far southwest Virginia is. Past Wytheville, I would say, and then past Abingdon. Unusual was the Virginian, even in "near" southwest Virginia towns like the micropolitan Roanoke or the university town of Blacksburg, who had traveled "that far" off of I-81, the interstate highway that is sometimes used as a folk designation to delineate the difference between southwest Virginia and *far* southwest Virginia. Far southwest Virginia is "far" relative to the rest of the state. Is easternmost border, at Bluefield, is over four hours' drive from state capital Richmond, nearly double that of any other district in the state.

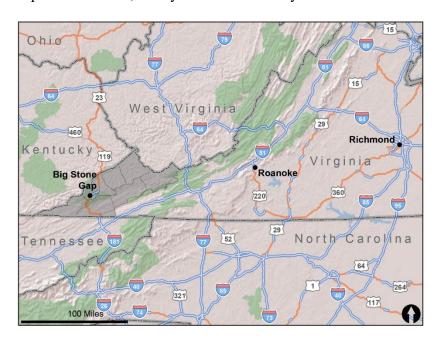


Figure 5: Map of fieldsite (in grey) relative to the larger regional center of Roanoke and state capital in Richmond. Map courtesy of Randy Haas.

46 This claim is, no doubt, intermingled with five of the seven counties' classification by a federal agency, Appalachian Regional Commission, as persistently economically distressed or "at-risk," a trait shared with adjacent counties in Kentucky, Tennessee, and West Virginia, but not shared with adjacent counties in Virginia.

The site is also characterized by internal "farness" within its bounds. A single journey across the region can see a traveler pass its full gambit of natural, built, and social environments, and slowly, given that four-lanes and other primary arteries transect its perimeters but the pathways within are formed mostly by secondary and tertiary roads. For example, it can take more than two and a half hours, without traffic, to traverse the approximately 100 miles between the furthest point west, on the Kentucky border, and the US-19 spur that provides access to I-81 on the east, or between Grundy, a coal town turned professional education center at the region's far north, and Bristol, an emerging component of a micropolitan area of Tennessee, at its southeast.

Such travel can be arduous and dangerous, especially when the roads are slicked with seasonal snow and ice, or are overrun with the large vehicles of the heavy industries that dominate the region – coal, timber, rock quarrying – and the large trucking industries in which many locals are employed. Primary state roads known locally as "four-lanes" bisect the fertile agricultural valleys that lie between gentle tree-blanketed slopes along the region's eastern and southern borders, linking working farms with manufacturing sites, services districts, and commercial centers. Along the western and northern boundaries, coal dominates the landscape with evidence of both slowed-but-ongoing production – cranes, dump trucks, signs warning visitors to the active use of explosives – and, more frequently, abandonment. Deserted tipples and coke ovens, boarded up seam entrances, and conveyors suspended, skeletally, mid-cycle are as plentiful as repurposed sites left by the controversial mining practices known as "strip" and "mountaintop removal," on which now sit thoroughfares, a few big box retailers, All Terrain Vehicle recreation sites, half-developed high dollar housing communities, and many, many blank visual spaces.

Between these boundaries, and throughout the region's interior, sit towns like Lebanon, Virginia City, and St. Paul that posit themselves as part of the new economy of technology, clean energy production and eco-tourism. Throughout the interior of the region run a network of secondary roads of variable quality, including many steeply graded switchbacks with the width and emergency exits capacity to allow coal trucks and eighteen wheelers to pass safely in low gear. The layout of the region shows how geographical positioning at the intersection of both natural landscape and built environment shapes access to services including but not limited to dental care. Dental practices center around the larger towns in the region, with considerable concentration in towns on the eastern and southern borders where residents also have more direct, and often more dependable, access to the other services centered in metro- and micropolitan areas. Conversely, in the interior of the region, especially in the coalfields at the tri-state intersection of Virginia, Kentucky, and West Virginia, access to services is much more limited.

While 100 sometimes very slow miles may be a minor inconvenience to an anthropologist whose work can bear such leisure, the incursion of such journeys or even smaller ones – twenty miles or more, for example, from a home far up a mountain or deep in a valley, to access grocery stores and other retail, employment, public works and services, education, and health care including dental care – into day-to-day lives is significant. Such travel is both excessively burdensome on the region's residents due to their low-income status and extremely necessary given their burden of disease. Of the region's almost 206,000 residents, approximately 22% live in poverty; thirty-eight percent of children in the region live at or *near* poverty (Weldon Cooper Center for Public Service 2015). Between one-fifth and one-fourth of residents aged 15-64 receive Social Security Disability Insurance, and 22% receive Supplemental Nutrition Assistance benefits (Bishop 2014, Weldon Cooper 2015). Residents bear a disproportionate

burden of disease including cardiovascular and pulmonary conditions, cancers, diabetes, preterm/low birth weight, and depression, "nerves," and addiction, many of which are conditions in which dental problems are co-implicated (ARC N.d.; Halverson et al. 2004; Healthy Appalachia 2008; Huttlinger et al. 2004; SHFA 2008.). Thirty-five percent of respondents to a household survey report loss of many/all adult teeth, a rate more than twice that of the state (Schaller-Ayers & Ayers 2007) and 7 times that of the U.S. as a whole (CDC N.d). Participants in this research reported that travel was a significant barrier to care, even when it was provided, for example by Medicaid transit. Contractors were frequently late or miscalculated the time needed to address barriers such as road construction or helping a person with mobility limitations into and out of the shuttle. Public transit in the region is limited to vans that only run by itinerary, across each county on a major road, and many low-income people lack access not only to personal vehicles, but also the money to put gas into them. Yet for low-income people suffering from dental or other health problems, travel to safety net care was urgent.

#### Far southwest Virginia's dental safety net

At the time that I conducted formative research, there were four sites spread relatively evenly across the region that offered ongoing dental safety net services: two community health centers and two public health dental clinics. One of the public health clinics had a mobile unit that it used at elementary schools to screen low-income children; those who needed treatment were referred back to the main office location. At all four safety net locations, children and adults could access a variety of services. Medicaid-enrolled children could obtain comprehensive dental services as part of their public benefit. For adults who were enrolled in Medicaid, emergency extractions was the only benefit covered. However, at two offices of the region's

multisited community health center, in Haysi and Ewing, low-income adults could obtain an array of preventive and basic services – for example, cleanings, fillings, and root canals – on a sliding scale fee, regardless of insurance status. There were two three-day RAMs in the region – one each July in the central town of Wise and one each October in the northernmost town, Grundy – as described in Chapter 1, where anyone could receive free dental care, as long as they arrived early enough to wait out the line and secure one of the spots, which tended to appear limited to around 1200 people, though recent post-event reports have documented capacity for 2000 individual patients.

In addition to these dedicated safety net settings were private practice dentists who accepted Medicaid or participated in donated services programs, either through the Virginia Dental Association Foundation (VDAF) or other avenues such as their faith communities.

Another private arrangement offered another dental care opportunity for young children: "Dental vans," as they were called, private companies from out of state who contracted with Head Start to provide services on-site as part of the program's mandate. Finally, I understood from conversations during formative research that three new opportunities were opening for dental safety net patients: another community health center just beyond the region but still within driving distance, which would be staffed with multiple clinician-trainees through a partnership with the Virginia Commonwealth University School of Dentistry in Richmond; a proprietary dental school that was trying to open in the region with an explicit focus on serving underserved rural populations; and the dental pilot project described to me, and offered as a research opportunity, by Dr. P. When I began fieldwork two years later, the reality of the dental safety net was very different from what I had understood during formative research.

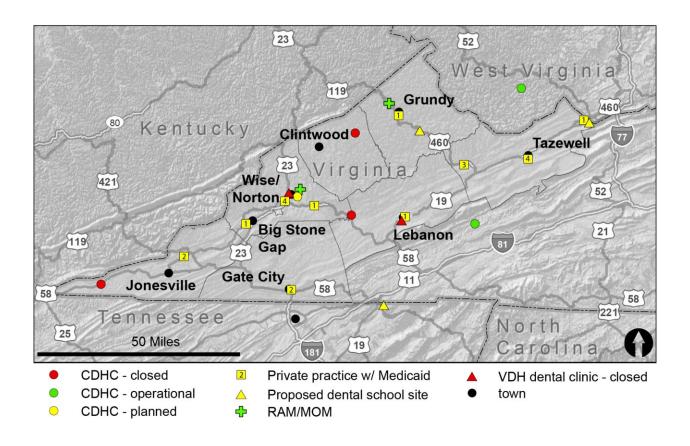


Figure 6: A map of the dental safety net in far southwest Virginia, circa formative fieldwork in 2008 and sustained fieldwork in 2010-11. Numbers in yellow boxes indicate private practices that accept Medicaid in each town. Map courtesy of Randy Haas.

When I arrived in the field in July 2010, I found that the landscape of the dental safety net had contracted substantially. The dentist at one public health clinic had been prohibited from providing services other than supervising dental hygienists and technicians' preventive care, due to his declining skill as a result of his advanced age and what was suspected to be undiagnosed Parkinson's disease.<sup>47</sup> One of the private practice dentists in the region with the largest Medicaid-insured patient rosters had been indicted on a federal fraud charge, and had had his license

<sup>&</sup>lt;sup>47</sup> Dr. P, who supervised this district, told me throughout fieldwork that he had had trouble finding a new dentist to hire. Shortly after fieldwork concluded, the Virginia Department of Health closed all remaining dental clinics, instead focusing their efforts on prevention outreach work.

revoked and his practice shuttered. Two other private practice dentists were under investigation for over-prescribing narcotic painkillers and, as such, had stopped accepting Medicaid-insured adult patients so as to deflect public attention. The community health center in the region had closed both locations of its dental services entirely, for reasons that were hard to verify; rumors circulated about financial mismanagement and about personality problems with the CEO that made staff retention challenging. A new community health center dental clinic just outside the region did materialize but its popularity precluded the extent to which its services could reach even a small portion of the patients who needed them. Staff told me that as soon as it opened, it quickly became such a popular destination that its wait list grew to six months for *emergency* procedures, and staff stopped taking new names.

The dental public health pilot into which Dr. P invited me was extremely slow to get off the ground, as described in Chapters 4 and 5, and had neither the patient reach nor extent of clinical services that I had understood from conversations during formative research. The implementation of the pilot had also necessitated the closure of the one remaining dental public health mobile unit; the expense of the dentist's salary for "low productivity" hours spent traveling to and from schools, coupled with needed repairs to the mobile unit's outdated equipment could not be justified in light of the more economically viable pilot. Finally, Dr. P. and his colleagues had "run off," in his words, the mobile dentistry programs which had been contracted by Head Start once their parasitism was revealed: They conducted expensive examinations of children for which they could be reliably reimbursed by public insurance, but then failed to perform or facilitate referrals for the care that children actually were found to

need.<sup>48</sup> Finally, while discussion of the potential for a dental school in the region continued throughout fieldwork, the effort failed to materialize a tangible outcome.

### **Study Population and Recruitment Methods**

I collected data from 131 unique participants who represented three "types" of dental safety net populations: patients, dental providers, and stakeholders. Patients (n=104) included adults who had successfully obtained safety net dental care for themselves or their children; patients who were *trying* to obtain dental care, and patients who had *tried* to obtain dental care but had not succeeded. Dental providers (n=14) included dentists, dental hygienists, and dental assistants working in or retired from private, public health, or safety net clinical settings in the region. Stakeholders (n=13) included local public health administrators, health safety net advocates, medical providers, and others who had an interest in or held influence over the dental safety net. For individuals who might have been more than one of these categories, primarily dental providers whose engagement with the dental safety net had also to do with policy or administration, I counted them in the sample that best represented their current role as it related to the dental safety net.

#### **Patients**

Patients (n=104) included a balance of men and women ages 18-74. Two patient participants identified as Black; consistent with the demographics of the region, the rest of participants identified as white. Almost all were all life-long residents of far southwest Virginia.

<sup>48</sup> This problem has been observed in a number of other states.

Patients' dental problems included advanced caries, abscesses and other infections, gingivitis and bleeding gums, broken teeth or tooth loss (edentulism), problematic dental prosthetics (cracked crowns or mal-fitting dentures), and pain, as well as staining, "rot," crooked teeth, and bad breath. For most patients who participated in this research, dental problems were but one among many health problems they were living with. The most frequently cited included diabetes mellitus; chronic pain other than dental pain; and depression, anxiety, and dependence on prescription narcotics.<sup>49</sup>

A number of other inter-related factors drew the patient sample together. Most patient participants were unemployed, under-employed, or employed doing contingent work such as managing convenience marts, serving fast food, and staffing call centers; service work, typically low-skill, in-home health care or the public school system; or unofficial work such as unlicensed trades (e.g. carpentry, plumbing) or bartering within their social networks. Two-thirds of patient participants derived at least part of their household income from Social Security Disability Insurance, often as a result of chronic pain due to injuries from accidents or from employment that required physically demanding manual labor. Disability retirement status and the low fixed income that accompanied it also conferred for participants Medicaid and Medicare insurance coverage; as previously discussed, Virginia Medicaid covers comprehensive benefits for children but offers only an emergency extraction benefit for adults. Among those few patient participants who had full-time jobs, only one participant's employer offered dental insurance as part of its benefits packages. Many patient participants lacked access to other resources instrumental to

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<sup>&</sup>lt;sup>49</sup> See discussion of syndemics in Chapter 3.

<sup>&</sup>lt;sup>50</sup> While SSDI precludes beneficiaries from working, officially, many recipients I met cultivated other resources, for example through unofficial jobs, due to the inadequacy of SSDI fixed income to provide for basic needs. The average monthly benefit of SSDI, nationally, is \$1017.30, or \$12,207.60 annually (Social Security Administration Monthly Statistical Snapshot, December 2014). By comparison, the federal poverty level for an individual adult is \$11,770 (http://aspe.hhs.gov/poverty/14poverty.cfm)

obtaining medical and dental care such as reliable transportation, credit, or a cellular phone with continual service.

I recruited patient participants using a variety of methods, including convenience sampling, snowball sampling, and targeted sampling. I posted recruitment flyers on community bulletin boards at gas stations, convenience stores, public health clinics, restaurants, libraries, schools, churches, a mobile free clinic, and anywhere else I was granted permission. I distributed flyers and described my research to patients waiting in lines at the RAM free health care event. Virginia Department of Health pilot project staff included my recruitment flyers in its own recruitment packets. Whenever I completed an instance of data collection, I encouraged participants to pass along my contact information to people who they knew who would want to participate in research.

# **Dental providers**

In total, 14 dental providers participated in this research: 8 dentists, 4 dental hygienists, and 2 dental assistants. Participant demographics reflect, broadly, long-term national trends, for example the gender distribution of the professions.<sup>51</sup> All dental providers identified as white and all made references to the role – specifically, the importance – of Appalachian "culture" to their personal and professional identities. All dentist participants were men, and most were in their late 50s or early 60s. All but one were "born and raised" in far southwest Virginia. While all dentists had lived outside of the area for up to a decade – typically during training and/or military service – all told me that they had moved back to the region deliberately, so they could raise their families at "home" and, for three of them, practice in partnership with their fathers, who had

<sup>&</sup>lt;sup>51</sup> Footnote re: gender.

been dentists before them. Partnership arrangements were not unusual among dentist participants though, more frequently, they were in solo practice.

All of dental hygienists and dental assistants who participated in research were women, and all but one were in their 30s or 40s. With the exception of one dental assistant, all of them had worked for more than one dental practice; most of the dental hygienists and assistants who worked in ongoing dental safety net settings had previously worked in private practice. All of the dental hygienists and assistants had lived in southwest Virginia for the entirety of their lives including for the duration of their professional training. In fact, dental hygienists and assistants cited the ability to be trained locally – dental assistants, through on-the-job training, and dental hygienists, through a two- or four- year program at a local community college or four year university in the region – as influential to their career choice.

I recruited private practice dental providers using a combination of targeted recruitment and snowball sampling. First, I called all private practice dentists listed in the regional phone directory (26 total). When given the opportunity, I left messages describing my research and inviting them to participate. Eight private practice dentists returned my call and, of them, 5 participated in the study; the remaining dentist participants worked in or retired from safety net settings. I also asked all private practice dentists for permission to recruit dental hygienists, dental assistants, and front-of-office staff directly from their office, but I was never granted permission to do so. This gatekeeping is but one example of the uneven power dynamics that characterize dental teamwork. While it is understandable that an employer would not want his employee utilizing work hours to contribute to any effort other than the tasks for which they are being paid, the dentists' refusal to allow me to propose my study to staff meant that they were also not made aware of the opportunity to participate in it outside of their compensated work

hours. Moreover, it gave the impression that staff members were not entitled to express their own opinions.

In retrospect, primarily through reflecting on interactions with clinicians who *did* enroll, I realize the limitations of my approach. Unbeknownst to me at the time of data collection, dentists in the region were already feeling guarded about their desire to interact with outside parties due to a combination of unanticipated events, for example the aforementioned investigations of three, and successful prosecution of one, of their colleagues. Inter-collegial tensions were beginning to arise as well, as local dentists, who claimed long histories of service to their local communities in need, observed non-local colleagues praised, by the media and patients alike, for their volunteer service in the RAM. Moreover, as the oral health movement was launching in the mid-2000s, and explicitly leveraging a health equity agenda, dentists were vilified as perpetrators of social inequality; whether or not this is a fair reflection, coupled with what a number of dentists' described to me as their profession's history of social stereotyping – specifically, as sadists who enjoyed causing pain - it is unsurprising that dentists did not want to respond to the outreach of a stranger like me. 52 Ultimately, the dentists who were most responsive were either dentists who lived in the region and had strong – typically, strongly negative – opinions about the dental public health pilot project or charity care, or dentists to whom I was introduced by mutual contacts, typically, elites in the region, as a "vetted" and trustworthy contact. As explicated by the dental hygienists and assistants who did participate in my research, recruiting their colleagues was uniquely challenging due to the fact that many of them were wage-earning working moms whose personal and professional responsibilities rarely left them with adequate time for outside

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<sup>&</sup>lt;sup>52</sup> During interviews, dentists frequently characterized their colleagues, and to some extent themselves, as paranoid, stoic, and depressed, citing such personality traits as common in the profession. Many participants cited the disproportionately high rate of suicide among dentists, as compared with other professions (see Sancho and Ruiz 2010).

pursuits, like participating in my research. For dental public health providers, I less "recruited" them than was recruited *to* them, as described in Chapter 1.

#### Stakeholders

Stakeholders (n=13) included professional organization staff, oral health advocates, faculty of dentistry or dental hygiene training programs, "thought leaders" from both local and statewide settings, case managers from local social services agencies, and other interested parties. This group was the most diverse in terms of gender, age, educational background, socioeconomic status, region of origin and residence, and other demographic traits. Their shared characteristic was a self-identified concern for and commitment to improving far southwest Virginians' oral health status and access to dental care. Because stakeholders had such specific roles and unique information to offer, I used targeted recruitment strategies to reach them. I called, e-mailed, and/or asked them to participate in person, as was appropriate. Rarely was I turned down outright, although there were some stakeholders from whom I was unable to collect data because our schedules never aligned. As I frequently learned during data collection with stakeholders, their enthusiasm for my research and willingness to participate was often due to their hope that, through my research, I would be able to offer practical solutions to help them resolve the region's problems with oral health and dental care. Specifically, many of them expressed the desire for my help in developing social marketing campaigns that focused on changing underserved patients' home behavior.

#### **Data collection and analysis**

I collected data using individual or small group semi-structured in-depth interviews, a short demographic survey, informal discussions, and structured and unstructured observations. <sup>53</sup> I recorded the audio of all interviews for which I was granted permission. I took some written notes during interviews, but found note-taking to be disruptive to rapport during interviews and, often-times, observations. As a result, I recorded most of my fieldnotes into my audio recorder while I drove the often long distances home from collecting data. In addition to this primary data, I collected data from a number of other sources throughout fieldwork, analysis, and write up. Sources include white papers, grey literature, popular media, websites and blogs, and a dental public health listserv in which I occasionally participate. The protocol for this research was approved by the University of Arizona Institutional Review Board; In addition, the protocol for research with parents of children enrolled in and by the Virginia Department of Health's dental pilot project was also approved by the Virginia Department of Health Institutional Review Board.

# In-depth interviews

I developed an initial thematic interview guide before entering the field based on (1) canonical medical anthropological methods of understanding health, disease, illness, and care, (2) my formative trips to the field, (3) my reading of the dental social science literature, and (4)

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<sup>&</sup>lt;sup>53</sup> At the request of a local social services agency, I also conducted three focus group discussions that I did not analyze for this dissertation because the conversations rarely stayed on oral health or dental care. When I originally conceived of this project, I also planned to use photography, to capture in imagery participants' experiences of the pain of untreated dental disease. Almost immediately, as soon as I realized that suffering extended to, and was often magnified by, participants' perspectives on how their poor dentition made them look, I decided to not include photography, out of concern that I might risk exploiting their suffering. The decision to utilize, in this dissertation and presentations based on it, others' photography, namely well-meaning journalists, has been similarly fraught for me, as I remain aware that it can, on the one hand, present a unique window into the experience of my study population and, on the other hand, perpetuate stereotypes, re-enact a "poverty tourism" motif, or otherwise run counter to the ethos of this study.

my experience in the region. I set up the interview guide to be flexible enough to be used with all study samples, with some minor adjustments to verbiage, for example on the topic of personal history in relation to the dental safety net:

- (Patient) What is your first memory of having dental problems?
- (Provider) How did you decide to become a (dentist/dental hygienist/dental assistant?
- (Stakeholder) How did you get involved with oral health and dental care in the region?

I piloted the interview guide in my third week of fieldwork, at the July 2010 Remote Area Medical (RAM) free health event. After completing data collection at RAM I made some changes to my interview guide in response to emerging topics, social dynamics, and other exigencies of the field and population.

Prior to beginning each interview I discussed in detail participants' rights using an Interview Disclosure Form. I answered any questions about the research and participation, and I gave each participant a copy of the Interview Disclosure Form to keep. I also asked each patient participant to complete as much as s/he wanted of a short survey questionnaire that I developed for four purposes: (1) to be able to describe the sample demographically; (2) to be able to adjust my recruitment techniques to recruit as diverse a sample as possible; (3) to be able to schedule follow up interviews and/or share a short summary of findings with participants who wanted to read them; and (4) to assign each participant a unique alpha-numeric code for the purposes of maintaining confidentiality in naming data files and being able to recall easily which patient subsample s/he fit into (e.g. RAM, dental pilot project, etc).

I conducted each interview at a location chosen by the participant, including: private homes, municipal parks, libraries, restaurants, the fairgrounds where RAM occurred (parking lot, grandstands, waiting lines), and parking lots, whether in my vehicle or sitting on the curb. I tried to encourage the participant to select a location in which I could try to keep our conversation from being heard by other people, but sometimes the participant selected a semi-public setting. In these instances, I selected the most private location available to conduct the interview, for example a table in an unoccupied corner of a library or restaurant. I also tried to keep the tone of our conversation quiet so as to not be able to be heard by other people. Because I believe that consent is an ongoing process that research participants should have the right to revisit – a philosophy common in anthropology – I sometimes revisited the topics covered in the Interview Disclosure Form during the interview, to ensure that participants knew they could choose to not answer a question, to end the interview, or to do whatever else they needed to feel cared for.

At times, interview participants invited other people (e.g. romantic partner, close friend, sibling) be interviewed at the same time. When this circumstance occurred, I offered each participant the option to do separate interviews; no participant chose this option. To conduct these small group interviews I followed the protocol for individual interviews but I performed disclosure using a form for Focus Group Discussions to make each participant aware that I could not guarantee the confidentiality or discretion of fellow participants. I describe these instances of data collection as small group semi-structured in-depth interviews, and count participants as individuals. A few individual interviews were as short as 15 minutes. A few small group interviews lasted upwards of 2.5 hours. Most one- and two-person interviews lasted around 1.25 hours. All interview participants except those recruited from the RAM free health fair<sup>54</sup> were

<sup>&</sup>lt;sup>54</sup> See discussion in Chapter 1.

offered \$20 gift cards to the regional grocery retailer, to thank them for their participation. All patient participants accepted the gift card. No stakeholders accepted the gift card. Two dental providers accepted the gift card.

#### Participant-observation

I did participant-observation in a variety of sites and settings. I spent multiple full days shadowing providers in the dental services area at RAM charity health fair and in the temporary clinics that dental pilot project staff set up in area elementary schools. At times I assisted with tasks like helping to set up or pack up equipment, running messages between clinical locations and administrative locations (e.g. offices), and recording notes as requested. I also attended a few in-service trainings, staff meetings, and virtual case reviews with pilot project staff.

Among stakeholders, I did participant-observation at professional meetings and outreach events, for example trainings that an oral health advocacy organization offered to social services agencies on establishing "dental homes" or professional meetings of the a rural health organization. Some of my richest opportunities to collect fieldnote data actually occurred once I became a "known entity" at these meetings. Other attendees began seeking out my participation in and opinion on various perspectives on increasing access to care and, in one instance, I was invited as a featured speaker to present initial observations from my research. These opportunities offered me both opportunities to collect primary data and to collect meta-level data, specifically participants' responses to my initial analyses.

Finally, I did participant-observation as a patient and everyday participant of life in the region. I made observations throughout my day-to-day routines, whether shopping at Wal-mart, traveling to the Tri-Cities for a minor outpatient surgery, or attending exercise classes at a local

recreation center or knitting night at a local bookstore. While not directly the experiences of trying (or failing) to find dental care, my experiences of life in the region exposed me to some everyday opportunities and exigencies therein.

#### Data analysis and the selection of case exemplars for this dissertation

Consistent with the methods of ethnographic research and, in particular, grounded theory (Bryant and Charmaz 2007), I analyzed data using an iterative process. Throughout my time in the field I listened to recordings of interviews and fieldnotes, and jotted memos to myself about emerging themes, topics to try to pursue in greater detail during subsequent data collection, and potential foci of analysis. After I departed the field, I listened to all recordings and rendered them into documents using a combination of summarizing, logging, and selective transcribing. I entered these data, as well as supplementary sources such as news articles, into Atlas.ti, a qualitative data analysis program; when I collected new data or supplementary sources following the sustained fieldwork period, I entered them into Atlas.ti as well. While I was turning the recorded data into documents, I also developed a list of major analytic themes and identified potential case studies that might usefully illustrate them. I then turned the themes list into an initial list of codes and coded approximately a third of the data, selected at random, in order to improve upon the coding schema. While doing initial coding, I notated ways to refine the codes list in two ways: to improve the specificity of each theme and to assure comprehensiveness of the overall list. I then edited the codes list to its final form and applied it systematically to the complete data set.

While coding the rendered data offered me the opportunity to iterate themes *exhaustively* and apply them *comprehensively*, in the milieu of qualitative research, the final analysis and,

indeed, this dissertation as a piece of writing derive more from a process of data familiarization and analysis that, for me, could was best achieved another way: by listening and re-listening to recordings of data. In particular, I listened repeatedly to recorded interviews and field notes that I thought might be usefully developed into case studies (of both individuals and situations) that would best illustrate the themes of this dissertation. I initially identified approximately twenty case studies based on the fulfillment of one of two criteria: (1) because they exemplified a theme often repeated in the data as in Janie's attempt to use her family's Medicaid benefits to obtain dental care for her children, presented in Chapter 3, or (2) because, while unusual or rarely repeated, as in the example of Delilah's intervention on the dental industry representative which closes Chapter 4 or my own participation in advocacy events which opens Chapter 5, they offered opportunity for crucial insight.

Throughout the entire process of data analysis, it was rare for me to listen to an interview or fieldnote less than twice. To data selected as potential case studies, I listened four or more times before deciding which case studies to include in this dissertation. Although I do not perform a linguistic analysis of data in this dissertation, I found that the nuance of the spoken word – particularly research participants' tone shifts, false starts, pauses, laughter, crying – helped to keep me grounded in the lived experience of bearing, witnessing, and attempting to resolve dental disparities, and improved the focus, content, and tone of my work. I repeatedly relistened to case study data and compared it with written renderings of other data while I iterated the outline of this dissertation, presented initial analyses at professional conferences and advocate meetings, and wrote this dissertation. In this way, the final analysis and development of case studies emerged in tandem with one another as well as with the initial writing of this dissertation, a technique that offered the opportunity for my analysis and writing to be

strengthened through the intensive engagement with the recorded word and the new layers of complexity revealed with each listen.

### Reflections on conducting research on/in the Appalachian dental safety net

This research project represents the extension of my long-term interests in Appalachia and health social (in)justice into a new, and admittedly unexpected, direction. I began graduate school with no interest in – really, no awareness of – dental disparities as an applied research topic or a theoretical problem. I initially viewed the opportunity to study the topic as merely a service to my region of interest, and likely a short-term endeavor. Conducting this research has inspired what I now experience as a passion, professional identity, and long-term research agenda. Throughout the process of conducting this research, I have aimed to stay true to my intellectual, political, and ethical priorities by focusing my critique on the sociopolitical dynamics through which underserved people are simultaneously excluded from dental care and vilified for having unresolved dental disease, as well as through which the dental safety net – and its advocates' good intentions – are shaped. While every study has its challenges and limitations I have come to realize, through this research processes, how closely many of mine mirror those of the dental safety net. This awareness offers opportunity for both methodological and metaanalytic reflection. Here, I consider one topic in particular: How patient self-selection shapes both the dental safety net's distribution of care and this study's results.<sup>55</sup>

The sample of patients in my study is relatively homogenous in terms of socioeconomic status, experiences of being excluded from dental care, and other traits that would be expected of

<sup>55</sup> Provider self-selection no doubt also shapes the dental safety net and the results of this study. This is a topic I hope to investigate in more detail in a subsequent study.

dental safety net patients in far southwest Virginia. <sup>56</sup> Yet, it is also homogenous in another way that, as I have come to realize, both mirrors the dental safety net but may also explicate its patients' homogeneity. Nearly all patient participants who I interviewed described, in great detail, their accordance with the messages of oral health education. Oftentimes they did so anticipatorily, before I even asked about them. Patients explicated their preferences for and use of American Dental Association-approved toothpastes and mouthwash, the elaborate methods with which they cleaned the areas surrounding emerging infection, and the enthusiasm with which they approached their children's and grandchildren's dental home hygiene. When patients spoke to me of the behaviors to which they attributed their dental disease – for example, drinking sugar-sweetened beverages, dipping snuff, or taking prescription drugs – they framed these in terms of regret. Only extremely rarely did I meet someone who acknowledged regularly forgetting to brush their teeth, disregarding the importance of home hygiene, or being skeptical of the causal relationship between some substances and tooth decay.

I am still trying to understand the ubiquity of these proactive assertions of dental self-care. Certainly, for people suffering from extreme pain, a predominance of descriptions of home treatment – to reduce existing pain and minimize the risk of recurrence – would be expectable. In that way, these narratives made sense to me. But more vexing is how these narratives centered on compliance with basic *preventive* behaviors. Here, I have found it productive to consider how patients' narratives of self-efficacy counter-pose those advanced by clinicians and the media.

As I have already discussed, media portrayals of the RAM held in 2008, during my formative fieldwork, advanced harmful tropes already familiar to critical observers of central Appalachia, in which the decayed mouth served as a synechdoche of the region's broader

<sup>&</sup>lt;sup>56</sup> The patient study sample is also predominantly white, which reflects the racial demographics in the region.

pitiable immorality. Little did I realize how much media attention to the event, and the topic of Appalachian oral health, would proliferate between that initial fieldwork and data collection in 2010 and 2011, and then continue to grow even as I write this dissertation in 2015. Coverage of the annual RAMs, held each July and Wise and each October at Grundy, has become institutionalized in national and international media outlets, and supplemented by coverage of other enactments of the dental safety net in the region.

# Life in the Sickest Town in America

I drove from one of the healthiest counties in the country to the least-healthy, both in the same state. Here's what I learned about work, well-being, and happiness.

By Olga Khazan

onald Rose has no teeth, but that's not his biggest problem. A camouflage hat droops over his ancient, wire-framed glasses. He's only 43, but he looks much older.

I met him one day in October as he sat on a tan metal folding chair in the hallway of Riverview School, one of the few schools—few buildings, really—in the coal-mining town of Grundy, Virginia. That day it was the site of a free clinic, the Remote Area Medical. Rose was there to get new glasses—he's on Medicare, which doesn't cover most vision services.









Figure 7: "Life in the Sickest Town in America," The Atlantic, February 2015

While the implementation of the Affordable Care Act has provided some context for a structural critique of the omission of dental care from the broader health care structures including the social safety net, many news stories still perpetuate the same negative images of Appalachians' oral health: either too ignorant to know how to take care of herself or so stubborn and brutish that she

enacts constant self-deceits – the sovereign right to swill sweet tea, to dip snuff – over and over again until, ironically, he looks to the state to pay for a full extraction and then provide dentures.

A similar impression of dental safety net patients was shared with me by many providers, whether during interviews or in my observations of, for example, providers interacting with each other in clinical and social settings. Clinicians told me how many of their safety net patient stubbornly refused to quit dipping tobacco because their grandfathers, lifetime tobacco users, died in his late '70s "with his teeth in his mouth," or refused to quit "the (Mountain) Dew" because they valued the "buzz" of its caffeine and sugar over its negative impact on their health. Even among the most empathetic dental clinicians I knew, there were always discussions of how "sorry" many patients were, a colloquialism that indexed pity and disgust, commonly in terms of inadequate self-care. Clinicians considered a patient especially "sorry" if the patient seemed to be lying about self-care, for example claiming to floss in direct contrast to the clinical evidence of calcified plaque, or was suspected of seeking care only as a means to obtain prescription narcotics.

The *implausibility* of many safety net patients' claims of self-care was a popular topic in my interviews with providers. Rarely did dental clinicians tell me about the patients who they believed were trying their best to take care of their teeth. Even more infrequently did providers posit that risk behaviors should be irrelevant to access to dental care; that all people, just by nature of their humanity, deserved care. In the context of donated services there was a strong frustration among providers who felt that much of the work they provided – services that patients did not pay for – were wasted on people who could not be trusted to take good care of their own mouth or health more broadly. Between media portrayals and providers' perspectives, I was left with the distinct impression that it is only the exceptional dental safety net patient like Jeff,

whose story introduces Chapter 1, who receives the benefit of belief in the veracity of their claims of attempting to achieve good oral health – who receives the benefit of legitimation. As I learned throughout data collection, and as will be elaborated in Chapter 3, patients, too, were aware of this dynamic. Considering this insight within a component of the larger body of theory that underlies this dissertation may help me understand why patients asserted their dental self-care anticipatorily and, moreover, how their self-selection into this study shaped its results.

This dissertation explores how patient and provider identities shape and are shaped through the dental safety net. As a number of scholars have observed the key to recognition, legitimation, and the justification of claims on services, in a healthcare marketplace in a neoliberal milieu, can be the demonstration of proper health subjectivity: self-discipline, selfadvocacy, persistence, gratitude justification in claims on services, and the like (Rivkin-Fish 2011; Willen 2012). Jeff's story, which opened Chapter 1, demonstrates the material benefits of this proper subjectivity, as providers mobilized resources to transport him home. But, as explored above and in more detail in Chapter 3, the benefits of proper dental subjectivity can be broader. That Jeff was posited to me as someone whose story I had to capture explicates the legitimizing benefit of belief even further, to an outside party, another elite. By contrast, the average safety net patient is often considered suspect – of inadequately evaluated or already vilified health subjectivity. I have come to think that patients' awareness of these roles, from their experiences with providers and from their observations of media portrayals of their care, motivated their decision to participate in this study, at least in part, and shaped their anticipatory explanations of self-care during interviews.

Considering patient participants' narration of their dental subjectivity through their own critiques of the portrayals of dentally underserved Appalachians, opens these scripts to a variety

of interpretations. For example, many patients stated or implied their eagerness to fight back against what they saw as their unjust and inaccurate portrayal by the media (as portrayed in this chapter) and clinicians (as documented in Renata's story in Chapter 3), particularly the blame placed on them for their dental problems.<sup>57</sup> Yet such explications often emerged well into the interview encounter. A more common topic to emerge early in interviews was patients' elaborate attempts at keeping their teeth clean, for example Tanya's description shared in Chapter 3.

Importantly, these descriptions were rarely provoked by my questions. Rather, participants frequently turned questions about other topics – the history of their dental problems, for example – into discussions of the comparative merits of floss versus toothpicks for retrieving different types of food debris, techniques used to incentivize children to brush, or preferred toothpaste brands, "ADA approved" a constant refrain. The preemptive quality of discussions of home hygiene suggest to me that patient participants felt an urgent need to have their self-care documented from the outset.

The frequency with which this sequence of events occurred, in which participants turned early questions about disease history into discussions of home hygiene and later critiqued dominant narrative of Appalachian dental disparities, begs a number of interrelated interpretations. While it is certainly understandable that participants would save their critiques of power centers until we had established trust, other dynamics may have been at play. Frequently, despite my explication of my project, participants through I was a journalist, clinician, or lay health worker who could help them find a "dental home." In this way, I think that their attempts to document, early in conversation, their excellent self-care were also attempts to evince for me their deservingness of services. By juxtaposing such self-assertions with their later critiques of

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<sup>&</sup>lt;sup>57</sup> Also, by advocates and policy stakeholders. See Chapter 5.

dominant narratives, I think another, perhaps more subtle, dynamic was going on: patient participants seemed to understand that the dominant discourses of Appalachian dental disparities worked to preclude their individual experiences of self-care and shape questions they thought I would ask. Through their sophisticated understanding of how Appalachian dental disparity discourses circulate, patients seemed to know the scripts they were expected to offer in order to explicate to a visiting researcher their unmet needs and, in the clinical encounter, self-advocate for care. They sought to demonstrate the deservingness of a hard-luck story in which they tried to maintain their oral health but were unable to, even as they knew that their portrayal would likely return responsibility for their dental suffering back onto their behavioral choices. They sought to preempt what they expected would be *my* interpellation of *them* into an existing and vilifying narrative.

Indeed, it seems that the desire to (try to) change this narrative animated many patients' decision to *participate* in this study and, thus, shape the results. But it wasn't just the decision to participate in this study that references patients' awareness of the circulation of identity narratives. Rather, I think that they have a strong sense of *how* to stake those claims, based on the sophistication of their awareness of how they have been portrayed by the media, by clinicians, and perhaps by researchers like myself. Specifically by asserting proper dental subjectivity as their *de facto* dental subjectivity, they are responding to the normalization of the aberrant dental subjectivity narrated by others, namely elites like journalists, clinicians, and, assumedly, anthropologists. By electing to participate in this study and then asserting their accordance with home hygiene behaviors, patients attempted to pre-empt the negative stereotypes perpetuated about them.

In many ways, the revelation of how patients in the region navigate, rhetorically, the roles pre-determined for them is among the greatest insights of my research methodologically as well as meta-analytically. It is an insight that might have occurred to me sooner, as the first hint of it came through in one my first instances of data collection. Misty, a 35-year-old single mother who sought to improve the visual characteristics of her dentition, as well as their pain, as she prepared to retrain to enter a new career as a medical technician, remarked to me, "I know what I look like." In this one declaration, she summarized over an hour of exposition on her sense that her dental problems made her look, rather than a woman who had suffered nearly two decades of structural violence – the termination of her Medicaid benefit when she turned 18, the repeated layoffs from contingent jobs that did not offer medical or dental benefits, and the scraping to get by that she had done as a single mother whose ex-husband did not fulfill his support obligations - instead, like someone undisciplined and disinterested in her own care, a drug addict, a glutton, an immoral person. Misty's next sentence further elaborated her self-consiousness, and drew awareness to the imbalance of power that was clear between us. She had paused after pondering the impression given by her dentition, while tears rolled down her face. On my recording of our conversation, I can hear only the sound of the air conditioning working hard to cool my car, where we held our interview, on that hot July afternoon. A good twenty seconds of silence passed. Regaining her composure, she turned the question back to me. "Where did you get your teeth," she asked. It was a question I would hear often throughout fieldwork, and a set of exchanges that has haunted me ever since.

There is a strong theme of ignorance – a derisive, condescending evaluation of both Appalachians' capacity for thought and desire for it – that runs through popular, scholarly, and policy discussions of, for, and about them. Misty's articulation of her experience, and many more

like it, demonstrates that participants' relationship with oral health is anything but ignorant. Even if, in interviews, participants exaggerated the consistency of their self-care, the decision to do so is nothing less than a sophisticated understanding of how they may have been prematurely interpellated by this researcher, an elite studying a controversial topic through which their marginalization has been reified, a sophisticated understanding made evident in their attempts to control the narrative by anticipating it. Jeff's story, which opened Chapter 1, demonstrates how the assertion of proper dental subjectivity has the potential to confer special benefits such as the securing of post-operatory care in an otherwise tenuous situation. While the dental safety net must, in theory, deliver care with equity in mind as RAM's rules seek to ensure, as Chapter 3 will demonstrate the reality is that it does not. Clinicians' assessments of patients guide their work, and when they feel that a patient is undeserving, is lying, or is otherwise "sorry," (as in a sorry state) clinicians can make gestures large or small that indicate how assessment of personal characteristic guides their care. Patients, aware of this overarching dynamic, may thus choose to (try to) enter into the safety net and risk being judged, mistrusted, or further excluded, or may keep themselves away from such evaluations and the way they shape care. Regrettably, I am concerned that this dynamic also shaped recruitment into my study and, thus, shaped the patient stories that were shared. It is also a concern that has guided some of my choices about which participants' narratives to portray and which to exclude.

While the dissertation I write represents patients' experiences with what I believe is both fairness and social justice in mind, I have wrestled with how to portray those aspects of participants' lives that are less "proper" (following Kingfisher), that contribute to the development of dental disease, and that risk perpetuating negative stereotypes about the region. For example, a number of participants portrayed to me their dependence upon legal and illicit

narcotics and tobacco, and their enjoyment of sugar-sweetened beverages. Following the example a prolific ethnographic literature that attend to the social structures through which health problems, behavioral "impropriety," and more generalized suffering are produced, I consider participants' reported "risk behaviors" – a public health term which implies full agency over decision-making – within the conditions of inequality from which they emerge, for example income disparities, exclusions from clinical services, and social stigma. While I don't shy away from the reported "facts" of participants' lives, for example the relationship among dental disease, addiction, depression, and obesity in the lives of research participants like Tanya, portrayed in Chapter 3, neither am I willing to divorce such suffering from the contexts through which it emerged.

On one hand, it is utterly insignificant to me and to the concerns of this dissertation whether someone skips brushing her teeth, drinks Mountain Dew, or utilizes prescription narcotics illicitly. My interest lies in critiquing the inequitability of access to dental care and the stratification of benefits – social, as well as clinical, for example the appearance of good dental subjectivity – conferred by the maldistribution of treatment. Put plainly, this dissertation is born from the political stance that all people deserve access to clinical dental care as part of a larger right to health care, and that it is though the stratification of treatment that the *appearance* of dental impropriety are also socially stratified. On the other hand, attention to the contexts that underlie risk behaviors, a project which necessarily requires acknowledgement of these behaviors, can offer specific insight into ways that dental treatment disparities can *animate* dental impropriety. As Tanya's narrative in Chapter 3 demonstrates, among the variety of self-treatment methods that dentally underserved patients utilize in lieu of access to care are behaviors that are illicit, vilified, or categorized by public health as "risky."

My research revealed a conclusion that may be unsurprising to other crucial medical social scientists but has yet to be fully uptaken in many clinical and health policy circles: That people take the best care of their bodies that they can given often extreme structural limitations such as inadequate income to meet all the needs of life, or exclusions from care. Not only do they do their best to prevent disease, they are particularly – and understandably – dedicated to addressing their pain, such as the pain of dental abscesses. With this background in mind, we can now turn to Chapter 3, in which we will come to understand patients' experiences in greater detail.

# CHAPTER 3: DENTAL DISEASE, STIGMATIZED SUFFERING: EVERYDAY EXPERIENCES OF UNDERSERVED PATIENTS

But there must have been a speck, a brown speck easily mistaken for food but which did not leave, which sat on the enamel for months, and grew, until it cut into the surface and then to the brown putty underneath. Then the weakened roots, having grown accustomed to the poison, responded one day to severe pressure, and the tooth fell free, leaving a ragged stump behind. But even before the little brown speck, there must have been the conditions, the setting that would allow it to exist in the first place.

- Toni Morrison, The Bluest Eye, p. 116

#### Introduction

It was near the end of our conversation when Tonya, a 43-year-old white woman who had invited me to her mobile home to tell me about her most recent dental problem, leaned forward from her loveseat and pointed across her living room. "I would rather just feel normal again," she said, "Normal like that baby over there." On a tan leather sofa, Tonya's toddler granddaughter wrestled with her teenage son, squealing with delight. "Normal and just be energized, you know," Tonya continued,

And look nice when I dress up. I mean, I'm a big woman so I feel insecure about myself. I used to not be big. I've always been (interested in) my appearance. When I go out in public I like dressing nice. If I go to church I like dressing in suits or if I go to meetings or something like that. But my teeth is so embarrassing to me, where I can't smile and I always have to hold my hand over my mouth, you know, 'cause I don't want people to see my teeth.<sup>58</sup>

Tonya's explication of hiding her teeth behind her hand was one that I had heard from a number of study participants. I observed this gesture among many people with whom I had

<sup>&</sup>lt;sup>58</sup> In transcribing interviews, I have made stylistic choices that attempt to preserve participants' speech patterns, while also doing some minor editing for clarity.

everyday contact – the check-out clerk at the local grocery store, fellow diners at the pharmacy lunch counter, the instructor of the water aerobics class I took at the municipal pool. While I had initiated this research to understand the impact of unresolved dental problems<sup>59</sup> on everyday actions like eating or working, participants often directed conversation to *social* aspects of their dental disease, such as the routinized gesture Tonya described, and the related emotional effects. "I like feeling good," Tonya continued, "And dressing up is feeling good to me. It's not being a snob, wanting to feel good. But my teeth is the only thing now that's gotten to me. The not smiling, you know, not smiling like I want to. I'm really discouraged about my teeth, really bad."

Scholars from a variety of disciplines observe that one of the ways that illness shapes identity or sense of self is by imbuing meaning in the social worlds that illness-bearers navigate as part of everyday life (Carr, Gibson and Robinson 2001; Yang, Kleinman, Link, et al. 2007). For example, diagnoses that are deemed pitiable, that have been effectively politicized, or that qualify a patient for certain claims can offer social legitimation, economic or legal entitlements, or access to other resources, though these "gains" are rarely unambiguous (Albrecht and Devlieger 1999; Hansen, Bourgois and Drucker 2014; Willen 2010). Conversely, illnesses that are maligned make their bearers – real, or suspected – vulnerable to a variety of social insults, from exclusion and discrimination to violence and other psychological and physical harms (Briggs and Mantini-Briggs 2004; Farmer 2006). Health problems that are vividly evinced through bodily markers or are hard to conceal can make a bearer feel especially vulnerable or burdened by the laborious effort required to minimize cues (Al-Omiri, Irbid, Karasneh, et al.

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<sup>&</sup>lt;sup>59</sup> By "unresolved" dental problems, I mean active decay, pain, infection, breakage, and other dental problems that have not been eradicated or stymied. While individual actions such as brushing one's teeth, using dental floss or toothpicks, or drinking water can help to impede dental disease, even nascent dental disease does not self-resolve and, instead, generally worsens over time. See Chapter 1 for a discussion of the ubiquity of dental disease, the inadequacy of individual patient behavior to treat or contain it, and the primary role of treatment disparities in the maldistribution of disease.

2014; Jacoby 2002; Rogge, Greenwald and Golden 2004).<sup>60</sup> For health issues whose overt effects can be effectively managed or resolved through treatment in a normative system of care,<sup>61</sup> the psychosocial burden of having *untreated* disease can feel doubled – that is, the encumbrance of having a health problem is compounded by the affliction of not being able to address it (Allen, Wright, Harding, et al. 2014; Sered and Fernandopulle 2005; Stuber and Kronebusch 2014).

Untreated dental disease is one such health problem. It carves itself upon one of the body's most exposed sites, marking the bearer with not only sensorial indicators – dark vines and black pits of cavities, teeth jaggedly planed at their points of breakage, sticky yellow plaque rimming gumlines, the scent of infection – but also with the evidence of its non-remediation (Locker 2000; Rousseau, Steele, May, et al. 2013). A health problem that progresses once established unless treated clinically, unresolved dental disease has come to symbolize twin marginalities in the United States: the *presence* of disease and the *absence* of care (Sanders 2012; USDHHS 2000).<sup>62</sup> These marginalities are frequently interpreted, in both public and clinical realms, through a lens that vilifies the disease-bearer rather than one that critiques the structural inequalities to which the (mal)distribution of dental disease and treatments must be attributed (Castañeda 2010; USGAO 2013; Raskin and Pratt 2014).<sup>63</sup>

Focusing on three case studies, in this chapter I describe research participants' experiences of living with dental pain and infection, of being unable to obtain adequate

<sup>&</sup>lt;sup>60</sup>The work required to maintain the appearance of normalcy by people whose illnesses are more amenable to camouflage can also feel unrelenting (Charmaz 2000; Corrigan, Larson, and Rüsch 2014; Joachim and Acorn 2000). <sup>61</sup>By "normative system of care," I mean the standard system by which health care is provided or *envisioned to be* provided in a given context. For example, the normative system of dental care in the United States is fee-forservice care, commonly financed through employer-based dental benefits. I address the composition of the US dental care system in more detail elsewhere in this dissertation.

<sup>&</sup>lt;sup>62</sup> As will be discussed in this chapter, exclusion from the mechanism through which market-based medicine is financed – private insurance distributed through the workplace – is its own source of stigma and shame.

<sup>&</sup>lt;sup>63</sup> For examples of how public and clinical discourse vilify underserved populations for their dental disease see Horton and Barker 2009; Linnemann and Wall 2013; Murakawa 2011, and Nettleton 1992.

treatment, and of navigating the psychosocial effects of both experiences. In addition to exploring Tonya's story in greater detail, I describe the experiences of Renata, a woman who turned to the dental safety net when she lost her private dental insurance as a result of her disability retirement, and Janie, an entrepreneur and single mother who attempts to utilize public entitlements for her young children's dental care. <sup>64</sup> These case studies lend empirical support to my larger argument that the dental safety net in far southwest Virginia both *reflects* and *produces* the suffering of those patients whose needs it (cl)aims to serve. By showing how dental-related stigma shapes underserved people's every encounter with clinical care – the clinical care that could, in fact, resolve both the physical pain of dental disease and the social suffering that it causes – I posit that stigma is not only a *consequence* of having unresolved dental disease, but also a *cause* of suffering.

### Stigma and social suffering: Theorizing the pain of untreated dental disease

The twinned marginalizations of unresolved dental disease illustrate powerfully the relationship between two of medical anthropology's core theoretical areas: social suffering and stigma. Initially described by Arthur Kleinman, Veena Das, and Margaret Lock in 1996, the concept of social suffering refers to the deleterious effects of "political, economic, and institutional power (on) people and, reciprocally, from how these forms of power themselves influence responses to social problems" (1997:ix). It has since been specified to address four related themes:

<sup>&</sup>lt;sup>64</sup> Since 2009, children whose households earn up to 200% of the federal poverty line, or \$47,700 for a family of four, have received mandated comprehensive dental insurance coverage through the Children's Health Insurance Program (CHIP) and Medicaid. Comprehensive dental benefits cover both preventive services such as examinations, cleanings, and the placement of dental sealants, and treatments, including extractions, surgeries, and some orthodontic treatments.

First, that socieoeconomic and sociopolitical forces can at times cause disease...Second, that social institutions, such as health-care bureaucracies, that are developed to respond to suffering can make suffering worse...(Third,) that the pain and suffering of a disorder is not limited to the individual sufferer but extends at times to the family and social network...Finally, the theory of social suffering collapses the historical distinction between what is a health problem and what is a social problem (Kleinman 2010:1518-1519).

While the first and fourth themes inform my broader thinking on oral health and dental care<sup>65</sup> it is on the second and third themes that this chapter focuses. As suggested by Tonya's narrative, some of the most powerful pain and suffering of unresolved dental disease derive from its intersubjective aspects, whether between a sufferer and her family, her broader social world, or her clinician, or "between" a sufferer and her socially-derived understanding of herself as aberrant, marked, or maligned (see Rousseau, Steele, May, et al. 2013).<sup>66</sup> Here, theories of social suffering combine powerfully with scholarship on stigma to help us understand this dynamic.

Building from Goffman's original theorization of stigma as a "spoiled identity" that needs be "managed" (1963), contemporary scholars of stigma now emphasize its social, moral, and political-economic dimensions (Kleinman and Hall-Clifford 2009; Link and Phelan 2001). Stigmatization is a process of structural discrimination enacted through local worlds in which "rejection, discrediting, and distancing" (Jenkins and Carpenter-Song 2008:363) are techniques of social, economic, and political power (Foucault 1990). Understanding the high stakes of stigma reveals that it is moral experience or, "that register of everyday life and practical engagement that defines what matters most" (Kleinman 2006 cited in Yang, Kleinman, Link, et al. 2007:1528) that is at risk in the intersubjective dynamics of stigmatization. Stigma, Yang and

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<sup>&</sup>lt;sup>65</sup> For example, in Chapters 1 and 2 I describe how structural vulnerability in the Appalachian context, such as contingent work opportunities that belie the national norm of employer-based dental insurance, underlies oral health disparities in far southwest Virginia.

<sup>&</sup>lt;sup>66</sup> My approach to understanding dental subjectivity in this chapter and my dissertation more broadly is also informed by the concept of medical citizenship. For example, the categorization of adult dental care in the United States as non-essential and the composition of care as fee-for-service bifurcates dental citizenship starkly along the lines of income and type of employment.

colleagues continue, can compound suffering, as can its management, an observation that we only need recall Tonya and others' vigilant shielding of their teeth from public view to understand (for example, see Hansen, Bourgois and Drucker 2014; Jenkins and Carpenter-Song 2008). In this way stigma can be understood a *cause* of suffering, as well as its effect. For the purposes of this chapter, then, my focus is on what I call stigmatized suffering, or, the social suffering mutually implicated with stigmatized disease – specifically, untreated dental disease.

For many participants in my research, stigmatized suffering derives from their feeling of abnormalcy as people who bear the vivid sensorial effects of unresolved dental disease or, in the parlance of both clinicians and patients I spoke with, a "bombed out" mouth. Tonya's case study will elaborate on this observation and allow for exploration of how an underserved dental subjectivity articulates with a lifetime of marginalization and pain, specifically in how she understands the origins of her dental disease. It provides an opportunity to investigate how the stigmatized suffering of untreated dental disease moves from one "place" – the mouth – to another – the psychosocial aspects of self – and then another – intersubjective relationships. Renata and Janie's case studies pick up on this theme and elaborate it to illustrate how stigma can compound suffering even when underserved patients obtain – or attempt to obtain – care. Their narratives also allow for an examination of the gulf between the clinically adequate resolution of dental disease – for example, the extraction of cavitated teeth, as is common in my fieldsite<sup>67</sup> – and its *subjective* resolution, by which functional, aesthetic, and emotional aspects of dentition are addressed, for example, as Tonya posits, the confidence to smile. As I will discuss, underserved patients' treatment exclusions hearkens their marginalization from class-based

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<sup>&</sup>lt;sup>67</sup> While extraction can resolve certain aspects of dental disease, such as abscesses and the risks they pose including sepsis, the risks of extraction are not negligible. They include erosion of the jaw bone and overall bone loss, systemic and cardiovascular disease and other physical complications, as well as the social implications enumerated in this chapter (Bui, Seldin, and Dodson 2003; Taylor, Tofler, Carey, et al. 2006).

norms, such as the maintenance of dental insurance through employer-based systems, as well as the devastation of the inability to pay for services.

# The (dental) pain of regret: Tonya's Story

Tonya had invited me over to tell me about her "stomach tooth," the most recent tooth to cause her pain. Two months into this episode and unable to get it resolved to her satisfaction, Tonya had seen my recruitment flyer at the community health center where she received primary care and support in managing her diabetes, depression, anemia, and chronic knee and lower back pain, as well as recovery from her former addiction to Oxycontin and heroin. Like so many other people who had called me to inquire about my research project, Tonya thought I might be able to offer her clinical care or refer her to someone who could. 69

Tonya's stomach tooth, one of the last seven partially-intact teeth in her mouth,<sup>70</sup> had been in decline for over a year. "The tooth was like a shell," she said, "And the nerve was sticking straight up. And food would hit that nerve and I mean it would numb the whole side of my nose." She continued: "It was severe." Familiar with the symptoms of advancing tooth decay

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<sup>&</sup>lt;sup>68</sup> "Stomach tooth" is a common term for the lower canine. Although the phrase typically refers to the primary lower canine whose appearance, generally between 17 and 23 months of age, is correlated with gastric symptoms, many adult participants in my research used the term to refer to their own teeth.

<sup>&</sup>lt;sup>69</sup> One of the most challenging aspects of this research, emotionally and ethically, was the limited extent of dental care in the region. As described elsewhere in this dissertation, the region is a Dental Health Professional Shortage Area in which there is a profoundly inadequate ratio of practicing dentists to residents, few of whom accept Medicaid or take payment plans. It was only after I got to the field that I realized the inadequacy of my ability to refer participants for care, as well. Two networked community health centers to which I planned to refer patients closed their dental services shortly before I arrived. Two other community health centers to which I referred participants reported wait lists for basic and "emergency" dental services of over 6 months. In response to my inability to find an adequate referral network, I took to conducting extended phone screenings of anyone who contacted me about participating in the research, to try to ensure that they understood that I had no better idea of how they could obtain dental care than they did.

<sup>&</sup>lt;sup>70</sup> Full adult human dentition is 32 teeth. Many American adults who are Tonya's age have 28 teeth because routine extraction of the third molar ("wisdom tooth") was common in the United States as a preventive practice throughout the mid- and late- twentieth centuries. In far southwest Virginia, 58.7% of adults have had at least one permanent tooth extracted for decay or gum disease, by contrast to 43.9% in the United States and 39.7% in Virginia overall; and household income disparity is a primary explanatory factor in the maldistribution of tooth loss due to decay or gum disease.

from her prior experiences, Tonya tried to care for her aching mouth as best as possible. She further restricted the list of hot, cold, sweet, solid, or sticky foods and beverages that she already avoided due to sensitivity or fear of breakage, instead eating applesauce, drinking milk, and taking her husband Johnnie's Ensure for overall nourishment when he was too ill, from Chronic Obstructive Pulmonary Disease (COPD), to finish the nutritional shake himself. Tonya continued to brush and floss her remaining teeth, as per usual, and ritualistically cleaned the hollowed-out structure of her stomach tooth to try to prevent infection. She used toothpicks to retrieve food particles and other debris, rinsed her mouth with the Scope – Listerine was too strong for her sensitive teeth – and packed it with temporary filling material purchased from the pharmacy. She treated her abscesses with antibiotics that her family saved from their own prescriptions, "cause they feel sorry for me 'cause my tooth is always giving me a problem," she said.

Unable to bear the pain any longer, but lacking dental insurance or discretionary spending money, Tonya called a number of dentists within an expanding perimeter until she found one, located an hour and a half away, whose quoted rate she could afford if she skipped some household bills for a few months. The comparatively low rate was due to the dentist's agreement, in response to Tonya's desperate appeal, to waive the X-ray component of the standard examination and, instead, perform a simple extraction for \$130.71 So he extracted her tooth. Yet, even after the recovery period ended and she had completed the course of penicillin he

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<sup>&</sup>lt;sup>71</sup> Simple extractions, commonly performed under local anesthesia, are generally appropriate for intact erupted (visible) teeth. They depend on the dentist's use of careful force to "pull" them out, after connective tissue and the supporting alveolar bone have been detached and loosened, respectively. Surgical extractions are required for more complex cases, for example teeth broken below the gumline or impacted teeth. Commonly performed by oral surgeons and requiring general anesthesia, surgical extractions are, as the name suggests, much more complicated procedures that may involve the additional extraction of soft tissue or jawbone. Clinical examination is warranted, in order to determine if a tooth can be extracted using simple procedures or if it requires surgery (Hollins 2013).

prescribed, Tonya continued to experience significant pain where the tooth had been. "I mean it was so bad that I was begging God to take that pain away." Tonya continued:

No pain medication was helping me. I was taking my pain medication, I was taking what the dentist gave me on top of that, and that was not helping either. That infection had to go. (The dentist) pulled it when it was still infected, but the infection would not go away. It was steady. I was in pain and, I ain't gonna lie to you, I kept taking painkillers. But I was in pain. Finally I went to the Emergency Room and I said "Listen, I'm not here for pain medication. I've got a really bad toothache," I was crying so hard, I said, "Please get me out of this pain." I said, "Do y'all have a nerve blocker?" I was crying so hard and this doctor was so compassionate, he started crying. I mean he had tears in his eyes too. He saw how much pain I was in and my jaw was swollen up out to there (*She gestured*). He had to give me three nerve blockers to get me through the night and I still couldn't sleep. It eased up enough to where I could doze every now and then but I kept having to keep that ice pack, get up and get ice packs for my jaw.

While the care that she received at the emergency room, which included the injection of antibiotics, seemed to resolve the infection, at the time of our meeting, six weeks after the extraction and a month after she had been to the emergency room, Tonya had the nagging sensation that the greater dental problem wasn't fully addressed. "It's still kinda swollen," she said. "My jaw right down there, it don't feel right. Like, there's still a bone down in there. But I mean it's like 85% better than what it was."

While Tonya was grateful that her stomach tooth had been extracted professionally unlike most of her other teeth, which had cracked when they became too decayed, she lamented the fact that this clinical procedure contributed to her looking "like a damned carved pumpkin," a metaphor she had begun invoking five years prior when her top right front tooth broke off at the gum line. At that time Johnnie worked as a contract carpenter for the Virginia Department of Transportation and did roofing on the side. While money was tight, it seemed plausible to Tonya that she would be able to afford to get all of her teeth pulled and get dentures made, like her parents before her. But then Johnnie developed COPD and had to take disability retirement,

which reduced the family's overall household income by more than half.<sup>72</sup> Meanwhile, Tonya's own multi-systemic illnesses – managed carefully so as to preserve her recovery from her addiction to heroin and Oxycontin – demanded substantial resources, even on the sliding scale payment system of the community health center. Her medications, alone, cost \$500 per month.

Ironically, she told me, the management of her diabetes had been a primary contributor to the decline of her teeth. "Where I have to take shots in my stomach all the time," she said, "We watch a lot of educational TV. That's where I learned that insulin messes with your teeth, messes with your organs." She continued:

Drugs will do that too, destroy your teeth. Pain medicine will destroy organs in your body, and that includes your teeth. My teeth was really good when I was younger. Then I got out there, got some experience in the world, I'm not gonna lie, doing some illegal things and that's what I think happened to my teeth. I was hooked on heroin for a long time and that's what made my body go downhill. I put on the weight and started going into depression and that sort of thing. I've been clean for many many years but the heroin, you know, people use that as pain medication...I regret the day I started. I regret the day I ever even knew what a Tylenol was. I would rather just be off everything, not be on anything. You know, all this stuff I've done has done so much damage to my body. I've gained over 200 pounds because dope will make you get depressed. I'd just lay in bed and get my dope going. Now I've noticed I can't get up and move around anymore because of what I've done to my body. And you can't get up and move around when you're on dope because you're depressed and I think 'cause you feel guilty. That's what I think. I feel guilty when I do it.

It was at this point in our interview that Tonya's lament turned from her understanding of the etiology of her dental disease to her experience of social marginality. For her, dental disease was not merely a circumscribed pathology. Together with her obesity, depression, addiction, and chronic pain, her dental disease evinced a lifetime of suffering. While each of her health problems has left vivid markers upon her body – the concentration of her excess weight around the area of her liver, the slowness of gait of her chronic knee and lower back pain – none had

<sup>72</sup> Johnnie's invocation of his right to social disability insurance forced a recalculation of the Supplemental Security Income (SSI) granted to Tonya to manage what she described as her son's anti-social disorder and learning disability. This experience is common among low-income families in the United States, especially those who have a

been harder to bear, was more resistant to camouflage than her mouth, where her few remaining teeth were yellowed and "rottening out." <sup>73</sup>

Even as she reclined, couch-bound by her obesity and chronic pain, her white shirt lay tidily across her torso, its small purple flower buds contrasting pleasantly the large multi-color floral print on her loveseat. Her bleached blond hair was pulled taut into a low ponytail and her fingernails, filed and painted pearlized pink. Her mobile home, a loaner parked on a dead-end gravel dog leg on a better-off relative's land beside the federal penitentiary, was decorated in a personalized manner. Children's school photos, Christian art, and inspirational quotations hung on every wall, and lace tatted doilies and glass vases containing artificial flowers sat on every table surface. Her attention to image, and the pride and practical outcomes she gained from it, had long been a hallmark of her life. Even when she worked as a school bus driver, she said, the kids loved and respected her because she carried herself with dignity and that started with the fact that she greeted them with a smile, the one she now hid behind her hand. The visual marker of Tonya's teeth betrayed, cruelly, her elaborate self-care regimen. In addition to keeping her mouth as clean as possible so as to stave off infection, she brushed her seven semi-intact teeth

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<sup>&</sup>lt;sup>73</sup> Tonya's experience also exemplifies the phenomenon coined by anthropologist Merrill Singer a syndemic, or "the aggregation of two or more diseases in a population in which there is some level of deleterious biological interaction that exacerbates the negative health effects of any or all of the diseases" (Singer 2014, citing Singer 2009). Singer continues, "Syndemics tend to develop under conditions of health inequality caused by poverty, stigmatization, stress, or structural violence, and contribute to a significant burden of disease in disadvantaged and marginalized populations." Reading Tonya's untreated dental disease as part of a complex syndemic helps us attend to, among other things, the ways that deleterious biological interactions are both cause and effects of illnesses born of marginalization. For example, Tonya traces the origin of her addiction to painkillers and, later, heroin to a lifetime of episodic depression that was exacerbated by an on-the-job injury. Among the other negative effects of her addiction to narcotics were the damage caused to her teeth, as well as the self-isolation that prohibited her from seeking medical care. Her addiction also mediated her relationship with food, causing cravings for fermentable carbohydrates that caused even more dental damage, as well as deepening her feelings of worthlessness, in which she ceased to practice self care such as dental home hygiene. Yet her dental discomfort also fueled her need for even more pain management, which she did using the resources at hand, even as she understood her propensity for addiction: pharmaceutical grade painkillers. Thus, Tonya's experience of a dental syndemic demonstrates how a lifetime of marginalization is suffered through the body in a recursive loop in which exclusions from dental care and, accordingly, independent management of pain, both foment and are fomented by other health problems.

with her granddaughter's training toothpaste – her mouth was too sensitive to use adult toothpaste – and flossed around them.

While the community health center provided Tonya management of her medical problems, resources for addressing even basic dental pain and infection were extremely limited, unpredictable, and, as her experience with her stomach tooth demonstrated, inadequate. Her rampant dental decay was a painful testament to her history of addiction, for which she blamed herself, and a constant reminder of the inherent trade-off between the necessary medical management of her diabetes and the care of her mouth; so, too, was her inability to get her teeth treated. She felt guilty for not being able to work a job that maintained benefits, and vulnerable to a dental market in which she had to "shop" for care whose low cost, she suspected, turned out to be an indicator of low quality. While Tonya's experience seeking treatment for her stomach tooth at the emergency room was good, and the doctor, compassionate, her prior experiences had not been. Known as a "drug-seeker," she had been turned away or shamed a number of times before, an experience common among many participants regardless of facts of their drug use or non-use.

Utilization of the emergency room as a dental clinic of last resort is common among dentally uninsured people in far southwest Virginia, such as Tonya, and the United States more broadly (Sanders 2012). For beneficiaries of public insurance, accessing adequate dental care can also be challenging. This is especially the case for Medicaid-insured adults in Virginia, where the benefit only covers emergency extractions.<sup>75</sup> The next case study documents what happens when

<sup>&</sup>lt;sup>74</sup> While I am not a clinician and am, therefore, unable to evaluate the appropriateness of her care, I have inferred from my many conversations with dental clinicians and medical practitioners that it is not only not indicated to extract a tooth prior to the assurance that the infection has been resolved, but that it is incredibly risky to do so.
<sup>75</sup> Among the many critiques of Virginiaadult Medicaid's dental benefit is the slow speed of pre-approval, which is a

<sup>&#</sup>x27;s Among the many critiques of Virginiaadult Medicaid's dental benefit is the slow speed of pre-approval, which is a source of frustration and explanation for non-utilization by patients and providers alike. Processual inhibitors such

that benefit conflicts with the actual clinical and social needs of the patient. It also highlights the stigmatized suffering of someone who previously had private dental insurance through her workplace – what she felt was a benefit of a middle class lifestyle she had worked hard to achieve – to someone whose services were severely contracted as a result of their public source and, thus, her sense of self re-rendered.

#### From "dental citizenship" to directed dependence: Renata's story

I met Renata, a 48 year old white woman, on a Thursday morning in 2011, late enough in the spring that the redbuds were in vibrant bloom along the valley road where she lived in a modest brick rambler, her natal home. Renata had called me at the urging of Nancy, a dental assistant who she had known originally as a clinician, but now considered a close friend. Their relationship dated to 2007 when Renata had sought care for the first time at the public health dental clinic where Nancy worked. Renata had lost her dental insurance in 2000 when she had to leave her job as an emergency room nurse due a variety of reasons. Her strength and mobility were diminishing due to a then-undetected chronic inflammatory disorder and she suffered chronic pain from a serious car wreck. Her abusive ex-husband stalked her at her workplace, and she spent all of her hours at home caring for her mother – whom she described as her best friend – and her mother's identical twin sister until their deaths three months apart. After suffering an

as approval delays are hallmarks of bureaucratized public services and the disentitlement that people experience when attempting to use them (Danz 2000; López 2005; Stuber and Kronbusch 2014).

<sup>&</sup>lt;sup>76</sup> I knew Nancy through our mutual contacts at the public health department, including the district director whose key informant interview during formative research catalyzed this research. He had instructed all dental staff, including Nancy, to "do anything they could" to help me complete data collection. While this admonition sounds directive, the dental staff and I got along very well and I was ever-grateful for their friendship during fieldwork (and after) as well as their practical assistance. Nancy, for example, pointed out my recruitment sign to every patient at the dental public health clinic and, of her own initiation, made a list for me of the names and phone numbers of patients who expressed interests in participating.

acute psychiatric episode, Renata spent much of the next five years in what she described as a catatonic state. "I really, really crashed," she said, continuing, "I was very close with Mommy. When she died, I died too. I didn't want anybody to know (about her declining mental health). I didn't want to talk about it and I was so embarrassed. I wouldn't even leave the house."

In 2004, with the gentle urging of a trusted former colleague who persisted in reaching out to offer support, Renata began to resurface and address her needs. She obtained Social Security Disability Insurance, Supplemental Security Income, and Medicaid, and found a doctor who diagnosed and helped her manage, medically, her rheumatoid arthritis. She began working informally, teaching piano to children and assisting medically homebound neighbors with their blood pressure gauges and portable oxygen, translating medical jargon into "plain talk," or "just listening to what people have to say." Renata began to feel engaged again and, her life, purposeful and normal. So when, in 2007, her tooth started hurting, she did what she had done in the past as soon as she felt a toothache: she called the dentist she had seen since she was a young woman. It had been nearly seven years since she'd seen him, due to the loss of her dental insurance, but she had previously been a diligent patient, always seeking timely preventive services as well as the treatments she needed.

The dentist was sympathetic to her plight, he told her, but he also had a standard set of fees from which he could only deviate so much. He would waive the examination fee. He would work with her on a payment plan for the balance above a \$350 base charge for what they both suspected would be another root canal. But he needed her to bring that base fee in cash. Renata couldn't believe it. On a fixed income of \$869/month, of which over a third went to her

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<sup>&</sup>lt;sup>77</sup> Aware that the official earning of income could threaten her public entitlements, Renata explained to me very carefully that she considered herself a community volunteer who didn't expect tips for her informal work, but did accept them, or goods or services in exchange. Even as we spoke, two men worked on her sewage field, a task that they had, effectively, bartered for Renata helping them create a system to manage their mother's medications.

mortgage, she did not have that amount of money, and it would take her much longer than she could hold out, with the amount of pain her tooth was in, to save toward the procedure. As a long-term patient, she was mortified that he wouldn't let her pay the entire bill on payment plan. She was adamant that she deserved this concession as reward for being a "good" patient, who sought to get a problem fixed as soon as it emerged rather than waiting until it got really bad. "When I have a problem I want it fixed," she said, "I want the pain gone. I don't want to take pain medicine for my teeth. I don't go to the ER, I go straight to the source." Moreover, she felt abandoned by the dentist, who had "known me since I was a newlywed" and earned what she imagine was tens of thousands of dollars on the "major, very expensive dental work" he performed when she had dental insurance, including a number of root canals and crowns. Unsure what to do next, Renata turned to her social worker, who suggested she call the dental public health clinic.

Renata brought a folder of paperwork to her first appointment at the public health clinic, to demonstrate her qualification, as a person on fixed income, for a reduced fee root canal and crown. Instead, she found that the public health dentist working there only performed extractions and minor fillings. She lowered her voice and said to me, "Doc...You've met him? He needs to retire but he doesn't want to and," she pointed at her head, "he's not well." Renata continued:

And I mean, he works so hard and takes his time and I hate the situation that he's in. I'm worried that if he doesn't work – I asked Nancy, do you think that he would hurt hisself [sic] because he doesn't want to quit work...But (when) he comes at you with the needle he's constantly shaking and (Nancy) has to tell him, "It's this tooth," because he'll start working on (another) tooth. I think he's getting a little bit of dementia. They're talking about, well maybe he can just work a couple of days a week and that way he won't feel left out or anything... I think it's coming down to the where where that he's gonna have to (retire). You know, that needle, his hands shaking, and the drill and he can't see, and you know with all the nerves in your mouth. And I'm sort of a little bit weary and a little scared but I've got Nancy showing him what to do. 78 She tried to talk quiet so I wouldn't

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<sup>&</sup>lt;sup>78</sup> In Chapter 4 (Provider Experiences) I draw on this and other examples to explore how the exigencies of the dental safety net in far southwest Virginia shape provider subjectivity as well, for example how Nancy felt caught

hear. Bless her heart, she didn't want to hurt his feelings. She's what's running that dental clinic right now. It's really hard with her because she's having to pick up the slack with him. I think he has a torn retina and he says he doesn't have to have surgery. Well if you do have a torn retina, yes you do 'cause you can lose all vision in that eye. I don't want him to get fired but I think he needs to retire. It's time for him to rest. It's bad in this area because people don't have insurance and they're like me. They can't get a root canal, they can't do this, they can't do that, and when their tooth is hurting bad enough, you'll about jump off a cliff or do anything for it. And it's just like with Doc. "Pull it." That's the option. I didn't have any other option."

Renata took a breath. I remarked on the extent of her knowledge and experience, not just of the public health dental clinic itself but also the complex emotion and identity issues woven through it. Again she referred to her friendship with Nancy, who she felt had her best interests at heart. Since their initial introduction four years ago Renata had had to get a number of teeth extracted, an outcome she attributed in part to the limits of Doc's skills and in part to the medical management of her rheumatoid arthritis. <sup>79</sup> "I took care of my teeth," she continued, "I'd brush them and I don't eat a lot of candy. I drink pop, that's a big (problem) – but just all a sudden it was like all the teeth, all the teeth. They were so soft, basically, and (Nancy and I) figured out it was the Humera. It thins your enamel. That and the methotrexate." But she needed to take those medications, Renata said. Her rheumatoid arthritis was just too unbearable without them.

I asked Renata her thinking on her teeth, at present, given the fact that she needed her medications to manage her rheumatoid arthritis. Nancy and Doc had recently extracted her last lower front teeth, and were advising her through the process of getting a lower denture from a

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between professional ethics and state practice law that prohibited her, as a dental technician, from performing certain procedures, and personal ethics that required her to intervene on the diminishing skill of her dentist supervisor.

<sup>&</sup>lt;sup>79</sup> While Renata's attribution the service limitations to Doc's skill set is understandable, it fails to account for the official role of state policy and unofficial role of the distribution of services in treatment planning for underserved patients. As previously discussed, Virginia adult dental Medicaid only covers emergency extractions. Thus, that is the only service that could be provided by the Virginia Department of Health dental clinics, which served only to people insured by Medicaid. (They have since closed altogether, as part of statewide austerity measures.) Unofficially, underserved patients had, at times, been directed into treatment "tracks." For example, incomequalified adults could obtain a more expanded array of dental services on sliding scale fee at the few community health centers (CHCs) to keep dentists on staff, though both of the local/regional CHC dental offices had closed by the time I arrived to the field. See Chapters 1 (Background and Theoretical Framework), 4 (Provider Experiences), and 6 (Proposed Solutions) for extended discussions of the composition of the dental safety net in the region.

chain retailer, for which her friend was paying. They wanted to do the same with her upper teeth. Nancy and Doc were compassionate and very helpful in terms of explaining the process, Renata said, but she wasn't happy with it so far. The temporary denture – meant to maintain the structure of her mouth for nine months while her gums healed – no longer fit properly, a problem she attributed to her gums shrinking following the extraction of most of her teeth, and the fact that the denture was of a standard size, rather than customized. Even after being tightened to its smallest setting, it didn't "stay in place," she said. "Polygrip, fixadent, whatever, doesn't hold it cause they're so loose. I don't think I can handle having dentures on the top too."

Renata told me that, early in the process of deciding whether to go forward with the treatment plan that Nancy and Doc had proposed, she sought a second opinion from a dentist at one of the community health center dental clinics in the region, now closed. But the dentist "was absolutely so rude to me," she said, continuing:

He talked to me like a dog. He wanted to know why that my teeth was in the shape that they were. And I said, 'well if I had money, they wouldn't be'...I was in tears and the dental hygienist was in tears too because she was embarrassed by the way he was acting. He would come in and he'd go back out, and he'd come in and say something smart and he'd go back out. That's how he done. He talked about Doc, what a sloppy job he did. And I said, 'If it wasn't for Doc I wouldn't have what I've got.' (re-voicing the dentist) 'Well, it's not very good job. And why did you let your teeth get in this shape before?' I says, 'I don't have the money to get my teeth fixed. That's why I come over here.' Like I said, I was in tears, the dental hygienist was in tears. He went out (to the billing department) and said 'she doesn't have to pay anything' but I wasn't gonna pay nothing anyways...I won't tolerate (rudeness). I won't be talked to hateful or talked down to because of the situation I'm in. I will speak up. I'm easy going but I'm not gonna take no crap...I mean, I wasted gas driving over there for nothing...to drive over (t)here and get treated like crap."

<sup>&</sup>lt;sup>80</sup> Dentures are one type of dental prosthetic, fabricated for both functional and aesthetic purposes. They range from standardized "full plates," available for a relatively low cost (generally, around \$200) at chain retailers nationwide, to customized fixed partial and complete prostheses that can cost thousands of dollars and are virtually indistinguishable from natural teeth (Nallaswamy 2006). Unlike the crowns utilized in dental implants or placed over teeth following root canals, dentures are not permanent, and must be removed for cleaning and other purposes. In my fieldsite, the use of low-cost standardized "full plates' is common, and also quite obvious. "Full plates" rarely look natural or fit users' mouths well. Many participants reported to me dissatisfaction with their full plates, which made them "talk funny," look unintentionally comical, not be able to taste food, or become afflicted with sores from poor fit. Many participants who reported having full plates reported to me that they eventually made the choice to not wear them, for these reasons.

Renata felt particularly affronted by the suggestion that her dental disease was her fault. While she came from a family in which tooth loss was a norm, it was not for lack of self-care. Her mother, whose family couldn't afford dental care when she was young, took great pride in going to the dentist until shortly before she died to have her six "real" teeth cleaned, and instilled the same ethic in Renata. Even when Renata was first getting to know Nancy, she experienced Nancy's inquiries about her home hygiene as accusatory, though over time she'd come to understand them as part of the standard assessment. "I know there's no shame in being poor," she reflected, "but it sure can make you do things you'd rather not do."

For Renata, these "things you'd rather not do" included supplicating herself to dental treatments that failed to resolve her broader set of needs, needs she had both been accustomed to addressing in her prior experience of utilizing employer-based dental insurance and that she felt she deserved to have addressed as a responsible health subject. It meant subjecting herself — and the public health dental clinicians by whom she felt well-cared for, emotionally, if not clinically — to ridicule and insult when she participated in the practice of "shopping around" that characterizes contemporary understandings of full medical citizenship. It meant discovering the way that her dependence upon public insurance marked her as untrustworthy and expendable. In summary, it meant bearing the suffering of one who could not erase the marks of stigmatized disease and, moreover, seeing that suffering compounded as the limited care options served to remind her of exclusions from the broader array of treatment options — for example, root canals and crowns, which can camouflage dental problems by blending into dentition — to which she had previously had access.

Like Tonya, the dental exclusion that Renata experienced must be understood within a longer history of hardships and the present navigation of double binds, specifically as they have

to do with managing the multiple health problems whose treatments cause, among other things, damage to her teeth. Their experiences evince the way that unresolved dental maladies threaten one's sense of dignity and self-worth, while also opening up minor glimpses of the merciful, albeit temporary, balm that can be provided to dentally marginalized people by sympathetic clinicians, even if they can't address the full extent of underserved patients' needs. While an extended discussion of clinicians' experiences in the dental safety net is the topic of the next chapter, an introduction to their influence on dentally underserved people's experience of stigmatized suffering continues with the next case study.

The next section portrays the experience of Janie, a single mother of four who attempts to obtain care for her children. While Janie is, herself, not dentally insured, nor has she been for some time – she is an entrepreneur who previously worked in a contingent, low-wage position managing a convenience store – her children have comprehensive dental coverage as a result of their enrollment in public insurance. However, as other scholars have pointed out, there is an entrenched gulf between the rhetorical extension of benefits and their utilization in practice (Castañeda 2010; Danz 2000; Lopez 2005). As Janie's case study will show, this disjunction derives, in large part, from dental providers' selectivity. Unlike the medical system, in which a network of federally qualified health centers, free clinics, and emergency rooms have created some modicum of access to care among low-income, publicly-insured, and under-insured people, the dental industry has failed to systematize its social obligation. Private practice dentists routinely exclude patients based on type of insurance, or obligate them to burdensome bureaucratic processes, a clear refutation of the emphasis on patient "choice" advanced by

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<sup>&</sup>lt;sup>81</sup> While U.S. medical care leads dental care in terms of prioritizing and systematizing the safety net, it is still a site of stratification, discrimination, and contestation. See, for example Boehm 2005, Horton 2006, Lamphere 2005, Shaw 2012, and Waitzkin 2005.

market-based approaches to health care reform. Whereas a case study of children's public dental provisions and the comprehensive benefits they confer *could* offer a counter-narrative to the stigmatized suffering experienced by dentally underserved adults, Janie's story demonstrates how what Castañeda and colleagues call "false hope" (Castañeda 2010) or what other scholars describe as bureaucratic disentitlement (Danz 2000, Lopez 2005)— that is, the legislative extension of benefits that are unusable in practice — implicates entire families into experiences of stigmatized suffering, in which parents must cope with their own feelings of inadequacy.

### Feeling like a "terrible, terrible parent:" Janie's story

Janie called me on a Wednesday morning in late April 2011 and asked if I could meet her two hours later at the McDonald's in Wise. She was just finishing up work for that morning's client, and if she cleaned up her equipment, paid out her helpers, and showered quickly she would have a sliver of time to do an interview before picking up her kids from school. I obliged. Two hours later we sat together in the bustling restaurant, drinking coffee. By the time we met in person, Janie and I had spoken by phone a number of times. She'd wanted to meet sooner but the obligations of work and parenting were demanding. A white, 30-year-old single mother to four young kids, Janie had recently left her job managing a convenience store to open a yard care service. Pleasantly surprised by how quickly her business had taken off, Janie was learning to navigate life as an owner-operator who was, ultimately, responsible for all aspects of the enterprise. On one hand, she was grateful that self-employment allowed her the flexibility to take care of needs that went unaddressed due to the rigidity of her former job, namely, kids' needs that could only be taken care of during routine business hours. On the other hand, she found herself busier than ever, with seasonal demand for mowing extremely high. With her help

unreliable – mostly her ex-husband's cousins, who might or might not show up to work – Janie often found herself completing the physically demanding tasks of her new business alone, on top of her administrative tasks. Beside her, on the plastic bench where we conducted our interview, sat a canvas bag filled with file folders. "Flyers," "Estimates," and other business categories were coded in blue. "Bills," "Insurance," and other personal categories, yellow. Each child had his own file folder, Janie told me, to keep front and center in her mind his most urgent needs. The folder marked "Forest" for her 7-year-old, the primary reason she called me, bulged with hand-written notes.

Each of Janie's kids had unmet dental needs. Nine-year-old Shane had two fillings that had come loose. Six-year-old Skye's speech impediment was partially attributable to the crowding in her mouth. Taylor, 4-years-old, just needed a good cleaning. But Forest's problems were the most severe. His front teeth were "completely rotten," she said, and they had been for some time. While Janie attributed his dental problems, partially, to the sugary treats with which her ex-husband plied the kids' favor, it was Forest's constant grinding that concerned her most. Forest was her most sensitive child, she said, and he took the divorce really hard. He had been the only child to see Janie's ex-husband hit her, and whereas Shane was a real rascal who reveled in rough-housing with his dad, tender-hearted Forest bore the brunt of their relentless teasing.

Janie had tried for some time to get Forest treated by a dentist, and to come up with some ways to address the grinding that she thought was a manifestation of his feelings of anxiety and fear. While Forest had, like the rest of her kids, previously seen a dentist through their enrollment in Head Start, those encounters were merely diagnostic, an approach that Janie said was "pointless. They send you a copy of the report," she said,

And tell you if (your child) got cavities or this or that to where we can make an appointment for the dentist...I mean really, it's pointless. You're going to have a child sit in a chair, do this, but you're

not going to do anything to fix it? That makes no sense to me whatsoever. I mean, I understand that it's through Head Start and everything but why even take (the exam)? Why not go ahead and get it fixed? Unless it's such a severe problem that a parent needs to be there. It's not like it couldn't get fixed at that time.

In fact, Janie *had* tried to follow Head Start's admonition to take her kids to the dentist. She had tried to make appointments for the dentist or, more accurately, attend the appointments she had made, but throughout the last few years she had encountered a number of barriers.

Of all the children, Shane had received the most dental care, primarily from the dentist who Janie had seen, herself, as a young adult. But that dentist, who she described as compassionate and good with kids, had relocated her practice to Roanoke, some three hours away. In her absence, Janie called all over the county in search of a pediatric dentist or a general dentist who was willing to see young kids. She found none.

They'll take my 7-year-old and my 9-year-old," she said, "But not my 4-year-old. I have to travel to Kingsport, Johnson City, somewhere like that. It really hurts us because I don't make that much. I'm a single mom, four kids. I'm supposed to get child support, don't get it. And I've had bad experiences with all the dentists who would take them. It's just got to where I don't know what to do 'cause they need it and there's nothing I can do about it.

The bad experiences to which Janie referred were of two types. One had to do with her exhusband, who had threatened two different dentists with physical harm when he felt that they hadn't sedated Shane adequately when drilling his teeth in order to place the fillings. As fearful that her husband would make good on the threat as she was embarrassed by his public outbursts, Janie had promised herself that she would never again let her ex-husband take the kids to dental appointments, no matter how much she needed the help.

Equally troubling was the Catch-22 that Janie experienced in getting her children to their dental appointments herself. As recipients of public insurance Janie's children qualified for full coverage of dental services plus transportation to and from appointments, a welcome relief from the burden of transporting her children to the nearest major city, at \$75-\$100 per trip. But the last

two times Janie had arranged for Medicaid transit, the taxi failed to show up, and her kids missed their dental appointments. "I called (the dentist) that morning and told them, 'Well the Medicaid cab ain't here. I'm not gonna be there," she said, continuing, "But, you know, where I guess you gotta call within so many hours prior that, it didn't matter." When she went to reschedule the appointments the office manager told her that she had to schedule all three kids on different days, "where they've missed in the past." Right around the time that she was starting her business — and divorcing her husband — she started using a new calendar system. "I forgot about every single appointment," she told me, with a sigh, "Every single one of them." She continued:

(My ex-husband) is \$30,000 behind on child support and I don't see me getting any of it any time soon. So, I mean, it's all me. Every job I've ever had didn't hardly pay. You know, they pay enough where I could my rent, pay my lights, pay my vehicle, pay my insurance, you know. My kids were getting free breakfast and free lunch at school. My kids have never been on vacation. It's really hard to add gas to that. To go to an appointment. And I call Medicaid for them and they don't show up. I'm like, what am I supposed to do because Medicaid pays for (the taxi) to take us over there and then (when it does come) we end up getting dropped off, and then we're sitting there two hours waiting on Medicaid to come pick us back up (after that appointment) which makes it even worse, you know. Especially when they show up (to take you home) and your kid's sleeping 'cause she's wore out (from having to leave at 4:30am to make a 6am appointment) 'cause she went and had surgery. And that's just something I'm not gonna make my child do.

Janie told me that she was hoping that staff from dental public health pilot project, through which we had been introduced, would help her get her kids into treatment – not just Shane and Forest, who were, technically, the ages targeted by the project, but also Skye and Taylor, even though they were, officially, too young. She told me she was being proactive in communicating with the staff, to show them her motivation and commitment to getting her kids treated by a dentist, and to see if they could facilitate or expedite appointments. While Forest's were the teeth she worried the most about, clinically, Skye's concerned her for other reasons. "She complains about her teeth," Janie said, continuing:

The pain. Her speech therapist told me we have to take care of that. She's really self-conscious too. She's my prissy child so I think a lot of it has to do with that. She's even cried 'cause of the way

they look and that makes me feel like I'm a terrible terrible parent because, you know, there's nothing I can do about it... I'm scared to call back over (to a dentist she's previously seen).

In lieu of an appointment with a dentist Janie had been keeping an eye on Skye's mouth, just as she did on the rest of her children. "I look for white spots," she said, "I look for dark spots, I look for holes."

Cause I know a lot of mine, before I had mine pulled, they started off with white spots on them. Like, a really white spots. And then yellow spots. I noticed that some of my teeth had yellow spots on them too. The yellow spots, they tell me, was build up, I can't remember what they called it. But I look for that (on my kids' teeth)...and the white spots (the dentist) tell me would be the start of cavities or the start of a hole. They told me to (look at my kids' teeth) 'cause I had so much trouble on my teeth and 'cause I don't want their teeth to end up like me, you know, bite into a piece of bread and another tooth comes out...

The recipient of a full set of extractions and dentures by the time she was 20, procedures she attributed to her incessant sucking on lemons and the degradation it caused to her enamel, Janie was extremely sensitive to the early signs of tooth decay.

Having "basically raised myself" after her mother died when she was 11-years-old, Janie was also extremely attuned to what she saw as the obligations of parenthood, primarily, making sure her children were provided for materially as well as medically. This was one of the reasons she liked the dental public health project so much, she said. As opposed to the private practice system by which she felt constantly blocked or the Head Start exams which put the full responsibility for obtaining treatment on parents, the dental public health staff actually, to her mind, *did* something for the children. "Instead of sending a paper to say "hey, you follow up," they do follow up, you know," she said, "And that's a big difference." She hoped the public health dental hygienists could just get her scheduled with a dentist who was willing to see *all* of her children at one time, she said, but she was willing to settle for appointments to treat Forest and Skye's existing decay and crowding, respectively. Shane's teeth were doing pretty well, she said, and could hold on a while

longer. And Taylor's were still pretty clean too. If she could just be connected with a dentist who would start with Forest and Skye – preferably, in back-to-back appointments – Janie believed that that dentist would see how motivated she was to get her kids' dental needs addressed, and would be willing to schedule the rest of her family too.

Like Tonya, with her meticulous home regimen, and Renata, with her efforts to obtain appropriate treatment, Janie's continuous attempts to get much-needed care for her children modeled the self-initiating dental subjectivity inculcated by neoliberal patient models. Like Tonya and Renata, too, she suffered the insult of dental exclusion. But Janie's experience evinces an even more compound version of the stigmatized suffering of untreated dental disease. Whereas Tonya lacked dental insurance and Renata's dental insurance covered only one service, Janie's children had comprehensive dental insurance - a benefit that *should* be able to be used to treat Forest's cavities so they wouldn't progress, reshape Skye's painful crowding using orthodontic techniques, and provide all of the children with examinations and standard preventive technologies such as fluoride varnish and dental sealants. Yet these benefits, so appealing on paper, proved worthless as Janie found her family excluded from care both explicitly in the form of refused services and tacitly as she was confronted with bureaucratic hurdles. As an entrepreneur who expressed repeatedly, throughout our interview, her strong belief in what she understood as the American ideals of meritocracy, capitalism, and "taking responsibility for what's yours," Janie's dental exclusion affronted her identity as a business-owner, a consumer, and, most importantly, a mother. The dental exclusion she experienced despite her hard work get her kids' teeth treated served to remind her, continuously, of her exclusion from those ideals, despite her best attempts to enact them.

## Metastasis: The compounded suffering of dental stigma

The case examples presented here offer a window into both the embodied experiences of un- or inadequately-treated dental problems and the psychosocial effects of bearing them. I described the experiences of Tonya, an uninsured adult who obtained incomplete treatment from a private practice dentist and follow-up care at the emergency room; Renata, an adult safety net patient who had formerly obtained care using private dental insurance as part of her compensation package in her former workplace; and Janie, the parent of children extended comprehensive dental benefits as part of their public insurance. The foundational medical anthropological concepts of stigma and social suffering provide a useful way to interpret their experiences. Following Yang and colleagues, I posited that dental stigma compounds social suffering, for example subjecting patients to a proscribed treatment pathway that defines the adequate resolution of dental disease as the *clinical* reduction of immediate pain and infection, in stark contrast to its subjective resolution, which addresses functional, aesthetic, and emotional aspects of dentition. I showed how the presence of unresolved dental need, especially when combined with dependence upon public benefits, marks a patient as undesirable and thus excludable from a system of care predicated upon provider selectivity. That is, that providers can refuse certain kinds of patients, or make the process of treatment so onerous that they eventually, as in Janie's case, consider stopping their attempts to obtain care. At a moment when patient choice is venerated as a major accomplishment of health insurance reform, this under-examined dynamic poses a clear threat to the triumph of the market to bring health care to all.

In closing, I offer the concept of metastasis, from the original Greek μετά (meta or, "next") and στάσις (stasis or, "placement"), read together as "displacement," to help us understand how the stigmatized suffering of untreated dental disease travels *through* "local

worlds" (following Yang, Kleinman, Link, et al. 2007) and how it "jumps" locations and scales such that it becomes, in many ways, even more encompassing than the acute but persistent pain of dental problems themselves. For example, for Tonya, the stigmatized suffering related to her stomach tooth – first, the tooth pain itself and then the inadequacy of its clinical resolution – recalled a lifetime of social alienation and regret. Her teeth are merely the latest insult in a history of illness, threats to bodily integrity, and the iatrogenic trade-offs of taking care of one need in place of another: using insulin to control her blood sugar but seeing it wreck her teeth; using opioids as a salve for the encompassing pain of depression, only to find that they worsen it. Yet for Tonya, for whom self-care remains a core moral value despite, in her words, "all this damage I've done to my body" – or, perhaps, because of it, because self-care normalizes her through the exertion of control – the "damned carved pumpkin" that she feels that she looks like, with her broken teeth, is an insult she can't hide behind a tidy shirt or a perfect manicure. The damage to her teeth cannot be hidden without access to greater resources than she has and, thus, so is the damage to her sense of normalcy. Her unresolved dental decay has, literally, taken over her *self* in the world.

Like Tonya, Renata is coping with the insidious way that her dental needs weave themselves throughout her lived experience, and the ways in which they articulate with her past: the loss of her job and medical and dental benefits, the medicines she must take to manage her rheumatoid arthritis despite her knowledge of the damage they do to her teeth, her reckoning between the dental patient subjectivity to which she previously had access and the one she embodied when we spoke. Unlike Tonya, Renata has identified some opening into a world of care but it is an opportunity for care that fails to address her social needs and, arguably, the full extent of her clinical needs too. Here is one site where her suffering is compounded. Moreover,

unlike Tonya, Renata, a former employee in health care and a social contact of medical and dental clinicians at present, is keenly aware of micro-nuances of the source of her stigmatized dental suffering – the bureaucratized system of care that causes the suffering it claims to address. Her powerlessness to challenge or reform it thus comprises another way in which the stigmatized suffering of untreated dental disease metastasizes, as it undermines her sense of self. Whereas Tonya has, over time, accepted her stigmatized subjectivity as a safety net patient, and identifies the benefits, ambiguous though they may be, that that subjectivity confers – for example, the gumption to beg a private practice dentist for a negotiated procedure, or to go to the emergency room despite the likely accusation of drug-seeking – Renata retains an orientation toward the active citizenship imbued by the neoliberal system of medical governance. Despite her exclusion from the normative system of fee-for-service dental care, Renata approaches the dental safety net as a health care consumer, pursuing all available avenues for treatment. Unfortunately, however, she finds that it is one more site through which she is made to suffer the limits of insurance eligibility and a predetermined and inadequate pathway of care. Moreover, it is a site through which her stigmatization persists and, in fact, compounds, as she senses her jaw shrinking away for lack of restorative treatment, and the emergence of indiscrete holes in her dentition and sense of self.

For Janie, too, mobilizing the resources to address her family's needs – financially, but also organizationally and otherwise – represents that highest "stake" in her local world (following Yang, Kleinman, Link, et al. 2007:1530). The stake indexes the specific contour of being a parent attempting to fulfill what she thinks is one of her most fundamental responsibilities: Taking care of the health of her children. While Janie accepts that her own forgetfulness is but one of the causes of her family's exclusion from dental care – an accident

that is understandable, given the other stressors in her life and the general demands of contemporary parenting and entrepreneurship – she is affronted by the ways in which bureaucratic errors and structural barriers to access, for example the Medicaid taxi's failure to arrive or local dentists' refusal of young children, exert their force on her local moral world such that her experience is constrained and her values, eclipsed in practice as a result of the stigma with which they mark her.

In this chapter I have shown how the suffering of untreated dental disease is not merely a physical one, nor does it limit itself to the individual realm. By sharing the stories of Tonya, Renata, and Janie, I demonstrated how dental suffering is fundamentally intersubjective, primarily the result of stigma by which the bearer experiences exclusion from two social norms: the norm of not having dental disease – or, more aptly, the norm of not *appearing* to have dental disease – and the norm of being able to access treatment for dental disease. Drawing on scholarship on stigma and social suffering, I argued that the suffering of untreated dental disease is, at its core, suffering related to stigma, and the ways in which stigma compounds suffering by the way that it poses threat to what matters most in a local moral world.

Moreover, I have argued that stigmatized suffering is not merely a result of untreated dental disease itself, but that the stigmatized suffering of untreated dental disease is generative, (re)producing itself as it moves from one "place" – the mouth, the psyche, the clinic – to another, reinscribing underserved patients' stigmatized suffering through their encounters with clinical providers, friends, and strangers, as well as with themselves. In these encounters, patients struggle to reconcile social norms such as having full dentition or being able to participate in market-based care with their limited ability to achieve them. While the pathways that are carved by the stigmatized suffering of untreated dental disease do create openings for clinicians to

respond to patients' needs – to affirm them and attempt to offer them care, in whatever way they can – this is not, unfortunately, the norm. The organization of dental care in America countervails equity, and even dentists who want to improve care for safety net patients are limited by structural constraints as well; their stories comprise the next chapter in this dissertation.

Tonya, Renata, and Janie's stories were not unique in my dissertation data; in fact, it took me a long time to decide which stories to use, from among the approximately two-thirds of 94 patient stories I collected which reflected similar themes. These stories are not unique to the region either. Increasingly, this is the story of dental care in America. While physical pain may be the immediate effect of untreated dental disease, it is the subsequent effects of social suffering and stigma that are more lasting and harder to address. Moreover, these effects are compounded and dispersed, as people with untreated dental disease cannot obtain care, and are reminded of their exclusion from a societal norm and a personal ideal.

Importantly, while these examples call attention to the strong role of visual evidence in the stigmatized suffering of untreated dental disease, they also evince an ironic feature of the metastatic quality of dental stigmatized suffering. By the time Tonya reached the topic which opened this chapter, nearly three hours into our interview, she had long since relaxed the vigilance of her gesture to cover her smile and, instead, rested her hands upon the two closely shorn poodles that sat on her broad thighs, sniffing and snipping at each other across her substantial belly. Indeed, although I had observed in Tonya's mouth, as she opened it to speak, black pits where her teeth had broken off at the gumline, red, puffy areas where infection seemed a threat, and the bobbing of her remaining teeth, wobbly-like, throughout her speaking, I would

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<sup>&</sup>lt;sup>82</sup> See Chapter 1 (Background and Theoretical Framework) for a discussion of the epidemiology and political economy of oral health in the United States.

not actually have needed to have seen the inside of her mouth to call to mind the visual detail of which participants in my research spoke. Certainly, the dental staff with whom Tonya, Renata, or other participants spoke were not able to see their mouths, or the mouths of Janie's children, as they spoke by phone about the possibility of obtaining treatment. The mere reference to untreated dental disease, especially when combined with an almost equally stigmatizing dependence upon public insurance, provoked exclusion from and barriers to care, for example in the form of overly bureaucratized processes. In other words, while the visual evidence of a "bombed out mouth" prompts stigmatization in lived encounters in public and clinical settings, the social power of that reference extends beyond visual depictions and into the realm of recall, one more way in which the stigmatized suffering of untreated dental disease marks its bearers metastatically, this time in the realm of the imagination. The mere act of seeking a specific kind of care, using a specific form of payment interpellates them into a degraded position, one that shapes their sense of self as well as any subsequent clinical encounters.

In this chapter, I have aimed to show how underserved patients' untreated dental disease does not merely *reflect* the structural factors by which it was caused, but also that it *produces* a specific kind of social suffering in the form of the stigma by which they are anticipatorily interpellated into undesirable patient roles and excluded from care or directed into treatment pathways that are inadequate to meet their needs. Underserved patients are stigmatized as undesirable patients and, in a system of market-based dentistry, perpetually excluded from care. I now turn, in the chapter that follows, to the experience of providers who see themselves as serving safety net patients, in one form or another. Their perspectives on providing safety net care through the absorption of Medicaid patients, employment in the public sector, or donation of services through charity networks is a crucial component of understanding the decayed, missing,

and filled, dental safety net in far southwest Virginia, and of identifying ways that it might be improved.

# CHAPTER 4: EXPERTISE AND THE MORAL ECONOMY OF DENTAL CARE

#### Introduction: "The patient didn't know who was supposed to be doing what"

I was eating lunch in April 2011 with Evelyn and Kristin, two public health dental hygienists employed by the school-based dental public health pilot project that, as described in Chapter 1, comprised a primary research site for this dissertation. They were reflecting on their experiences working in public health versus private practice. Kristin, a mother of two elementary school aged children, said she missed working part-time, an option not available through the pilot. A self-described buoyant personality, she loved doing oral health education and networking but she missed having more time with her kids. Evelyn, by contrast, missed clinical work. She wasn't much for public speaking, she said, and, more, she loved the focused, technical work of cleaning teeth. She told me that her favorite job ever had been for a periodontist, or a dentist who specializes in gum disease. "Sometimes he would let me scale and plane the subgingiva," she said:

He seen what a good job I did removing the calculus up above it. Man, I'm so O.C.D., I just love to flick it off. He knew I was meticulous and could handle the equipment better than most dentists. So he would point to the hand scaler<sup>84</sup> and say "You know what to do."

"Evelyn!" shrieked Kristin, "Weren't you worried about getting caught? You could have your license revoked for that!" Evelyn shrugged off Kristin's concern. "I didn't worry too bad," she said, "The patients didn't know who was supposed to be doing what and the dental board wasn't gonna come all the way down here to investigate something little like that. Besides, dental hygienists in other states get to do it all the time!"

<sup>&</sup>lt;sup>83</sup> The subgingiva is the area below the gumline.

<sup>&</sup>lt;sup>84</sup> A hand scaler is an instrument with a hook-shaped metallic end, used to remove dental plaque and calculus.

At the time, the only aspect of Evelyn's statement that gave me more than a passing thought was the matter of patient misunderstanding. By then I had interviewed a number of parents whose children were enrolled in the dental pilot and had come to understand the centrality of *mis* understanding in patients' (or, their parents') experience. Although the pilot's recruitment flyers and consent forms stated explicitly its hygienist-led model of care and emphasis on preventive services (see Chapter 1), a number of parents told me that their children had received some basic dental treatments at school, at the hand of a dentist or dental student.<sup>85</sup>

It was only when I became more familiar with local, state, and national proposals to increase access to care through dental team reform that I understood the stakes of Evelyn's claim, and of Kristin's response. As discussed in Chapters 1 and 3, low-income people's access to dental treatment is shaped by a number of factors, from the priority that national thought-leaders place on oral health – or, do not place on it – to individual private practices' willingness to accept public insurance. In order to reduce barriers to care and increase low-income people's access, a variety of proposals are being developed and implemented in settings across the US. Among these proposals are dental team reforms, or reforms which either expand the duties and reformulate the supervision structures of *existing* allied dental professionals (e.g. dental hygienists) or create *new* allied dental professionals, generally called "mid-levels," whose duties and supervision structures vary by proposal (see Chapter 5).86

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<sup>&</sup>lt;sup>85</sup> The cause of this misunderstanding is at least two-fold. First, as described later in this chapter, many parents remembered that the public health dentist had previously come to local elementary schools to provide basic care to their older children and, for those parents who were young enough to have experienced the school dental outreach first-hand, themselves. Secondly, the recruitment information and consent forms were long and densely written, easy for someone with high literacy skills to gloss and those with low-literacy skills to not understand.

<sup>86</sup> As discussed in Chapter 1, it was one of these newer, more liberal formulations that I (mis)understood myself as entering into, prior to arriving in the field. I describe the differences between these two archetypes briefly in this chapter, and in more detail in Chapter 5.

In this chapter, I examine dental team work as both a practice and a rhetoric. The distribution of tasks among multiple members of a dental team, primarily a dentist, dental assistant, and dental hygienist, is now standard in the US. As documented in the literature and suggested by the vignette which opened this chapter, team work is a boon for dentists and, to some degree, the allied dental providers who enact it (Burt and Eklund 2005). It allows dentists to off-load tasks they deem mundane, other team members to work "to the top of their licenses," and the dental hierarchy to persist or even expand, for example as Evelyn's supervising dentist legitimated and gate-kept the illicit use of her skills. Task distribution also improves a practice's profitability, or in dental parlance "productivity," as it creates efficiencies and maximizes service volume. Yet many private practice dentists who participated in this research opposed dental team reforms in safety net settings as a way to increase access to care. 87 Why? In this chapter, I argue that the contradiction between the *maximization* of dental team work in private practice and its limitation in the public sphere betrays a key stake in the debate over access to dental care: the cultural and moral authority to determine how to resolve dental disparities at a moment of increased attention to them.

Private practice dentists seem to want to maximize dental team work to their advantage in fee-for-service settings while simultaneously limiting its expansion in the public sphere. The American Dental Association (ADA), professional dentistry's membership organization and a vociferous and well-resourced special interest group that has long advanced an agenda of fee-for-

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<sup>&</sup>lt;sup>87</sup> This distinction between private practice dentistry and the dental safety net is not as clear as such neat verbiage implies. Dental economist Howard Bailit describes private practices as the "largest" dental safety net, since dental care financed by Medicaid is envisioned to be delivered there (1999). By contrast, many private practice dentists in far southwest Virginia and, indeed, nationwide, who don't accept dental Medicaid describe their participation in the dental safety net vis a vis their volunteerism in charitable clinics. The ADA estimates that donated dental services comprise hundreds of millions of dollars in care, annually.

service private practice, service private practice, claims concerns over patient safety and quality of care in contemporary debates over dental team reform (2013). Critics dispense with these concerns by citing nearly three decades of evidence from 54 countries (Nash 2013; Nash, et al. 2012) and argue, instead, that the ADA's primary concern is to ensure its membership's continued economic enrichment and dominance at the top of a strict professional hierarchy. Yet, such a crass reading and rigid view of power fails to account for two inter-related topics that comprise my interest in this chapter: (1) how politicized rhetorics about dental team reform can fail to reflect actual practice and (2) how proposals to use dental team reform to resolve dental disparities do not merely leverage a technical solution but also constitute a complex political economic, cultural, and moral problem. How can we understand the contradictory dynamics and high stakes of dental team work? I analyze how critiques of the stratification of dental care invoke sociopolitical projects by examining how dental teamwork is *practiced* in the school-based dental public health pilot (henceforth "the pilot") and *regarded* by the local private dentists, upon whom the pilot's short- and long-term success depends.

I begin this chapter by summarizing the history of dental professionalism in the United States with an emphasis on the emergence and development of dental team work. I frame this within scholarship on the pluralization of the health professions and expertise in late modernity. I then describe the pilot's enactment through an extended ethnographic vignette and the teamwork through which it was enacted. Next, I move to a discussion of how the pilot, as an exemplar of dental team reform, was interpreted by local private practice dentists, specifically the "slippery slope" many of them believed it represented toward a larger threat of dental pluralization. Their

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<sup>&</sup>lt;sup>88</sup> Public health and community dentists I know state explicitly that they do not feel represented or advocated for by the ADA, arguing that they maintain membership strictly for the entrée it provides for them to track objectionable proposals and agitate for more of a community focus. Public health and community dentists tend, rather, to belong to the American Public Health Dentistry Association.

perspectives on the pilot are important for at least two reasons. First, pilot staff depended on private practice dentists to take referrals of low-income children – typically, publicly-insured – who needed a "dental home." Second, the terms of dental teamwork are legislated by the state dental board which comprises primarily private practice dentists or their organizational representatives. I then discuss how dentists' fear that the pilot advanced an agenda of mid-level autonomy belies the realities of their practice, in which they recognized the benefits of, sometimes encouraged, and even took pride in redistributing an increasing number of tasks among semi-autonomous team members.

I show how, by distributing clinical tasks, dentists are able to maintain their strict professional hierarchies, even as they improvise novel dental team formations. However, I argue, it is more than the maintenance of a strict professional hierarchy that motivates private practice dentists' attempts to circumscribe teamwork. Increasing recognition of the maldistribution of dental disease, care, and suffering, have unsettled, in the words of Steven Epstein, the "cultural authority" (1995:411) naturalized to dentistry as an area of health expertise; the popularity of dental team reform risks unhinging it entirely. To help explicate the stakes of the debate over the role of dental professions in improving access to care, I counterpose private practice dentists' perspectives on safety net dental team reform against other models that they advanced during data collection among the many proposed (see Chapter 5): private practice team reform and donated services. This juxtaposition reveals private practice dentists' desire to determine, as a privilege of cultural authority, "what is taken to be the truth" (ibid.) about dental disparities and their resolution. In this case, the truth that private practice dentists seek to maintain is one which minimizes their profession's precipitating role in the emergence of dental disparities, as dental care was constituted as an entrepreneurial endeavor rather than one of service, and which

*maximizes* dentistry's leadership and altruism in their resolution. Far from merely a technical question, the resolution of dental disparities – or, at least, attempts at structural reform toward that end – is a topic fraught with moral and emotional gravity.

# Expert entrepreneurialism: the emergence and persistence of professional dentistry in the United States

The organization of professional dentistry in the United States, and its complex relationship with other dental professions such as hygiene, dates to the late nineteenth and early twentieth centuries. Dentistry prior to the 1900s comprised, primarily, two types of services conducted by two sets of people: the extraction of painful teeth by barber-surgeons or traveling showmen whose crude and unsanitary methods often caused as many problems as they resolved, and the crafting of false teeth by denturists. Just as medicine in that era sought to bring credibility and status to its profession and, to that end, used techniques like formalizing credentialing, castigating proprietary approaches, and, eventually, embracing scientific epistemologies, so too did dentistry. The advent of a number of technologies – for example, antiseptics, anesthesia, high speed drills, and amalgam composites – as well as increasing recognition of the preventability of disease and possibilities of repair of cavitated teeth galvanized the formalization of dentistry as a vital and elite skill set whose professional status required, like medicine, protection from hucksters through the formalization of training, licensure, and legal statute. Moreover, eager to elevate its status after its perceived denigration when medicine organized in the early 1900s, dentistry flourished under a model of entrepreneurialism and profitability rather than social welfare (Burt and Eklund 2005; Davis 1980).

Changes in the dental professions have long focused on enhancing value to dental private practice by circumscribing perceived threats to it. For example the ADA opposed community water fluoridation when it was introduced in the mid-1900s, in large part out of concern that improvements in children's oral health would obviate need of their services; this move precipitated scientific claims to the proliferation of orthodonture, which assured dentistry's ongoing viability in case of potential declines in decay (Picard 2009). What attention the ADA gave to the prevention of dental disease focused on educating patients in community settings on the proper techniques of self-care and the screening and referral of patients whose treatment might benefit scientific discovery, as well as address existing disease. In a move that foregrounded the pilot that is the focus of this chapter, the ADA's Oral Hygiene Committee recommended that

the dental examination of all children, referral of reports to parents in order that correction of defects might be initiated, the establishment of dental clinics not only for treatment but for research into the problem of children dental hygiene, and a campaign for the education of the lay public largely through the medium of newspaper and lecture." (Dunning 1986:46)<sup>90</sup>

Distinct from the pilot, however, these examinations were to be conducted by a dentist, sometimes with the help of an assistant or, more controversially, a hygienist.

While political and public support has been mobilized around the prevention of disease and maximization of physical health, particularly for children and other "vulnerable" populations, oral health concerns have long been diminished relative to medical ones. While

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<sup>&</sup>lt;sup>89</sup> Labor historian Alyssa Picard details the profit motives that underlay organized dentistry's opposition to community water fluoridation, which persisted for twenty years beyond the scientific demonstration of its efficacy. Conversely other sources including the ADA's own publications, argue that dentistry was reluctant to support community fluoridation until its benefits could be assessed and its low-risk status assured, a process that would require at least fifteen years of longitudinal cohort research.

<sup>&</sup>lt;sup>90</sup> The specific history of Virginia's school-based programs is, unfortunately, lost. While the VDH website verifies that Virginia was the second state to have a school outreach program, employing four dentists across the state starting in the 1920s, my repeated attempts to obtain records, or a historical document previously posted to the VDH website, have gone unmet, as staff responded that they don't have access to these records or the summary historical document either.

state dental services were expanded using federal aid in the years following the Social Security Act of 1935, the scale of operations have been disproportionately limited by comparison to other services within maternal/child health. The actual infrastructure and financing of public dental care have never been prioritized in the public sector or among the populace at large (Bailit, et al. 2006; Bailit, et al. 1999; Burt and Eklund 2005). Federal and state allocations that could have ensured the ongoing support of adequate dental programs through community health centers, free clinics, and clinical services in public health settings have been rare, inconsistent, and often considered disposable in moments of budget imbalance (Bailit, et al. 1999, Burt and Eklund 2005). Only 11% of National Health Service Corps clinicians are dentists or dental hygienists, a personnel effort that addresses only 3% of the identified population need (Monson 2000). While a significant accomplishment over prior lacunae, such a proportion of professionals pales in comparison to the medical workforce that was increasingly mobilized through state departments of health, federally qualified health centers, charity hospitals, and other medical safety net settings (Bailit, et al. 1999). For example, only 7.3 million individual services of the 66.9 million services provided at community health centers nationwide are dental services (Rosenbaum, et al. 2010).

While the lack of enthusiasm for public dental care may be attributed to generalized ignorance throughout much of the twentieth century about the centrality of oral health to overall health, the ADA and its professional education constituency did little to advance professional tracks other than entrepreneurial ones (Burt and Eklund 2005). Public health and community dentistry training programs were symbolically as well as functionally contracted within a dental pedagogy that privileged for-profit business models. Dental school affiliations proved key to the implementation of indigent dental clinics, as did the support of local charitable foundations.

Relationships between dental schools and major charities cemented, in charity clinics, the "inextricable link (between) increasing the status of the profession and promoting good citizenship" (Picard 2009:35); a number of such projects aimed to shape recipients' moral subjectivities through the delivery of dental clinical services and patient education, for example "Americanizing" immigrant children (see, for a recent example, Horton and Barker 2009). The geographic distribution of these institutions often privileged urban populations by default and left rural populations' needs under-addressed. Despite the low priority accorded to community and public health dentistry, there have been times when private practice dentists actually benefited from public programs.<sup>91</sup> The Federal Emergency Relief Program of the 1930s gave employment to private practice dentists who found themselves out of work following the Depression, though the emphasis on this work dropped off as soon as the economy turned around (Dunning 1986; Meckel 2002). The entwining of private practice dentistry and community dentistry was perpetuated when Medicaid insurance began in the 1980s to include limited dental care and patients sought to utilize their public benefits in the private sector (Bailit, Picard 2009). Although Medicaid has long been viewed with skepticism by many private practice dentists, the financial boost provided by an ever-expanding set of approved services for children that can be extremely lucrative – for example the repeat (arguably, excessive) treatment of minor decay, the use of surgical anesthesia for simple procedures, or the placement of braces for diagnoses that may be more cosmetic than clinical – has served to increase its appeal.

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<sup>&</sup>lt;sup>91</sup> As discussed in Chapter 5, some dental economists argue that this is a particularly forceful trend at present, and that the future of private practice dentistry's solvency is in Medicaid acceptance.

## Health experts' "cultural authority" to shape access to care

The health professions offer a particularly insightful window through which to examine expertise, as a core feature of neoliberalism as explored in Chapter 1, 92 and all that it confers. Some scholars have argued that medical expertise is distinct from other types because its authority is "not just social authority rooted in the division of labor or in organizational hierarchies...but also cultural authority, which rests on an actor's capacity to offer what is taken to be the truth" (Epstein 1995:411, see also Starr 1983, Johnson 1993, McCormick 2009). In other words, medical expertise has a unique propensity to construct social order more broadly. For example, formerly-competing health epistemologies such as allopathic medicine, citizen science, and biomedical pluralism have been popularized and legitimated in the market place and society more generally (Clarke et al 2003, Epstein 1995, Starr 1984, Weisz 2005, Winnick 2005). At the same time, renegotiations of expertise within market-based care are circumscribed by other features of neoliberalism such as the rise of bureaucracy and proliferation of regulation. In dentristry, most aspects of treatment, from provider licensure to the management of billing data, are regulated with increasingly infinitesimal levels of detail (Hogle 2002; Mulligan 2014, Mol). Thus, competition as a market ideal becomes circumscribed through the governance of practice.

In addition to its epistemological and technocratic effects, medical expertise also has the capacity to construct moral order and shape affective attachments in the clinical setting and beyond (Good 1994; Wendland 2010). Fassin and Rivkin-Fish, for example, show how enacting health expertise in sites of deprivation such as medical humanitarianism and charity care can

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<sup>&</sup>lt;sup>92</sup> A core feature of late capitalism is the expansion and pluralization of the professions (Dean 2010, Johnson 1994, and Weisz 2005). As specialization has proliferated, expertise in neoliberal governance evinces the multiplicative quality of power (Reed 1996:576 following Giddens 1994:59; Foucault 1991 [1978]).

contract clinicians' critiques of the sociopolitical origins of disease maldistribution and move them, instead, toward an individualizing frame that justifies a paternalistic altruism (Fassin 2011; Rivkin-Fish 2011). These examples show how health expertise in the contemporary era is often constituted through tension and contradiction. In light of such observations, anthropologist E. Summerson Carr advocates approaching expertise as "something people *do* rather than something people *have* or *hold*...(something) inherently interactional" (2010:18, emphasis mine). Indeed, as in the example of Evelyn that introduced this chapter, understanding dental expertise emergently, through its enactments, is warranted.

Within the circumscribed practices of health care, improvisation can occur and the norms of expertise thus be renegotiated (Salhani and Coulter 2009). For example, providers working in safety net clinics must negotiate patients' needs, practice norms, and resource limitations, sometimes to creative and empowering effect (Horton 2006; Shaw 2012). Alternately, as Evelyn case suggests, expertise can also be renegotiated in better-resourced settings, owing, for example in her case, to a supervisor's recognition of his subordinate's competence. As Carr continues, expertise is "always ideological because it is implicated in semistable hierarchies of value" (2010:18). For example, in Evelyn's case, expertise was implicated in ideologies of supervision structure, legality, gender, and, as Evelyn's concluding comment suggests, dental governance. Indeed, conclude Salhani and Coulter, "the politics of professional autonomy and professional dominance are actually conducted through micro-political struggles" (2009:1221) – or, perhaps, as in Evelyn's case, micro-political opportunities.

These scholars' arguments read well together, and help to explain how the proliferation of "mid-level" medical providers has often been linked to ideologies of health social justice in which the development of new types of providers seems a logical solution to medicine's

marginalization of low-income patients, racial and ethnic minorities, and rural populations, and dentistry's historic exclusion of them. These renegotiations of expertise and turf can serve to formalize and legitimate such providers' mastery of technical skills and cultural and/or educational competence, as well as acknowledge "good" judgment and self-management (Fitzgerald 2008, Lindsay 2007, Martin, Currie, and Finn 2009, Zachariah et al 2009). They can also recreate existing hierarchies, for example gendered hierarchies of labor, the patronizing evaluation of personal skills, or assumptions of relatability among people who share traits such as race, ethnicity, or language (Ramirez-Valles, SHAW 2005).

Dentistry's ability to shape what is "taken to be the truth" (Epstein 1995) is exemplified by what may be considered its philosophy of patient base: that is, who it imagines as its treatment population. Dentistry persists in prioritizing privately insured patients and concomitantly fails to address its industry's stratified care, as an institutional and professional norm. For example, only 20% of dental private practices, both nationwide and in Virginia, report accepting public insurance, as compared with 2/3 of primary care physicians (Decker 2013). Organized dentistry's perspective on how to improve access to care among low-income adults also betrays another of its cultural truth-claims: That individualizing models which leverage the dental industry's philosophical foundation in entrepreneurialism are preferable to systematic reform (Burt and Eklund 2005). Although, as I discuss in this chapter, private practice dental team reform demonstrates this philosophy, dentistry's penchant for charity care exemplifies it. Almost sixty percent of private practice dentists report providing uncompensated care (Bailit, et al. 1999), whether through personal networks such as faith communities, or through participation in formalized donated services networks enacted by state professional organizations. Yet the reach of such donations can be limited and highly circumscribed. The Virginia Dental

Association Foundation's donated services program, for example, only serves senior citizens or adults who have a diagnosed developmental or educational disability. Organized dentistry's inadequate address of low-income adults' needs has particular salience in my fieldsite where, in 2000, the Mission of Mercy project or "MOM" was incubated by the Virginia Dental Association (VDA). Leveraging the compassion and goodwill (or, from a more crass perspective, the tax deductions, peer pressure, and public relations) of individual providers, who volunteer to treat any patients who wait in line for services as long as they are available, this model of massive, short-term charity care, exemplified in the vignette which introduced Chapter 1, is now replicated in 28 states. MOMs perpetuate a model of individual entrepreneurialism through which providers' sense of social obligation may be fulfilled by volunteering annually in a threeday temporary clinic as opposed to, for example, participating in systematic reforms like advocating for the extension of basic public dental benefits to low-income adults or agitating within their organization to assure such benefits' acceptability. 93 The prominence of charity care and contraction of public sector service exemplify how professional dentistry has utilized its expert status and the cultural authority thus conferred to incorporate a limited and highly circumscribed approach to fulfilling social obligations *into* private practice, rather than reforming its industry to address the stratification of care. Given that dental team expansion is both a canonical feature of contemporary health care governance and one of the industry reconfigurations that has been controversial, historically, I now turn to a discussion of how

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<sup>&</sup>lt;sup>93</sup> Oral health equity advocates in Virginia, including some private practice dentists and VDA executives, have described to me their failed attempts to increase the acceptability of public benefits in the dental community. For example, two clinician-advocates did a statewide "road show" to try to convince their peers to take on more Medicaid-insured children patients, to little effect. Relatedly, other social, political, and moral tensions surround the MOMs as well. I discuss these in Chapter 5.

dental hygiene has been legitimized, normalized, and authorized with an expanding set of responsibilities.

# Dental hygiene: How the original dental "mid-levels" highlight contradiction in the role of expertise

While dentists have final authority on patient examination, diagnosis, and treatment planning and execution, other professionals, known as dental team members, work with or, commonly, "under" dentists in a variety of supervision arrangements. The distribution of tasks and supervision arrangements between dentists and other team members follow some general patterns, though these vary by state. For example, the role of dental assistants is self-evident in the professional designation: they assist dentists in a variety of procedures including doing a number of tasks autonomously in preparation for the dentist to perform more advanced work, for example holding patients' mouths open using retractors, crafting temporary restorative materials, or, in some cases, administering local anesthesia. By contrast, dental technicians work in laboratories, typically autonomously, where they craft prostheses and appliances for a dentist to install. In between these two roles, in terms of autonomy, is the professional whose expertise lies in the clinical and pedagogical skills of disease prevention: the dental hygienist. Characterized by an expanding set of functions to prevent decay and an increasingly legitimizing set of characteristics – the independent use of tooth-cleaning instruments, for example, or the formalization of training and licensure – the hygienist's relationship to dentistry has been fraught since it emerged a century ago.

Dental team negotiations have been contentious since 1906, when second generation dentist Alfred Fones proposed the formalized dental hygienist role (Dunning 1986; Picard

2009). <sup>94</sup> Early and mid-century debates about dental team work focused on technical skills, intellectual capacity, and propensity for autonomy among women, who almost universally filled the roles of dental hygienists and assistants. Under the model of entrepreneurialism and profitability discussed above, some dentists recognized the business value of training semi-autonomous assistants who could help them expand their practice by marketing frequent cleanings to patients who did not need or want other treatments – quarterly was considered optimal at the time for both the patient's health and the practice's profit – and freeing up the dentist's time to use specialized techniques on those who wanted advanced procedures. As labor historian Alyssa Picard explains:

Dentists who wanted to be able to hire hygienists to work in their own offices or who favored having hygienists instead of dentists do the day-to-day work of school and industrial hygiene programs, argued that women were better suited than men to the fine, repetitive, mundane handwork required for hygiene treatments. (If this contradicted the frequent claim that women lacked the mechanical aptitude needed to make them successful dentists, the practitioners who advocated for the role of the dental hygienist did not notice it). (2009:31-2)

Picard's attention to the role of contradiction in the emergence of the dental hygiene profession summarizes well the ways that they have long been understood, by dentists, as warranting the simultaneous maximization and restraint of their autonomy. When dental hygiene training programs eventually won out, private practice dentists worked to circumscribe practice by "legally restrain[ing dental hygienists' independence] by narrowly crafting – usually sex-specific – hygiene practice acts that prevented hygienists from working without the supervision of a dentist" (Picard 2009:35). As Picard points out, dentists also felt that hygienists were less apt to seek independence or compete for patients by virtue of their gender.

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<sup>&</sup>lt;sup>94</sup> Dunning attributes the origin of the concept of dental hygiene to C.M. Wright in 1902, though he agrees that it was Fones who brought about the formalization of the profession (1986:47)

Dental hygienists are now recognized as experts in the clinical and pedagogical techniques of dental disease prevention. Moreover, they are major contributors to dental practices' "productivity" or in dental parlance profitability. Unlike dentists' work and that of their assistants, which can be unpredictable in terms of cost-efficiency, dental hygienists' tasks are relatively stable in terms of duration, frequency, and, therefore, contribution to the practice's billings (Walsh 2015). Moreover, ever since mid-1980s, two dental practice reforms have made hygienists even more valuable to the profitability of private practice dentistry (Burt and Eklund 2005). First, dental hygienists in the United States were authorized to perform their tasks semi-autonomously under "general" supervision, initially in institutional, public health, and other community settings and, later, in private practice (ADHA Nd.c.). 95

While the definition of general supervision varies by state, it is commonly taken to mean that the supervising dentist does not need to provide direct oversight in the room where the dental hygienist performs her work. In states with more liberal supervision laws, dental hygienists can conduct their work when the dentist is out of the building altogether and, sometimes, on a schedule asynchronous to the patient's examination by a dentist. In more restrictive states, general supervision is taken to mean that the dentist is within the building, has previously examined the patient's teeth, and may inspect the hygienist's work upon completion, but is not in the room while she does it. Second, in the 1980s legislation emerged to authorize dentists to be able to supervise more than one hygienist at a time; most states cap this number at two or three hygienists. Through these combined efforts, a single dentist could ensure the profitability of his practice by managing multiple dental hygienists who conducted a relatively predictable and financially high-yielding set of tasks.

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<sup>&</sup>lt;sup>95</sup> Dental allied professionals in many other countries have been licensed to practice semi-autonomously since midtwentieth century.

These reforms, further, positioned dental hygienists as contingent labor from their inception. Predominantly the domain of women, 96 many private practice dental hygienists are generally not, like dentists, salaried FTE employees. Rather, many are part time employees who earn wages through a hybridization of hourly rates and commission based on service volume, and are exempted from the extension of medical insurance, retirement, or other benefits based on an assumption of husbands' employment. The gendered aspect of this labor practice, through which hygienist-driven profitability can sometimes subsidize the lower cost-efficiency of (historically male) dentists' work, has extended since the late 1980s in another direction: elective care. As some trends in cosmetic dentistry migrated from specialty practice to general practice, dental hygienists were implored to utilize their "skills" of personability to up-sell patients on cosmetic procedures that are performed in the clinic, such as the installation of porcelain veneers, and para-clinical technologies available for use at home such as prescription whitening kits. Through these developments, and others, dental hygienists' opportunities for autonomy deepened concordant with their obligations to it, as hygienists' expertise in certain techniques of entrepreneurialism – for example, sales – became tied to their paychecks.

The dental hygienist/dentist relationship has been shaped by contrasting ideologies about expertise, in which dentistry envisions semi-autonomous team members like dental hygienists as both contributors to the success of their businesses and as potential competitors whose threat must be contained through legislative and other means (Burt and Eklund 2005). While advanced programs in dental hygiene training, a professional organization, and licensing regulations for hygienists have been established; fights for higher wages succeeded; and the profession lauded as one of the most secure of the late twentieth and early twenty-first centuries, the profession has

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 $<sup>^{96}</sup>$  The word "female" was in the charter and bylaws of the American Dental Hygienists Association until 1964 (ADHA 2015).

also been continually obligated to defer to dentistry's ultimate authority. Allied dental professions remained governed through state and national statutes that are shaped, in all states but two, primarily by dentists.

# Recent attention to dental disparities and proposed dental team reform

The case of dental hygienists exemplifies the curious relationships between dentistry and mid-level allied professions. Whereas the emergence of autonomy among allied medical professions such as midwives, physicians' assistants, and nurses traces to sociopolitical events such as the women's and civil rights movements, attempts by organized labor to enshrine health as a human right, and the crisis in general medicine brought on by the increasing specialization of doctors, the dental profession largely exempted itself from such pressures (Picard 2009). Recent attention by influential bodies such at the Office of the Surgeon General and Institutes of Medicine to three related phenomena – the centrality of oral health to overall health, the failure of the dental industry to adequately address stratified care, and the strong evidence base, globally, of the safety, skill, and effectiveness of mid-level providers in many areas of care – has prompted thought-leaders *outside* of the ADA to advocate for the creation of semi-autonomous dental mid-level professions to improve access to care (Edelstein 2010b). Thus stakeholders including charitable foundations, dental training programs with an explicit emphasis on community and public health dentistry, and local collaborators such as Native American Nations are increasingly challenging orthodox dentistry for the privileged status as not only guardians and innovators of oral health, but also the moral and social standing conferred by their emphasis on equity (Burt and Eklund 2005). By imagining new workforce models that aimed to address

the stratification of care under existing dental industry norms, these efforts also rendered suspect the compassion and motives of the dental private practice industry.

The ADA's seeming disregard for the social stratification created by its organization of care – or, at least, the perception of this outcome – has recently created movement in favor of a new kind of mid-level dental provider in the United States. More precisely, this dynamic has created movement for a variety of mid-level proposals, eleven proposals at present, of which three have been implemented and two more are presently under development (see Chapter 5). These providers have been charged with addressing the needs of underserved populations – without exception, low-income people, racial or ethnic minorities, and/or rural residents – and their work has been, as such, highly circumscribed. This development has been highly politicized and, as I found during fieldwork, has continued and perhaps intensified private practice dentists' concerns about dental hygienists' autonomy at a systemic level, even as they encourage and can benefit from it in individual private practice.

Whereas the pilot discussed here, whose success depended on private practice dentists, mirrored closely the most conservative dental team reform – one initiated by the ADA – local private practice dentists' evaluated the pilot *as if* it represented the most liberal model.<sup>97</sup> Importantly, while all of the dental team reforms described in Chapter 5 and the pilot described here explicate clearly the supervision of hygienists by dentists, local private practice dentists I interviewed believed that the pilot, and all other dental team reforms developed for safety net

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<sup>&</sup>lt;sup>97</sup> A critical distinction among these types of models is what types of services they envision their respective mid-levels providing. More liberal models like Dental Health Aide Therapists, which are opposed by the ADA, advocate for mid-levels' utilization of a small group of procedures that are considered irreversible or invasive, such as simple extractions. By comparison the conservative model advanced by the ADA, the Community Dental Health Coordinator, is envisioned as providing primarily education, fluoride varnish, and facilitated referrals to care by a dentist. As discussed in Chapter 1, these are the same responsibilities tasked to pilot staff. The major innovation of the pilot was that, for lack of an appropriate supervising dentist in the three rural regions where the pilot was implemented, teams of dental hygienists and assistants were supervised remotely by a public health dentist headquartered in the state capital, who made bimonthly trips to each region to spot-check care.

settings, represented the risk of full mid-level autonomy and, eventually, market competition. These concerns were not made transparent, however. Rather, consistent with the ADA's approach, they were framed as concerns about the safety and quality of mid-levels' semiautonomous work if conducted outside of the watchful eye of not just any dentist but specifically a private practice dentist. Even in their skepticism about dental team reform in the public sector, 98 dentists evinced their commitment to dental team renegotiations in private practice, and identified their own expertise – as clinicians and as businessmen – as guarantors of their staff's high quality and, as discussed below, their own commitment to altruism. The symbolic weight of the pilot was particularly pronounced among local dentists and their colleagues who sought to remedy their profession's failure to adequately distribute care. Even as they attempt to propose structural reform, for example by endorsing the pilot to varying degrees or working to increase the acceptability of Medicaid among private practice dentists, they still navigated a professional norm that naturalized an individualizing and entrepreneurialist humanitarianism to increase marginalized patients' access to care. With this background in mind, we can now turn to an ethnographic vignette from the pilot, through which the navigations and stakes of expertise may be understood.99

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<sup>&</sup>lt;sup>98</sup> Some critics of the pluralization argument – including internal critics (of whom I consider myself one) – also express discontent that arguments in favor of liberalizing dental teams in the safety net may produce a two-tiered system of care in which underserved people are made to have only their barest needs met by such providers and, on the other hand, people of privilege get to enjoy the full extent of all procedures that private practice dentistry has to offer. As discussed in Chapter 3 the negative social effects of extremely stratified treatments, for example stigma in liue of restorations, are a concern of my work. I address concerns about tiered systems of care in more detail in Chapter 5.

<sup>&</sup>lt;sup>99</sup> The genesis of the project and its general goals are described in Chapter 1.

# Enacting expertise in a school-based dental public health pilot project

Nurse Heather came around the corner of the curtained off area of the multipurpose room with three second graders just as Evelyn, the dental hygienist, and Monica, the dental assistant finished setting up the curtained off stage of the multipurpose room with a portable dental chair, suitcase-sized compressor, and packets of sterile instruments. Screenings with the first two children went as one might expect. Some eye-rolling from the kids. Some prodding for them to brush better from Evelyn and Monica. Fluoride varnish and a couple of sealants, and they were done. The case of the third child, a red-cheeked, crew-cutted boy in a threadbare Spiderman shirt, no socks, and fatigue-print pants that were noticeably short, was more complicated.

The boy took off his glasses and lay quietly in the dental chair, his arms folded across his belly. Monica placed protective glasses on his eyes to shield them from the bright portable dental light, then turned to the sterile water and suction. Evelyn peered around in the boy's mouth for longer than she had the previous kids, first just looking and then using the dental mirror and probe, gingerly. "I'm just counting your teeth," she said, a phrase that I had come to understand as common, meant to allay young patients' fears.

But then she looked at Monica and mouthed, with a wince, 'poor thing!' The boy's hands now gripped his opposing forearms tightly. When Evelyn asked him if his teeth hurt, he nodded. Evelyn called me over to "help us a sec," an excuse to show me, as promised, what Monica and she meant when they called a mouth 'bombed out.' Most of the boy's teeth had signs of rampant decay: His gums were rimmed with sticky-looking yellow plaque. Dark vines of cavities crept across the outward-facing surfaces of seven teeth; two of his three fully erupted molars — or, molars that had fully moved from below the gums to the surface of his mouth — were cleaved

with black pits of decay. The area surrounding the last molar, partially erupted, was red and puffy. Hot looking. Angry. Evelyn asked him, gently, when he last saw a dentist. The boy shrugged and responded meekly. 'I don't remember.' She probed, 'Do you have a dentist?' 'I don't think so,' he responded. Evelyn continued, asking if he could remember the name of any dentist he'd ever seen?' He couldn't, a sign, she later told me, that it had been way too long since he'd seen a dentist, if he ever had. "Kids tend to hate their dentist something awful," she said. "They know who they hate, and if they can't tell you what dentist they hate, it means they ain't got one."

Herself a mother, Evelyn cajoled the boy to look at her directly. She turned off the bright portable light, removed her protective mask, and said. 'I can't do anything to help your teeth today, baby, because they're already tore up real bad.' She explained that she was sending home a referral to a dentist, and that his mother needed to take him to the dentist as soon as possible. "I know you want to take care of your teeth," she said, and he nodded. "But the dentist has to make them stop hurting first." He nodded again. A moment passed and he stayed in the chair. Evelyn cajoled him. What was the matter? The boy responded, meekly. "My mommy can't take me places. She can't drive. She's disabled." Evelyn probed, what about his daddy? He's dead, the child replied. Evelyn asked the boy who took him places. "Uncle Kermit," he said, "But he has to do stuff for his own kids and his car breaks down a lot." "Well, lemme think on it," she said, grabbing her paperwork and heading toward the exterior door, "and you listen to Miss Monica."

Monica showed the boy how to wipe his teeth with a paper towel and water after he ate breakfast and lunch at school, which would be more gentle than a toothbrush on those painful spots, she said. She walked him to the "treats" table and encouraged him to take as many items as he wanted. "Get you enough to share with your cousins and your brothers and sisters if you

have them, too." He lingered at the table, selecting one Spongebob Squarepants toothbrush for himself, another for his mother, and a full sized tube of toothpaste.

Evelyn returned, looking flustered. She handed the boy his home report and reminded him to have his mom call her. "We can try work out a ride," she said, "Just tell her to call us. It's really important." OK, he said, and thanked her for the toothbrush. He left the stage to join the other kids, who were waiting for Nurse Heather's escort back to class. Nurse Heather paused with us, tears in her eyes. It's a sad situation, she whispered, the extent of the family's poverty and isolation. It has been for generations. She should know, she explained, she'd been Uncle Kermit's classmate. Evelyn asked that Heather keep an eye on the boy's abscess and let her know if it worsened. Heather agreed.

It was only on our long drive home that Evelyn told Monica and me what she'd been doing when she left. She'd been trying to reach Dr. Bayer, the public health dentist supervising the project from headquarters, to see if he could find a nearby dentist to see the boy immediately. The abscess around that semi-erupted molar really concerned her, she explained, and she felt he couldn't wait for treatment. But her call kept cutting out before she could relay her needs. Way out at the end of the state as we were, her phone kept toggling between local and roaming, and she couldn't hold a signal. The school office staff wouldn't let her make the call – it was long distance – but they did let her call the director of the local health district, to whom she answered administratively. That call proved fruitless too, as it went straight to voicemail.

Some months later, I asked Evelyn if she ever found out what happened with that boy. She responded, with a heavy heart, that she didn't. His mom never called us, she explained, and when we tried to call, their phone was disconnected. How often does this happen that you just don't know what happens with the child, I asked Evelyn? Too much, Evelyn said. Too much.

She explained, "I mean, there's the ones who don't follow up with us but then there's also the ones where the dentist won't take our referral. Even though they told us they would. To my face! But now they won't. I'm not sure which is worse – the ones you don't know, or the ones you know it's the same old same old."

# Novel enactments of expertise or recreating the status quo?

What is the "same old, same old" that Evelyn referenced? From my observations, it is a complex set of relationships among dental providers in which dentists, from their positions at the top of the dental team hierarchy, both depend on and benefit their hygienists and assistants' from yet are somewhat suspicious of their autonomous yearnings. Dental hygienists and assistants, conversely, rely on dentists for employment and supervision, but have to cope with the whims of the dental professional hierarchy as well. These complexities seem more pronounced as dental team members' roles are increasingly renegotiated, both by the structures that govern them and within moments of practice. For Evelyn in the pilot setting, for example, these complexities were not only the customary ones of dentist/dental hygienist relations. They were also heightened by technical challenges to communication, the rigidity of her scope of practice in this "experimental" setting, and her awareness of her status as an actor within a highly politicized – and therefore closely scrutinized – initiative. Cognizant of the evaluation of, on one side, champions of the pilot including her professional group and the public health director who initiated the pilot (and, of course, her patients) and, on the other side, its skeptics including the Virginia Dental Association and school staff, Evelyn was aware of the need for propriety in her every professional action. This feeling of obligation was particularly heightened by the dependence of the project's success on some of its foremost skeptics, for reasons I describe

below. In this way, Evelyn, Kristin, and the other pilot staff were obligated into a particular kind of expert role, in which they had to utilize the clinical skills or prevention education skills for which they were hired as well as navigate the thorny sociopolitical arrangements that were necessary to the pilot's success. In other words, they had to demonstrate the cultural authority of clinical and social competence while at the same time bow to the mores of dental industry and school culture against which the pilot was cast. The crucial character of these navigations was apparent to me from my first introduction to the pilot and, as I describe in the next section, I quickly found myself caught up in them as well.

When I came to the pilot at the beginning of fieldwork, in July 2010, its protocol had been finalized but implementation had been temporarily delayed by the public schools' summer recess. At the time, the teams of public health dental hygienists and assistants were focused on introducing the pilot to two audiences: school administrators so as to obtain their commitment to schedule, and local dental private practices so as to obtain their commitment to take referrals of patients who needed treatment. Many of my earliest observations with the dental teams were of their work in their office spaces, where they organized the material infrastructure of the project: copying and collating consent forms, ordering supplies like toothbrushes, and interpreting school schedules so they could strategize their own around teacher in-service days, football tournaments, and other likely impediments. They spent a lot of time calling school principals, school nurses, and local private practice dentists to try to, in Evelyn's words, "sell" the project. While broader permissions had been negotiated higher in the project hierarchy – for example between the district health director and the school superintendent, or between VDA leadership and private practice dentists – the hygienists, themselves mothers of school-aged children and

former employees of private practices, knew that the key to project implementation would be not only permission at the individual level, but also enthusiasm.

The selling of the pilot that Evelyn described was not that dissimilar from private practice, in which sales was a key performance metric. Even early on I was keenly aware of how important it was for the pilot teams, like other examples from public and third sector services evaluated under neoliberal governance, to meet "sales" metrics like number of children served (see, for example, Sloan 2015). 100 The dental hygienists who led the teams understood service volume and cost-effectiveness as key to the project's economic viability<sup>101</sup> as well as to project evaluation, potential renewal, and, therefore, continuation of their jobs. The target audience for sales was, however, different, than in private practice and, in the hygienists' opinions, more challenging. Whereas they observed that dental patients tended to respond to their sales pitches by balancing vanity against available resources, sometimes opting to take specialized credit lines for procedures, dentists were generally wary of accepting publicly-insured children and elementary school staff's interest was shaped by a number of externalities, for example their obligations to ensure that state-determined instructional hours mandates were met in preparation for standardized testing. School staff's openness to the project was also shaped by their experience of its predecessor, the dental public health mobile unit in which a *dentist* was able to treat decay, not just screen or try to prevent it. Convincing many principals and school nurses of the importance of the pilot without gas-lighting the health department with a description of why

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During the pilot's "down time" from schools, teams also provided educational and preventive services in a few other institutional settings such as WIC clinics and day programs for adults with intellectual and developmental disabilities. The service goals of these settings were more relaxed, considered "add-on" benefits of the pilot. So, as I observed, were dental teams' experiences, as they seemed to enjoy the pace and service orientation of these settings in a way that hearkened a similar emotional tone among dentists who volunteered at the RAM.
101 The pilot billed Medicaid for reimbursable services such as the application of fluoride varnish and dental sealants. While the HRSA grant partially funded the dental team's salaries, Medicaid reimbursement was key to its ultimate economic viability.

dental services were being slowly phased out was key to many of these early "sales" conversations. A few months later, once the administrative mechanisms were set up, some referring dentists were agreeable, and some schools were scheduled, the project got underway. I accompanied the dental teams to a number of schools which followed this general pattern:

We would meet at a central location early enough in the morning to drive the distance to the school and get set up. Oftentimes we would depart from a central meeting area by 7am to drive a minimum of 35 minutes and sometimes as much as an hour and a half to the school. Prior to meeting me, the dental hygienist had frequently begun that day or ended the prior one at the local health department office, where she loaded up either a state car or, more frequently, her own car with equipment, and then left to meet the dental assistant and me. After arriving, we would check in at the school's office, unload equipment from the vehicle and set it up, then work with the office staff or the nurse to conduct a number of tasks: comparing consent forms with attendance sheets to determine which patients were present; timing classroom-based health education to test preparation; and pausing all operations during lunch, fire drills, or indoor physical education periods on rainy days. Then, unless we were returning to that school the following day, in which case we could leave the equipment in place, we would have to make sure that we completed these tasks in enough time to pack up the equipment and drive home.

The timing of the workday was crucial because, as state employees, the dental teams were required to count travel among their work hours but explicitly prohibited from working longer than an 8.5 an hour a day in which half an hour was allotted for lunch. Unlike in the private practice setting, where procedure surplus opportunities could be incentivized through bonuses, overtime was strictly prohibited. Thus, accounting for the amount of time required for each activity, loading and unloading equipment, driving, and completing clinical and

administrative accounting, the actual time available for seeing children was frequently limited to three-and-a-half hours in the middle of the day, of which at least a half-hour was usually non-usable due to the lunch period that, in the context of a high rate of state-subsidized lunch, could not be impeded upon. While on no day that I observed was the team ever at risk of having to *skip* a child's services in the interest of time constraints, more than once did I observe some relief among teams when some small percentage of children consented into the program were absent from school that day, because it meant that the dental teams could have a little padding in the time required to complete all of the children's clinical services in the limited amount of time available; the consonance between the pilot's low response rate and the ability of its teams to complete its tasks left me wondering how the pilot could have been completed successfully had it had a larger rate of response.

As the discussion in this section suggests, one of the foremost enactments of expertise demonstrated by the pilot staff was not just time management but, in the interest of meeting volume-based metrics, the *gracious* management of time. Pilot teams had to maintain outstanding personal relationships that were crucial to the implementation of the project even as they were extremely pressed by such externalities as bureaucratic limitations on their hours. Of course, such areas of expertise have long been understood as central to the dental hygiene profession, even in – especially in – private practice. Despite the ADA and local dentists' protestations that mid-level autonomy in safety net settings risks empowering them, through the expanded delivery of clinical work, beyond their rightful role, thus facilitating their desire to open their own practices in the public or private sector, the opposite was evident here. Through their work in the pilot the dental teams spent even *more* time conducting the emotional and bureaucratic tasks that might ensure their success and had even less liberty to conduct clinical

tasks under loosened restrictions like in the example which opened this chapter. Moreover, there is the question of whether pilot staff would want to take on the tasks and obligations of independent practice.

One of most interesting lacunae in the literature on dental team reform is the topic of interest among potential semi-autonomous mid-level providers: Would the members of the workforce who are envisioned as taking on these roles – women, racial and ethnic minority, graduates of technical colleges, rural residents, and so forth – want to practice independently, initially in the safety net and, perhaps, in the marketplace? Beyond a few small surveys and anecdotes held up by professional organizations, it is hard to tell. So, I asked this question of pilot team members. Generally, they had no desire for full autonomy. Working mothers, many of them single or the primary earners in the family, they juggled the obligations of home with those of offices whose schedule flexibility they appreciated, and they just didn't want to take on the risks and burdens of entrepreneurship: "Getting your business plan together, always stressing about making payroll, carrying your own insurance," Tina, a dental assistant who was considering hygiene school told me, "whew, that's just not for me. Besides, I'm not sure independent practice would help poor people anymore than the arrangement we have now anyway." She continued:

It's not the capability thing I have a problem with, it's the convenience thing. The hygienist is capable. She's gone to school and she's certified. But she'd still have to refer her patient to the dentist for fillings, for extractions, whatnot. That's just not convenient for the patient. Isn't that the point, the convenience thing? So instead of one dental office they have to go to two now? That taxes the patient. It just doesn't make sense.

Among the dental hygienists and assistants who participated in research, only Johnna, a 25-yearold mother of a preschooler, and her family's primary income earner aspired to independent practice, citing what she imagined would be a contracted period of study. "A few years in a dental therapist program versus seven to finish my Bachelor's and then dental school? That would help a lot," she said. A first generation college student when she pursued her dental hygiene degree while also working as a dental assistant, Johnna's goals centered on the advancement of her education and skills in order to help more underserved people in her home county, with an understandable preference for expedience: She hoped to have another child soon. Given the unlikelihood of independent practice among dental hygienists coming to Virginia or a neighboring state any time soon and her unwillingness to move to one of the faraway states where dental therapist programs existed – Alaska or Minnesota – dental school (and the prerequisite Bachelor's degree) remained her only option. Indeed, almost a year after I left the field she updated me that she enrolled in a local college to complete her undergraduate degree. As I write this manuscript, she has further updated me with the news that, pending her forthcoming graduation, she was accepted to three dental schools. Two of them offered her large scholarships. Johnna's dream of independent practice, albeit as a dentist, is underway.

## Dentists' perspectives on dental team reform

As small as the provider community in southwest Virginia was, it wasn't long before I interviewed dentists who knew of the pilot. In fact, at some point, given that I was introduced to a number of these dentists by a mutual contact from the medical field who openly endorsed the pilot, I started getting the impression that dentists I interviewed saw our interaction as an opportunity to pump *me* for information about it. Mindful of the confidentiality engendered by the pilot, which mirrored my own to research participants, I tried to share information that would be publicly available in project reporting, such as how many kids received sealants, but I was cautious about more detail and I explicitly refused to answer dentists' questions about which of

their peers were seeing referred kids. Over time, with increased confidence, I would muse, warmly but pointedly, "would you want me telling another dentist about <u>your</u> payer mix?" Frequently, private practice dentists took this tête-à-tête as an opportunity to turn the conversation to dental team reform more broadly, and the facets of it that they supported...or didn't. Charles, a general dentist, offered this example:

My brand new hygienist...is licensed to give anesthesia. Local. That's a big help to me to get more care delivered. She can get somebody numb while I'm doing something else. You know, I walk in, all of a sudden I'm ready to do the filling or whatever...If you could get where my expanded function assistants could actually place the restorations and make temporaries and do a lot of the hands-on care, I think that would be a huge step toward being able to deliver more quality care because these girls, and I say girls because most of them are girls, are very meticulous and they are able to do things that I think dentists over time tend to see as sort of somewhat menial tasks.

So I asked him: Is this the kind of thing that it would make sense for *all* mid-levels to do? He said no. Given our prior discussion, I was surprised. He had spent much of our conversation venerating his employees' skills and judgment, and I had expected that stance to extend to other team based settings. But Charles was insistent. Workforce movements like the pilot were being organized from outside of what he called "professional dentistry" – a term by which he tacitly excluded public health dentistry – in contrast to the cultivation of dental hygiene and dental assisting, which had occurred from within the profession. The origin of the dental team reforms in public health dentistry made him suspicious of their ultimate goals. They're aiming to "hang a shingle," he said, and he just didn't agree with that.

One of the region's few dentists who saw a high percentage of publicly-insured patients — he was the only local dentist I knew who accepted adult dental Medicaid — Charles worried that safety net expansionism could threaten his bottom line. Initially, I didn't understand this concern. His practice appeared to be thriving; his waiting room, parking lot, and chairs were always filled, and pilot patients who were referred to him told me of his long wait list. It was only when I realized how one of the characteristics through which publicly-insured families are stigmatized

that I understood his concern. While many publicly-insured patients were ongoing clients, dentists often believed, as described in Janie's story in Chapter 3, that they were, ultimately, undependable – oriented toward absenteeism, "flaky" – and strategized scenarios that anticipated the replacement of potential lost income, such as over-booking. Even within the context of extremely low ratio of providers-to-residents – and even lower Medicaid-accepting-provider-to-resident ratios – dentists paid close attention to market competition and seized upon strategies that would give them an edge. For some dentists whose practices excluded publicly-insured people and targeted patients with private insurance and/or disposable income, this meant always keeping up with the latest technologies to be used for advanced cosmetic procedures.

Consistent with many other dentists in the region – and, indeed, the ADA, who originated this argument against mid-level expansionism (2013) – Charles framed his concerns about dental team reform *outside of the private practice setting* in terms of safety and quality. He feared such changes would risk loosening the kind of assurances that he felt only a "professional" dentist supervisor could provide. All dental team members should still "answer to an overseer, a dentist," he said, continuing:

I'm a great supervisor. Ask any of my girls. They'll tell you! I know I could be *that good* at mentoring even more auxiliaries. The expansion they need around here is to loosen up the supervision ratio so dentists can supervise more than two auxiliaries at a time. *That* would really open things up for more Medicaid patients.

Importantly, the mid-level expansionism that Charles supported was within the auspices of general supervision and employment by a private practice dentist, rather than the use of remote supervision posited by the pilot program (see also (Nash, et al. 2012). In the case of Charles and others who accepted public insurance for payment this meant, among other things, maximizing productivity through extended team formations. Were he able to bring on more high-yielding supervisees, he could simultaneously (1) expand his practice's productivity, (2) ensure his

position at the top of the team's hierarchy, (3) circumscribe any threat of autonomous mid-level competition, (4) transfer the risks of business expansion from himself, as salaried staff, to his mid-levels, whose employment would likely follow the standard model of contingency, and (5) continue to (cl)aim to increase low-income populations' access to care.

Charles' perspective on dental teamwork was common among dentists I interviewed, and it tells a lot about how dentists' identities are re-asserted paradoxically through teamwork. Private practice dentists claim to be business savvy and innovative in hiring highly skilled workers to offer more patient care, increase the practice's "productivity" (profitability), and free themselves up to do more exciting work. Yet maintaining professional hierarchy and containing the threat of competition were apparently nonnegotiable. They wanted dentistry, as an area of expertise, to retain the cultural authority, following Epstein, to determine certain "truths," such as the appropriate payer mix or a plan of care. Buddy, the dentist I knew who was most amenable to broader dental team reform in highly selective safety net settings, offered another idea:

There is an access to care problem and people need to be treated but what I would like to see is satellite offices for my practice. I mean, the stuff we've got now with YouTube and the ability to stream digital videos – you can take an intraoral camera into a mouth at a satellite clinic, send that to me in my office, as a trained hygienist, a D(ental) A(ssistant) II, a mid-level provider, whatever the case is, and say 'Doc, they're not on any blood thinners, they don't have any medical issues. This tooth is tender when I touch it. I just e-mailed you additional photographs. A digital x-ray. In fact, here is the patient. Why don't you talk to her? Why do I need to be there when I can say 'OK, numb her up and take the tooth out.'...If it's a new patient exam, though, send her over here. I can formulate a treatment plan.

Paradoxically, Buddy's proposal would not necessarily increase access to care for low-income people, at least not in his practice; he was one of the region's dentists who did not accept public insurance. Yet when I asked him about the use of teledentistry in combination with semi-autonomous midlevels in the dental safety net, he hedged a little. He felt that the professionals "on the camera end" couldn't be "just anyone with a two year degree," as he – wrongly –

characterized most of the new mid-level models (see Chapter 5). They needed to be "backed up" by the assurance he felt only an experienced private practice dentist could provide.

Through Charles, Buddy, and other dentists I came to understand this paradoxical position on dental team reform. Private practice dentists want to retain the authority to negotiate and even exploit contradictions in the organization of dental team work in order to benefit their practice's profitability and, arguably, patients and even the mid-level team members, as in the case of Evelyn which opened this chapter. They were open to loosened supervision arrangements, such as the renegotiation of supervision ratios advocated by Charles or the use of telecommunications proposed by Buddy. But dentists were also adamant about retaining the authority to determine under what circumstances these negotiations might occur, at both the micro-level of practice and the macro-level of policy, so that they could circumscribe any threats to their business models. For them, this meant an openness to reform so long as it benefited private practice, but not if it was to be carried out where it was most needed: in the safety net.

These negotiations were deeply ideological, as suggested by Carr, Salhani and Coulter, and other scholars. They spoke to fundamental understandings of the nature of practice, of professional hierarchy, and even of propriety, for example in terms of abiding with existing statutes versus bending the rules for reasons like benefiting patients, affirming team members' skills, or, of course, contributing to profitability. Many dentists felt put upon by regulations such as the restrictions on supervision capacity mentioned by Charles; the irony of their perspective did not escape me, as it was many of these same dentists who proposed to regulate the dental pilot tightly, and surveil it closely for compliance. While some dentists, like Charles, conformed with these regulations even though they didn't want to, other dentists – and, by extension, their

dental teams – did not. Evelyn's story, which opened the chapter, was far from the only case in which the areas of expertise renegotiated were patently illegal.

Whereas, as Evelyn mentioned in the vignette that opened this chapter, dental hygienists in several states are allowed to treat the area below the gumline, in no state is an unlicensed dental assistant allowed to clean teeth, a practice common among older dentists in my fieldsite who employ their wives as assistants. Similarly, in very few states are dental hygienists or assistants licensed to do extractions, a procedure that, when simple – meaning, without need for surgical anesthesia – some proposed dental mid-levels would be able to do. But as the story of Renata, presented in Chapter 3, shows, some are already doing it. During an interview with Nancy, the dental assistant who referred me to Renata and had been present for her care, her lack of authorization to extract posed a moral quandary. Her boss, she explained, "really" needed to retire. He was losing the physical strength to extract teeth well, and he had already lost the eyesight and level of concentration to reliably numb — and extract — the correct one. On a number of occasions, she guided his needle to inject anesthesia, his instruments to cut into the right area, and, on one occasion, his hands to help him pull the tooth out. Conscientious and mild-mannered, Nancy felt morally wrought: She didn't want to practice outside of her legal scope. But she didn't want her boss to practice what participants in my research called "poor dentistry" either.

Thoughout data collection with dentists, quality was a constant referent in dentists' concerns of dental team reform. As the example of Nancy shows, the "poor dentistry" that dentists hoped to guard against by opposing dental team reform was already being practiced by a few of their colleagues. I could not help but note how private practice dentists assumed that the care performed by mid-level colleagues would be of poor quality and high risk, conducted by

inexperienced and inadequately trained clinicians; this rhetorical frame suggested, to me, the success of the ADA's campaign against all dental team reform except the Community Dental Health Coordinator position it advocated. As Vince, a second generation dentist in the region, said:

Dental work takes a lot of training. You can mess up just like that (snaps). It takes a lot of skill and the person with that skill is the dentist. Hygienists say they'd love to drill teeth. (sarcastically, miming handing me a drill) 'Here you go.' They think it's simple. It's not simple, it's scary. Bad things can happen pretty quick. My associate cut the floor of the mouth, just barely. There's a big artery there. You can kill someone quick. It's surprising we don't have more problems than we do and I guess that's 'cause we're trained. To pass that (work) on to people who aren't as trained? (pause) Now, is there a huge access to care issue (long pause). There is but I'm not sure – Is having cheap care the answer? It shouldn't be. I guess that's what we're up against if it happens in other states. I don't like it. It's a real disconnect people have.

Such commentaries contrasted the level of skill by which dentists, Vince included, venerated their own dental teams, typically within a framework that, like Charles, validated their role as talent scout and mentor, and sometimes vilified the skills of their younger DMD or DDS associates, who sought to work with them. This observation was one of a number of contradictions I gleaned from dentists' discussion of dental team reforms in the safety net.

My interviews with dentists not only confirmed that they preferred assigning the mundane tasks of prevention and preparation for basic procedures to dental hygienists and assistants, respectively. They also revealed an additional characteristic of dental task assignment that I was not expecting to hear: dentists' admission that even the advanced work they did was not, in the words of Vince, who had just finished telling me how specialized and delicate dental work was, "rocket science." "Root canals, fillings, crowns," he said, "Anybody can do it."

Aware, by the time of our interview in June 2011, that dentists believed me to be an advocate of dental team reform based on my relationship with the pilot, I seized upon my interpellation and asked him who "anybody" was, and if "anybody" might be, in the case of safety net patients, one of the new kinds of proposed dental team members. "Absolutely not," he said. "You're throwing

too much responsibility on people when they start taking out teeth or filling teeth." I tried to reframe the question, to better understood where the line of responsibility might be drawn within dental team reform, but he was already heading off in another direction: He didn't want his son, who had recently completed his DDS, to have studied for eight years, incurring \$200,000 in debt on top of a \$250,000 loan for a new practice, just to see some person with less education "waltz in" and undercut his prices. "And you know I care, Sarah," Vince told me, "you see me at the MOMs. You know I want to fix this too, but not this way." Indeed, I knew Vince to be one of the most avid volunteers around. But I also had the sense that his tether to organized dentistry's orthodoxy was clouding his understanding of the dental public health pilot, as it did with so many dentists in the region. Because, as it turned out, he was one of those dentists who had told Kristin "to her face" that he would see clients she referred, and then never, to her knowledge, scheduled them.

## Cultural authority: The high stakes of provider approaches to dental disparities

Vince's conversational pivot, from dental team reform to the MOM project, didn't strike me as especially noteworthy at the time of our interview, nor did similar conversational turns with other dentists. As I have revisited my conversations with private practice dentists in the region I have come to observe that these two instantiations of the dental safety net – dental team reform and charity care – seem somehow bound together in dentists' minds. I have also come to believe that this binding helps explain what's at stake in the debate over access to care. Namely: whose approach will reduce dental disparities? Stakeholders external to dentistry, whose advocacy of dental team reform serves to highlight dentistry's failure to provide for the *entire* population, rather than just the well-resourced segment? Or organized dentistry, whose emphasis

on individual altruism might serve to enhance its public image and preserve not only the technical aspects of its expertise, but its moral and cultural authority as well?

It is an obvious choice, if not an expected one, for a critical social scientist like me to critique a power center such as the ADA when dental disparities can be attributed, in no small part, to the organization of care. Yet it is also extremely uncomfortable, to me, to paint such a cartoonish picture in which private practice dentists, on one side, appear to be deliberately limiting the care delivered to low-income and other underserved people and extrinsic stakeholders, on the other, stake an advocacy claim. Such a position would fail to account for more subtle politics at play, for example the potential of dental team reform to enshrine a truly two-tier system of care that differentiates standards of care not in terms of safety or quality, but kinds of services – for example, customized and therefore "natural looking" prosthetics versus often false looking and ill-fitting standardized prosthetics – by income level.

This discomfort is compounded by my observations in the field of dentists whose eagerness to reduce dental disparities is apparent in their practices, whether Charles' prioritization of publicly-insured patients or Vince or Buddy's frequent donations of services. They welcomed the opportunity to participate in this research as an opportunity to brainstorm with me toward oral health equity. Mostly men and many of them from the area, they had spent years considering how the dynamics of the area shaped their practices, their patient populations, and their status as employers: the busts in the coal industry, for example, which resulted in patient declines, with that, their need to lay off staff people – assistants, office managers – with whose families they had long histories. Moreover, they were keenly aware of the ways in which their profession's practice norms vilified them at a moment when dental disparities was gaining

increasing political attention, an attention that, combined with attention to the MOM project, thrust far southwest Virginia's dentists into an unwanted spotlight.

It has long been claimed that the dental profession has the highest rates of depression and suicide among professions in the United States, a statistic that despite academic critique (CITE) has become a social fact in the dental practice community. Dentists spoke to me of their feelings of depression and inadequacy, as they took very personally patients' critiques of their work, and as they saw what they felt was so little change in the status of the dentition of their neighbors. Indeed, in conversations I had with some of the MOMs' earliest volunteers, the topic of depression frequently came up. They had imagined their commitments to be for five years tops, during which time they anticipated that larger dental reform, broader oral health education, and other interventions would limit the duration of time for which the MOMs would be needed. As a former volunteer health educator, I empathized with their frustration that public outreach and altruism were not enough to reduce dental disparities. Yet as I have come to understand the urgency of clinical treatment to reduce both existing dental problems and encapsulate newly emerging ones, as well as the importance of dentition to psychosocial identity, I have also become a more vociferous critic of private practice dentistry as well, and the stratified ways in which it organizes care. The cultural and moral standing that accompanies its carefully maintained role at the top of a professional hierarchy calls for critique for both practical and political reasons, and I have endeavored to do that here.

During one of my last instances of formal data collection, at an October 2011 public summit on oral health in Virginia, a panel of experts discussed initial results from the pilot. From a stage in the grand ballroom of an historic hotel in Richmond, Virginia, the Virginia Department of Health dental director shared what she framed as indicators of the success: At that point, six

non-consecutive months into operations (due to summer recess), the three dental teams had screened around 1,500 children in three health districts. They had placed, on average, two sealants per child and referred about half of the children to dentists for fillings, evaluation for orthodonture, and other services. The remote supervision aspect demonstrated a savings of almost \$5.00 per sealant placed, when cost-compared with direct supervision by a dentist in a VDH dental clinic; this represented a cost savings of nearly half when compared with private practice (see VDH 2012). The director declared the project a modest success, noting her desire to increase the number of children seen and to work out unanticipated kinks such as the low enrollment rate of children identified by school nurses as most in need of services. She then opened the floor to questions.

From the back of the room Delilah Walton, an outspoken leader of a large charitable foundation, stood up. She began her question: Now that we have these indicators of success, a large pool of applicants to staff projects like these, <sup>102</sup> and funders like her organization to support them... She turned to a VDA representative who sat on the panel and asked, how can we get these initiatives made permanent in all public health settings through changes to practice law? No, she corrected herself, in *all* dental safety net settings? Before the VDA representative could answer another audience member stood up, introduced herself as a pediatrician whose practice served primarily publicly-insured children, and posed an addendum: in *all* health safety net settings. She would love to have a remote-supervision dental hygienist on site, she said, suggesting her broad construal of the safety net to include medical practices with a large Medicaid patient base. The VDA representative smiled like the Cheshire Cat, an impish twinkle

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<sup>&</sup>lt;sup>102</sup> There were approximately eighty applicants to the three dental pilot hygienist positions. This overage reflects a combination of factors, for example the close proximity of three dental hygiene training programs and the inadequate number of dentists in the region to employ graduates.

in his eye. He had anticipated Delilah's provocation, but the unexpected compatriot's request represented precisely the expansionism his constituency was working to guard against. "Baby steps, Delilah," he said, returning to the original question, "You know I have to answer to my colleagues."

Later, during subsequent interviews, Delilah and the VDA representative independently recounted to me their experiences of that moment. Long-time colleagues and negotiators, it turned out that the exchange was just the next iteration of their long-term tête-à-tête. She tried to push him to state, publicly, the VDA's failure to support what she saw as innovative and sustainable reform. He tried to navigate his role as representative, guardian, and employee of his professional organization and, as I describe in Chapter 5, one of its strongest internal critics, though not so strong as to endorse the location of remotely-supervised mid-levels in Medicaidaccepting pediatricians' offices. Ultimately, both parties threw their energies behind other initiatives – for Delilah's foundation, marketing a Medicaid payer mix model to community health centers in the state; for the VDA representative, advocating for the ADA's Community Dental Health Coordinator role – and one measure upon which they could both agree: the allocation of state funds to charity dental care, to be distributed equally through Delilah's foundation and the Virginia Dental Association Foundation in support of its MOM projects. As in the past, the action deemed most politically expedient was also one that perpetuated stratified care.

Advocates of the pilot had envisioned its routinization into ongoing VDH services, and perhaps other safety net settings, as in the case of the # states where similar remote-supervision school-based programs already operate. In some ways their hope has come to fruition: The temporary changes to practice law were made permanent, although these gains were severely

hindered by the limitations of their distribution to only VDH settings rather than the extended safety net – for example, community health centers or homeless shelters – to which Delilah's question spoke. Following the completion of the HRSA workforce grant, only one of three of the public health districts where the pilot was implemented have been able to continue it, and just barely, through the redirection of some discretionary monies. Meanwhile, public health clinical dental services have been retracted statewide as part of austerity measures and, concurrently, the Virginia Dental Association has focused its advocacy on two other areas that represented those I heard advocated by dentists during fieldwork: the implementation of the Community Dental Health Coordinator initiated by ADA and the allocation of millions of dollars toward the MOM project. As discussed in Chapter 5, the Virginia Dental Association has, like the ADA, had majorly de-emphasized efforts to increase Medicaid acceptance rates among private practice dentists. Despite the fact that, as Evelyn said, the dental pilot project was literally putting money in their pockets by referring patients for treatment, dentists' anxiety about the disruptions they believed it might cause – disruptions in professional hierarchies, disruptions in competition in an open marketplace, perhaps even disruptions to what Epstein argues is a specific cultural prestige associated with the health professions – appear to have won out.

## **CHAPTER 5: PROPOSED SOLUTIONS**

## **Introduction**

In May 2014 I presented at a regional summit of DentaQuest Foundation <sup>103</sup> (DQF)'s Oral Health For All initiative, and participated in two days of grantee workshops that followed. As the event's first invited speaker, I was charged with giving attendees grounding in the lived experiences of barriers to care faced by dentally underserved people. Many people at the meeting would not be familiar with these everyday realities, the organizers told me, because they were invited, in large part, for their ignorance. DQF had called the meeting to prepare current grantees for a forthcoming funding solicitation that aimed to expand stakeholder networks to include primary care clinicians, healthcare administrators, and others who did not yet – but meeting organizers posited, should – understand oral health as part of overall health. <sup>104</sup> The meeting's organizers felt that my talk could not only impart knowledge, but also incite critical reflection, commitment, and, most importantly, action from people who were hearing about dental underservedness at that level of detail for the first time.

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<sup>&</sup>lt;sup>103</sup> DentaQuest is three-pronged institution. Its corporate arm is the country's third-largest dental benefits administrator, a term used by dental "insurers" to distinguish its economic model, prepayment of rates negotiated using bulk pricing, from the pooled risk model which typifies medical, life, and other types of insurance. Its Institute is a research and education branch aimed at improving practice management in both private and public settings. DentaQuest Foundation is the institution's charitable arm, and one of the major funders of the oral health movement in the U.S. While the activities of each of DentaQuests' branches are administered independently, there are many areas of overlap. For example, the company administers public dental insurance benefits in 29 states, work that stands to benefit from the Foundation's advocacy to expand dental public benefits and the Institute's emphasis on increasing and making more efficient practice productivity. In these ways among others, the threeprongedness of the institution exemplifies neoliberal health governance, as introduced in Chapter 1, for example as it advances the private management of a public good and blurs the boundaries between profit-driven, nonprofit educational, and charitable work. While my talk for DentaQuest was uncompensated, the Foundation does fund a significant portion of the work of the Virginia Oral Health Coalition, on whose Board of Directors I serve and in whose grant-writing efforts I have been involved. The ethics of funding sources for oral health in an extremely limited field primarily driven by payers charitable arms has been a major and ongoing discussion topic among VaOHC Board members.

<sup>&</sup>lt;sup>104</sup> Oral Health 2020 is "a multi-year effort to strengthen and unify the (national oral health) network, build upon current initiative strategies, and expand impact" (DQF 2014). Its four goals are explicated below.

Aware of the Foundation's "systems change" approach and the grant opportunity's emphasis on health equity, I developed my talk to foreground the next day's workshops, which promised to critique oral health disparities from a social justice perspective. <sup>105</sup> I shared extended case studies of dentally underserved people including Jeff and Janie, introduced in earlier chapters in this dissertation, then discussed systemic barriers to care, for example the inadequate safety net infrastructure in the region (see Chapter 2) and impediments to patients' utilization of dental Medicaid in private practices (see Chapter 3). My talk followed rousing opening remarks from DQF's President, in which he shared his vision of an oral health movement inspired by women's rights, civil rights, marriage equality, HIV/AIDS and breast cancer community organizing, and other social movements. The audience responded enthusiastically to his talk, initiating an impromptu discussion that included many commendations on the politicized nature of his vision; this sentiment would persist after my talk as well, as workshop leaders from a social justice organization facilitated a half-day workshop on racial equity using a module that included, among other topics, an extensive discussion of red-lining, or the systematic exclusion of Black-Americans from home ownership in the mid-twentieth century.

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<sup>&</sup>lt;sup>105</sup> DQF contracts with the Interaction Institute for Social Change (http://www.interactioninstitute.org/) on grantee meetings and other events. For more on DQF's system change framework, see http://dentaquestfoundation.org/impact.



Figure 8DentaQuest Foundation's Systems Change Dashboard

I found this discussion exhilarating. Perhaps wrongly, I had assumed the meeting would be apolitical, and I took participants' enthusiasm to portend positive reception of my talk's critiques of the constitution of the dental industry, and its identification of the urgency of reform.

Generally, this was the case. As I found out over the next two days, however, positing dental

industry reform as crucial to served more to reveal the limits to the systems change ethos of the meeting than it did to inspire work in that direction.

#### Box 1: Oral Health 2020 Goals

Goal 1: Mandatory inclusion of an adult dental benefit in publicly funded health insurance.

Goal 2: Oral health incorporated into the primary education system.

Goal 3: Comprehensive national oral health measurement system.

Goal 4: Eradicate dental disease in children.

Nowhere in the meeting's discussions was made mention of the role of dentists in achieving oral health equity. When I asked fellow attendees about the absence of clinical dental care from discussions, referring to not only the presentation that I had just given but also the robust evidence of the unusability of public insurance (see, for example, Castañeda, et al. 2010; Catalanotto 2012; Kelly 2005; Milgrom 2008), a number of attendees responded with puzzlement and support. Indeed, some agreed, this was glaring omission. Others responded differently. For example, an administrator of public dental benefits of one state in New England asked how I concluded that the problem with dental benefits utilization lay with dentists, rather than patients? The disparities between high medical utilization and low dental utilization, he argued, was attributable to publicly insured adults' disinterest in their oral health or, perhaps, lack of dental care needs. His critique aligned with a social justice philosophy in sentiment – that the utilization of public benefits for dental care needed to be improved – if not in conclusion. At a moment when adult dental Medicaid utilization in his state was low and public pressure for austerity high, he struggled to justify the ongoing expense. But his explanatory reductionism served only to recapitulate the "consumer responsibility" ethos of market-based health care in a

neoliberal milieu that characterizes public entitlements in the United States (Maskovsky 2000; Rivkin-Fish 2011; Willging 2005), and obviate the structural inequalities that DQF urged grantees to address. Medicaid patients "just can't get it together for dental like they can for medical," he sighed.

The administrator's emphasis on responsibilizing underserved patients was reflected in the Initiative's goals, more generally, which emphasize providing prevention education and dental benefits to patients without also carving pathways for their utilization. This ethos persisted throughout the meeting, as well. Thinking that any dental clinicians in attendance might offer some insight into how the empowerment of patients vis a vis education and dental benefits might translate into clinical care, I tried repeatedly to ask one. To my disappointment, the only dentists I met worked in public health, primarily in non-clinical managerial roles, and professed themselves deliberately distanced from the private sector. Theirs was a sentiment I had observed in other settings as well. For example, on a dental public health listserv in which I participate, a number of safety net dentists terminated their membership with the American Association of Public Health Dentistry in Spring 2015, in protest of the organization changing its bylaws to limit voting rights to members who have DDS or DMD degrees, a change that excluded nearly a third of membership from the decision-making process. This change in governance was, according to both former and current members, a concession to the ADA's influence, which sought to limit the propensity of the organization to be guided by the motives of non-dentists, specifically the dental mid-levels who the ADA imagined would constitute a larger share of governance over time. At the DQF meeting I met only a few private practice dental hygienists, all of whom had left clinical work to become project directors, policy advocates, and public health administrators. By the end of the meeting I was confused by the dearth of dental clinicians

at the meeting, so I asked a senior DQF program official, who was also a former private practice dentist: Where *were* the dentists? "They aren't really our focus," he told me. 106

## Why – and how – should an anthropologist study dental safety net reform?

My unrequited search for practicing dentists at the DentaQuest Foundation meeting has, unfortunately, typified my experience in the oral health movement. From reading closely the reports of many institutions that address dental disparities to participating in local, state, and regional networks via in-person meetings, teleconferences, and electronic communications, I have found myself confronting one question time and again: Where is attention to the social and moral obligation of dentistry and its major professional organization, the American Dental Association (ADA), to address what I described in Chapter 1 as the twinned phenomena of dental disparities?<sup>107</sup> Aside from efforts to increase the dental Medicaid reimbursement rate (see,

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<sup>&</sup>lt;sup>106</sup> DentaQuest Foundation does work with dentists at times, though not on initiatives that drive systemic change. For example, it supports urgent, short term clinical work through its Community Response Fund; convenes "like minded" representatives from the dental industry through the U.S. National Oral Health Alliance; and promotes medical/dental safety net provider relationships through its Strengthening the Oral Health Safety Net initiative. However, these initiatives tend to appeal to clinicians and administrators already oriented toward supporting the dental safety net, for example community health center staff or private practices that accept Medicaid; outreach to recruit exiting dental practices to this mission is not a primary activity. While DQF engages with organized dentistry as a funder, for example providing resources to the American Dental Association to convene summits on access to care in 2009 and 2013, or funding in support of high profile dental charity events, such as the first Mission of Mercy free dental fair to allow dentists from across the country to volunteer, in the humanitarian landscape of post-Hurricane Katrina New Orleans, these convenings tend to be extremely distanced from controversy. My off-the-record conversations with DQF staff and some of its longest-term grantees suggest that DQF's engagement with organized dentistry is orchestrated extremely carefully. On the one hand, this approach is understandable for the sake of strategy. On the other hand, such self-censorship both inhibits the true systems change that DQF can achieve and contributes some assurance to the profitability of DentaQuest's corporate side. Conversely, the ADA has endorsed DQF's development of an oral health curriculum for primary care providers called Smiles for Life that focuses, primarily, on patient education and screening.

<sup>&</sup>lt;sup>107</sup> A few private practice dentists and many dentists employed full time in community, public health, university-based clinics, and other institutionalized clinical settings participate in and often lead oral health equity work.

for example, The Pew Center on the States 2011), an incentive whose evidence is mixed (Kenney et al. 2010; Nasseh and Vujicic 2014, Sparer 2012), there is little to be found.

When I began this research in 2010 I supposed that efforts to address oral health disparities were predicated in part upon actionable efforts to improve access to dental care. While I have found that this rhetoric persists in what I believe are the good intentions of oral health movement leaders and participants, among whom I count myself, I have become increasingly concerned by the emphasis on *patient* effort and accountability. This is exemplified by my conversation with the state dental benefits manager which opened this chapter, which centered its critique on what it believed was patients' failure to recognize the value in seeking dental care rather than on the dental *industry*'s efforts beyond the patchwork efforts of present. While many drivers of the oral health movement are working to put in place the infrastructure through which the dental industry *could* respond more effectively to dental disparities, for example as exemplified in Oral Health 2020, adult dental Medicaid expansionism, attention to the crucial aspect of adoption *within* the dental industry has been generally...toothless.

Calls for the dental industry to formalize and routinize its social obligations have been strongly-worded, at times extremely so (see, for example Catalanotto 2012, Center for Public Integrity, N.d., Potter N.d.). Yet the ADA has proved effective at shutting out external influences on its moral governance, primarily by stymying or influencing state and federal legislative efforts. By prioritizing initiatives that imagine expanded access to care through a framework that puts the onus of utilization on underserved patients without working to also ensure the *usability* of pathways to treatment such as expanded insurance provisions, the oral health movement risks perpetuating a "false hope" (Castañeda, et al. 2010) that is currently all too common, and exemplified in the case studies presented in Chapters 1, 3 and 4. Moreover, this approach

absolves organized dentistry of responsibility for its role in the formation of dental disparities: At best, a banal observer of the maldistribution of care as a "natural" effect of the fee-for-service system under which it developed; at worse, a site of systemic exclusion through which differential physical and social suffering have been perpetuated. Yet, there are signs of change, and the galvanization of new approaches to address dental disparities. For whatever my critiques of DQF's initiatives, they and other efforts by foundations, community and public health dentistry education programs, the American Dental Hygiene Association, the American Academy of Pediatrics, and other stakeholders attempt to ensure the prioritization of oral health equity in the minds of the American public and the power-centers that are poised to influence it.

Social and market forces beyond ethical responses to the recognition of inequality play a role here too. In addition to the variety of dental reforms proposed by stakeholders extrinsic to organized dentistry, the ADA has proposed a number of initiatives which claim to be aimed at reducing dental disease disparities, and which could have the effect of increasing access to care. ADA efforts appear to have transpired around concerns over falling revenues that have not recovered consistent with other health care spending since the recession of the late 2000s, malcontent over the reforms proposed from outside of dentistry, and the public's growing awareness of the importance of oral health to overall health and outrage over the unaffordability of care. Posited as a multi-pronged approach, these efforts continue in the tradition of exempting private practice from major systematic reform – emphasizing, for example, status quo approaches such as community water fluoridation and donated services – while advancing for private practice strategies that maintain professional hierarchies and ensure the maximum profitability, such as Medicaid administration reform, public/private partnerships, 108 and the

<sup>&</sup>lt;sup>108</sup> Importantly guidance on the cultivation of new dental safety net opportunities focuses exclusively on their development in traditional social safety net settings: federally qualified health centers, critical access hospitals, and

cultivation of a workforce to drive patients into care (Association 2014; Association 2015). The emphasis on Medicaid administration reform, for example increasing reimbursement rates – a reform that has demonstrated surprisingly limited effect – or implementing public/private partnerships with FQHCs, rather than expansionism, is particularly curious in lieu of the tremendous evidence of public insurance's contribution to the profitability of private practice, a trend that is being lauded by ADA-employed scholars who study the Affordable Care Ac (Bailit, et al. 1999; Vujicic 2015). In addition to the efforts advanced by DQF and the ADA, other thought-leaders have posited ideas to reduce dental disparities. Of particular importance to this dissertation are initiatives, driven by academic community and public health dentistry, the Kellogg Foundation, and influential others, to expand access to basic dental treatments by developing semi-autonomous mid-level providers, an effort that the ADA has, as discussed in Chapter 4, interpreted as antagonism toward organized dentistry.

In this chapter, I examine three categories of proposals to address dental disparities: 1) Medicaid reform, emphasizing adult Medicaid expansion; 2) practice management reform, primarily shifts in the financial management of clinical care; and 3) dental team expansionism with an emphasis on semi-autonomous mid-levels, specifically dental therapists. In the sections that follow, I examine these proposals in closer detail, drawing on brief case examples. I then read these reforms through the lens of my research in order to identify their promises and perils in the context of my fieldsite. While each proposal is treated, in this chapter, as distinct, it is crucial to keep in mind not only the complementarity of these initiatives, but the *necessity* of their coexistence and, often, coordination, for example how Medicaid expansion has driven the

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mobile clinics. While Bailit and other economists argue persuasively that the largest dental safety net is "within" private practice vis a vis Medicaid insurance, the ADA's Avenues to Access program clearly locates the dental safety net "out there."

development of large group practices, and how new dental team models represent another opportunity to extend group models of practice. Therefore, my discussion of them should be read as an examination of complementary approaches rather than options in competition. There is plenty of room in the field of dental care for a variety of reforms, and stakeholders tend to agree that they will work best in concert.<sup>109</sup>

Heeding the "call" to an anthropology of health policy issued nearly ten years ago by
Horton and Lamphere (2006, see also Castro and Singer 2004, Pfeiffer and Nichter 2008,
Sargent 2009, and Wedel et al. 2005, among others), my analysis derives from insights gleaned
through ethnographic fieldwork and ongoing participation in the oral health movement. I aim to
maintain a critical view that "challenge(s) the very assumptions about human behavior and the
nature of health care implicit in the economic arguments that currently dominate health policy"
(Horton and Lamphere 2006:33). Yet, based on my experience with in the oral health movement,
including my participation in leadership and advocacy at the state level, my perspective
necessarily maintains a pragmatic perspective on the centrality of finance in dental reform.
Solvency is critically important to the sustainability of the dental safety net and, as has been
shown in my fieldsite among many other settings, insolubility can be the downfall of otherwise
commendable innovations.

If navigating the tensions of contradiction has been an ongoing theme throughout this dissertation, in this chapter I find this characteristic both discomforting and also vital to my understanding of those tensions navigated by both patients and providers alike, as well as to what I understand as my emerging identity as a dental disparities thought-leader (Heckler 2008,

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<sup>&</sup>lt;sup>109</sup> It also seems to be widely recognized that these approaches – separately, together, or even apart from – would benefit from other reforms including the reform of dental benefits administration, the reform of dental education, and the reform of dental technologies.

among others, addresses such tensions of engagement.). Whereas Horton and Lamphere, and other anthropologists of policy, "document how such reforms play out in our tattered safety net" (ibid; see also, for example Boehm 2005; Maskovsky 2000; Nelson 2005), my charge is to address a "net" that hasn't even been woven yet, due to the separation of the mouth from the body (and dental care from overall health care) early last century (as discussed in Ch.4).

One more preamble necessarily frames the content of this chapter. This chapter responds to Horton and Lamphere's encouragement to denaturalize the governance of health, to interrogate "the ideological premises that make (reforms) appear common-sense" (2006:34). Yet, by my very selection of which categories of reform to evaluate, I betray my unwillingness to fully denaturalize the centrality of clinical care in the contemporary governance of oral health, and reveal my commitment to one aspect of it: the scientific knowledge base upon which it is built. As explained in Chapter 1, dental decay is a complex disease that, once established, progresses unidirectionally unless interrupted by specialized care, specifically the technical tools and skills enacted by dental professionals. Through my ethnographic research, I have come to understand the physical and social suffering that progressive decay can cause. Witnessing this particular type of hardship and inequality has come to serve, for me, as a call to participate, to use my scholarly voice toward not merely critique of the inequality through which dental disparities are so rendered, but to work toward their resolution. In taking seriously dental clinical orthodoxy about the biological origin and technical treatment of disease, I knowingly and deliberately distinguish my work from the rich tradition in medical anthropology that critiques the biomedicalization of everyday life and, rather, emplace my work within an engaged medical anthropology that works toward health social justice through, in part, the equitable distribution of care. Therefore, as a political stance, in this chapter I evaluate only categories of reform that aim

to broaden and bring justice to people's access to clinical care; I exclude those that are reductionisitic and focus primarily on education as the means to prevention that responsibilizes individuals for the maintenance of their own dental well-being, given that the risks of developing decay are multifactorial.

### Medicaid reform

As discussed in Chapter 4, dental care has not been considered a primary health care service in the United States until recently, even as medical care became recognized as essential throughout the twentieth century (Burt and Eklund 2005). While many features of this inconsistency must be addressed in order to bring dental care to parity with medical care, including the widespread understanding of the mouth as "separate from" the body, the differential financing of medical and dental care is key. Specifically, in the third party payer approach which constitutes health care in the U.S., insurance is the analytic through which "access" must be interpreted and interrogated (see, for example, Boehm 2005, Lamphere 2005, Horton et al. 2014, and Mulligan 2014). While private dental insurance is far from comparable to private medical insurance in terms of the composition of benefits and the financial burden on patients, access to care among publicly insured populations is even less assured, beginning with the inadequate distribution of coverage (Pew Nd.). Accordingly, this section addresses public insurance, primarily the proposal by many in the oral health movement to expand adult Medicaid to cover more dental care than it currently does which, in many states, means to cover adult dental are at all.

The history of dental access for low-income people is marked by failed attempts to institutionalize preventive care and treatment opportunities, which prompts me to describe the dental safety net as "decayed, missing, or filled." Safety net settings such as community health centers and public health clinics are under-funded and under-valued. Workforce pipeline programs to staff safety net clinics with recent graduates have extremely limited purchase among recent DDS/DMD graduates facing an average of a quarter of a million dollars in loans, and many public health departments have carved off clinical services in order to redirect budgets to their essential functions of primary prevention and surveillance. Hospital emergency department log \$1.6billion annually in attending to unaddressed dental needs, primarily for pain management and infection control as doctors in most states are not licensed to perform even dental surgeries such as the emergency extraction of abscessed teeth (Wall and Vujicic 2015). The health care marketplace created by the Affordable Care Act (ACA), laudable though it may be in terms of medical coverage, has littered many states' fields with products aimed at adults whose coverage of dental care is, at best, confusing and, at worst deliberately obscured; reports from numerous states detail beneficiaries' misunderstandings about the limitations of the "affordable" products into which they enrolled, including both low-cost plans aimed at low-income people and Medicaid in those few states where adult dental benefits are included (see, for example, Chazin et al. 2013, Flynn et al. 2014, Rovner 2014, Singhal et al 2015, Wides et al. 2014).

Prior to the passage of the ACA, adult dental utilization had declined overall, most starkly among the low-income population whose needs Medicaid was designed to address; it has not made significant gains since ACA implementation (Nasseh and Vujicic 2013). Over three times as many U.S. adults are dentally uninsured as are medically uninsured – about 108 million people (HRDA Nd.) – a population that disproportionately but not exclusively comprises low-

income, publicly-insured adults. Over half of state Medicaid programs offer either no adult public dental benefit or only emergency extractions; among those that offer more coverage, strict limitations and conscription into predetermined behaviors, such as rigid appointment-keeping obligations for preventive services in order to "earn" treatment, are common (McGinn-Shapiro/NASHP 2008). While the extremely limited adult public dental entitlements of the current era are commonly framed as austerity measures in response to the Great Recession (see, for example, Chazin et al 2013 and McGinn-Shapiro 2008), the history of dentistry demonstrates that the exemption of dental care from essential services has long been the rule, rather than the exception, (Burt and Eklund 2006, Picard 2009). Indeed, the very vulnerability of adult public dental benefits to cuts during periods of budget shortfalls evinces the low priority by which they were conceived. Despite both recent contractions and the historical deprioritization of dental care, the expansion of adult dental Medicaid is frequently posited as an evidence-based strategy (see, for example, Choi 2011) to address dental disparities in the U.S. A brief appraisal of the potential of the expansion of coverage to children can serve to frame consideration of a similar approach for adults.

Despite these significant challenges, some limited improvements to dental care under public insurance have been made in the last twenty years, primarily in the area of children's health. Children's comprehensive dental entitlements were mandated by Congress in 1997 as part of the State Children's Health Insurance Program (SCHIP, later CHIP), legislation that also required concomitant reform in Medicaid. The largest expansion of health care entitlements since the passage of Medicaid and Medicare in the late 1960s, the inclusion of dental benefits in

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<sup>&</sup>lt;sup>110</sup> CHIP extends public insurance coverage for families whose income exceeded Medicaid income requirements but is too low to afford private insurance. Jointly financed by the federal government and states, CHIP guidelines are typically calculated around 200% of the Federal Poverty Line (FPL), or \$42,400 for a family of four. Commonly, adults in these families work in contingent jobs that did not offer benefits such as medical or dental insurance.

CHIP was a substantial accomplishment by a relatively small group of oral health advocates, whose efforts drew on three major bodies of evidence: the impact of oral health on individuals' overall health; the negative impact of untreated dental disease on society, such as absences from school or employment; and the cost-effectiveness of routine dental care, particularly when it catches and treats nascent disease. Indeed, public spending on dental care comprises only 5% of overall public spending on health care nationally, most of it on children's services that serve to eliminate existing and prevent future disease (Stagnitti and Carper 2014). Aware of the limitations of the dental safety net in terms of capacity to serve what was anticipated to be an increase in children seeking care as public dental benefits were rolled out, advocates successfully sought increases to Medicaid dental reimbursement rates in many states, to incentivize private practice dentists to accept the provision. The meteoric initial impacts of these twin approaches – the expansion of coverage and the increase in reimbursement rates – were documented within five years of implementation. Children's public dental insurance enrollment doubled, from 23% to 47% by 2002 (Children's Dental Health Project, Nd.). The percentage of dentists who accepted Medicaid rose, from an uncounted but assumedly low number to 20% (ADA Nd.). Medicaid reimbursement rates rose in many states, to bring the national average to 40% of the average billed cost of care (Nasseh, Vujicic, and Yarbrough 2014). Yet, for the last decade-anda-half, the results of these approaches have plateaued, a far cry from their goals. For example, less than 40% of publicly insured children receive dental care nationally, or a quarter of lowincome children overall (USGAO 2010).

Observers attribute low dental utilization among publicly insured populations to a number of factors (USGAO 2010, Kelly et al 2005). State efforts to educate families to the terms of their benefits have been inadequate. This information dissemination gap is coupled with the

mixed messages that exchange between payers, state staff, parents, pediatricians, and others about the appropriate age for a first dental visit, only recently advised by clinical guidelines negotiated through consensus to be by age 2. As in the example of Janie in Chapter 3, general dentists often refuse to accept pediatric patients and, instead, refer them to specialists. Dental fear, a well-documented phenomenon among patients insured publicly as well as privately, can have transgenerational effect. A number of other structural disparities persist in the distribution and characteristics of dental practices as well, for example the disproportionately small number of dental practices in which languages other than English are spoken, that are located in less densely populated areas, or that hold appointment hours outside of traditional business hours. Among the most persistent impediments to the utilization of dental public benefits, however, is provider non-acceptance. Approximately 80% of dental providers, nationally, do not accept Medicaid insurance, and there is little insight into variation among the 20% of dental providers who report accepting Medicaid insurance, for example in the percentage of their payer mix set aside for Medicaid enrolled patients – that is, whether they dedicate less than 1% of their client base to publicly insured patients, a more substantial proportion. As demonstrated in this dissertation, and elsewhere (e.g. Castaneda et al. 2010) while most providers attribute nonacceptance to low reimbursement rates, slow claims processing, and other economic and bureaucratic factors, a number of other less overt factors are at play as well. For example, providers commonly excuse their refusal to accept Medicaid patients to their perception of those patients' poor records of appointment keeping, yet as I learned during fieldwork, this explanation is commonly understood, by providers and patients alike, as sanctioned discrimination, a way to stigmatize and exclude from care the patients they deem "less desirable."

The non-acceptance of Medicaid is a barrier to care with which organized dentistry is increasingly willing to reckon. Dental spending was on the decline since at least five years before The Great Recession and has not, unlike other health care spending, picked back up since.

Looking to identify new markets for the future, ADA economists have recently cited Medicaid as a substantial income source (Vujicic 2015) if reimbursements keep pace with inflation (Nasseh and Vujicic 2014, see also Buchmueller, Orzol, and Shore-Sheppard 2015 and Choi 2011). What, then, do some of these marketplaces, in which adult dental Medicaid have been successfully implemented in terms of *utilization* as well as distribution, look like?

In a comparative analysis of seven states that have successfully implemented adult dental Medicaid, Snyder and Kanchinadam argue that among the states that have had the strongest implementation of adult dental Medicaid are those in which adult dental benefits have built upon the successes of related efforts, for example contractual relationships and provider networks constituted through the successful implementation of children's dental coverage, or the leveraging of federal funds to expand Medicaid as a result of the Affordable Care Act (2015). Among these states, Washington stands out. For years a leader and model in offering extensive adult dental Medicaid benefits, 111 Washington, like many other states, cut dental benefits in 2010 for all populations but a few targeted ones, namely pregnant women, people with developmental disabilities, and institutionalized populations. Recognizing the opportunity in Medicaid expansion as a part of the ACA, in 2013 it moved to re-authorize dental benefits for its entire enrolled adult population, an effort that would be funded, in major part, by federal funds designated to underwrite public insurance for the newly eligible. In two years of

<sup>&</sup>lt;sup>111</sup> Extensive dental benefits are understood to include basic treatments such as extractions and fillings, as well as preventive care, periodontal therapies, and/or low-cost restorations such as bridges, crowns, and dentures, commonly with an annual maximum cost of services covered. Comprehensive coverage can extend to include orthodontic work and advanced surgeries.

reimplementation, approximately a quarter of the state's 874,000 Medicaid insured adults, received dental services, at a total cost of \$46mil (or, \$225.50 per beneficiary, on average) that was split between state and federal funds. Although this utilization rate reflects a decline from 2010, when a third of the pre-Medicaid-expansion population sought care, it represents an increase in the sheer volume of patients who successfully sought dental services. Key to the ability of providers in the state to respond to the increased need is the centrality of dental services within Community Health Centers (CHCs), where 70% of the dental caseload is adults who pay for services with either Medicaid insurance or at a modest out-of-pocket rate on a sliding scale fee. In addition, while Medicaid reimbursement rates are, at 25% of the billed cost of procedures, low, nearly a third of dentists of the state's 5000 dentists report accepting Medicaid, a more than 50% improvement over the national average.

The case of Washington State is instructive as it reconciles the likelihood of dental needs among the three-quarters of Medicaid-enrolled adults who have not yet obtained them, with the limitations imposed by a low reimbursement rate, a dental safety net whose costs are subject to inflation as in the private sector, and a seemingly flattened rate of dentists who accept Medicaid. Even among economists who project, optimistically, that the productivity available to dentists through Medicaid markets will force change in the profession, such predictions are not guaranteed. Moreover, incentives such as higher reimbursement rates are understood to have an effect that is merely "modest" (Buchmueller, Orzol, and Shore-Sheppard 2015, see also Borchgrevink, Snyder, and Gehshan 2008, and Manski et al 2014). In order to understand how the limits of Medicaid reform may be well-suited for enactment in concert with other reforms, we can turn to the concept of dental *practice* reform, which can serve to enhance utilization.

## Practice management reform

The practice of dentistry in the United States has long occurred under a fee-for-service model in which individual providers are owner-operators of standalone practices. Building from its nineteenth century origins as a set of proprietary techniques that emphasized pain relief and the craftsmanship of dentures, dentistry in the twentieth century continued in this spirit of independent-mindedness even as its training, licensure, and regulation were formalized and its objectives expanded to include preventive and routine care. Accordingly, a significant topic in dental education has been business administration, with the expectation that dental students would need not only clinical skills but also managerial ones. Even as practice models developed to include administrative and clinical employees to assist the dentist, managerial and fiduciary hierarchies have remained, with the dentist as primary stakeholder and beneficiary and most other staff members employed at will (Davis 1980). 112 Yet, current analyses suggest that this model is changing (Brown and Nash 2012).

Beginning in the 1970s, and continuing ever since, small practice partnerships became a more popular among dentists for a variety of reasons, not least that the enormous debt that most students incur to complete dental school is prohibitive to the purchase (and technological updating) of retiring dentists,' practices as in an older model (Garrison, et al. 2014; Okwuje, et al. 2010). At the end of the 20<sup>th</sup> Century, a third of private practices were jointly operated by two to four dentists, though this small group model still centralized ownership: 91% of practices were still held by dentists, even when those stakes were shared (Nash 1991). Since the turn of the 21st Century, however, the group model of dental care has both expanded and diversified such that

<sup>&</sup>lt;sup>112</sup> This norm is exemplified in the vignettes in Chapter 4.

some analysts anticipate that it may become a substantial practice model for new graduates entering into general, family, or pediatric dentistry, and are working to organize courses to prepare graduates to enter into it (Brown and Nash 2012; Cole, et al. 2015; Diringer, et al. 2013; Garcia and Santa Fe 2014; Gwozdek, et al. 2014). To understand the roles that group practices play in the dental safety net, a brief explication of their variety is warranted.

The small partnership model that arose in the 1970s has persisted, and diversified to represent a variety of administrative, managerial, and fiduciary configurations, in which the risks and benefits of entrepreneurship continue to accrue, primarily, to dentist-entrepreneurs. For example, Guay and colleagues (2012) typologize four models of group practices based on the distribution of governance, services, and management:

A traditional group practice—comprised of a variable number of dentists (generalists, specialists, or a combination) practicing as an entity with owners, associates, and employees...A group of small practices owned by a central entity with practice locations dispersed over a wide geographic area...A group of small practices...associated with a central entity that provides some services to the practices in the network...and a hybrid organization comprised of a combination of practices owned by a central entity and owned locally, operating much like a franchise (ibid. 1037).

Given that Medicaid-insured patients' low reimbursement rates and clinicians' charitable contribution of services are, historically, tacitly subsidized by the more expensive procedures paid out of pocket by patients who have the means, the group practice models enumerated by Guay and colleagues' model fit well the diversified payer mix advocated by a number of dental economists, in which the majority of patients – 80%, insured by private dental benefits or self-paying – balance the reduced compensation of a stabilized proportion of patients – 20% -- who are publically insured or extended reduced rates on an income-based sliding scale fee (Cole, et al. 2015; Millstein 2012).

While small group practice models can accommodate the underserved population by accounting for its income within its payer mix, another model that may be better able to

prioritize underserved patients has proliferated since the late 1990s, perhaps not coincidentally in co-occurrence with the anticipated expansion of patient demand resulting from the CHIP program discussed above. Variably called Dental Service Organizations, Dental Practice Managements, Dental Management Organizations, or Dental Management Service Organizations (DSOs/DPMs/DMOs/DMSOs), the economic models of these corporatized approaches leverage high patient volume in order to compensate for the low reimbursement rates of public insurance, which typically cover approximately 60% of the cost of services but, in some states or for some procedures cover approximately 20%. Strategies include negotiating bulk rates for supplies, centralizing administrative functions, and cultivating relationships with payers so as to expedite the preauthorization of services and reimbursements following treatment. However, interpreting the contribution of corporate dentistry to improve access to dental care is challenging.

It is well documented that on the bases of both strict volume of procedures and patients, as well as the ratio of Medicaid-insured patients-to-provider, DSOs distribute more care to more low-income families than do either small private practices or the inadequately funded dental public sector (Laffer 2012; Winegarden and Arduin 2012). Corporate dentistry has, however, become the subject of controversy. For example, while evidence demonstrates that DSOs provide both a greater number of dental services to Medicaid-enrolled children overall and that Medicaid reimbursement represents a greater proportion of productivity per-clinician, accusations of overtreatment and other exploitive clinical behavior abound (Freedberg 2012; Center for Public Integrity N.d.; Moriarty and Siegal). Such accusations tend to follow any dentist who files a proportionately high number of Medicaid reimbursements and tend to highlight the possibility of "perverse incentives" (Edelstein) in third party fee-for-service systems of care, whether the distribution mechanism is DSOs or, as in the case of my fieldsite, individual private practice

clinicians. Indeed, as Edelstein, writing on behalf of the Children's Dental Health Project observes, any concerns of "the legal, ethical, and moral responsibility for providing quality care" must be applied not only across all practice types, but also to all licensed clinicians. In this way, he continues, most DSOs meet ethical standards, as evident in the stringent metrics they employ to reduce the risk of overtreatment, and often even exceed them, by "locating in economically depressed areas (where real estate and employee costs are low), purchasing in bulk (to avail themselves of quantity discounts), and providing flexible scheduling that recognizes the impediments that many low income families face with transportation and work arrangements" (2012). Indeed, as Edelstein observes, accusations could be made of any model whose income stream derives, at least partially, from reimbursements, including public or community-based care in a neoliberal health care economic system. Here, the case of the United States' only large group practice that operates on a non-profit model is instructive.

Sarrell Dental Center was founded in Anniston, Alabama in 2004 by The Community

Foundation of Northeast Alabama, in response to a community needs assessment it conducted.

Recognizing the need to resolve its own insolvency and that patient demand far outweighed capacity, The Center hired retired food industry executive and business school faculty member

Jeffrey Parker to reorganize the management of the practice; under his leadership, Sarrell grew to include seventeen locations statewide, plus a mobile clinic. Moreover, Sarrell has bucked national norms of dental care delivery, not only self-sustaining but growing revenue despite its low-cost, high-volume model of care, while also achieving clinical outcomes among its patients that most other practices would consider enviable. It is recognized by both regulators and thought-leaders for the appropriateness of its clinical practices in terms of taking a clinically aggressive but socially supportive approach to disease encapsulation and management, as well as

persistent community outreach and relationship-building to ensure the timely and consistent delivery of preventive services to as many community children who need them as possible. Its cost per patient visit now sets an industry low. As journalist June Thomas describes:

Not a single complaint has been filed to the Alabama dental board about Sarrell, nor have any errors been found in Medicaid audits... (CEO Parker) was positively gleeful as he unveiled a chart that would make most chief executives weep. On it, one line, representing the annual number of patient visits to Sarrell's clinics, climbs upward to more than 140,000, while the other, which shows the average reimbursement per visit (almost entirely from Medicaid or CHIP, with minimal copays), plummets from \$328 in 2005 to \$124 last year. The drop-off is due to a combination of treatment and education. Once new patients' cavities have been attended to, and bad oral health habits addressed, subsequent visits for cleanings and checkups generally cost taxpayers less. "There's no business in the world that wants to say that every time someone comes into my store or my restaurant they spend less than they did the last time," Parker says. (Thomas 2015)

Widely recognized as an innovator in the field, Sarrell's model has been pursued by a number of stakeholders for replication or adaptation in other markets (Ashoka 2014). Yet, such attempts might be inhibited before they even begin. The vigor of accusations of DSOs of unscrupulousness has led to highly-publicized legal investigations – a few, though not all, justified and, ultimately, a consequences that will serve to inhibit innovations to large group practices in the future and their propensity to expand care geographically to reach underserved populations: Forty-seven states now have legislation prohibiting people who do not possess a DMD or DDS degree and current license from owning dental clinics.<sup>113</sup>

The ADA's lobbying for ownership regulations has been amplified, in the last decade, by not only the emergence of large corporate chains into the marketplace, but also its concern about the potential for autonomous mid-levels to own clinics in the future that would amount to

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<sup>&</sup>lt;sup>113</sup> Parker has spoken directly to this trend, which he critiques as "regressive," continuing, "I find it absurd that a nonprofit dental practice cannot be run by a nondentist if they employ licensed dentists to perform the clinical work...It happens already in the hundreds of FQHCs [federally qualified health centers] across the country. The CEOs of Cedars-Sinai Hospital, Children's Hospital of Atlanta, and Children's Hospital of Birmingham are businesspeople, not physicians, and no one questions their hospitals' ability to perform neurosurgery, heart transplants, or operate trauma units. These hospitals trust their CMO [chief medical officer] to manage physician's work, as our model similarly employs a CDO [chief dental officer] to manage dentist's work" (Edwards 2014).

competitors. Yet, the possibility remains that the investigation of deceptive practices in the corporate dental sector may actually bolster non-profit and community-based approaches to large group dental practices. Sarrell Dental is now affiliated with another non-profit dental clinic that serves over 60,000 patients in Dallas, Texas. Indeed if negotiations around the regulation of the free market is the downfall of unscrupulous large group practices, despite it also being an ideology through which dentistry has long staked its position in health care in the United States, an interesting tension is posed by the third proposed solution I discuss in this chapter: dental team expansionism in the form of semi-autonomous dental mid-levels.

#### **Dental team expansion**

As described in Chapter 4, the dental team concept emerged in the United States early in the twentieth century and has been configured in a variety of ways ever since. For example dental hygienists, initially introduced to cajole patients to enact good home hygiene and to relieve dentists of some of the tasks they deemed mundane, eventually, in most states, won the right to perform many non-invasive duties aimed at preventing tooth decay under "general" supervision, or with dentists supervising them from outside of their immediate workspace or building (ADHA Nd.). Dental assistants, initially trained to prepare dentists' materials but not interact with patients, can now, in many states, under a dentist's order, with certain training and licensure, independently deliver anesthesia and prepare dentals surfaces for some procedures. While these changes represent some official ways in which dental teams have been reconfigured other examples show how such negotiations occurred *in situ*, at times illicitly, as in Nancy's and Evelyn's cases presented in Chapters 3 and 4. As also presented in Chapter 4, private practice dentists have historically viewed these two related changes in dental teamwork – the distribution

and concomitant relaxations on the terms of their supervision can benefit practices' "productivity" (profitability), as well as dentists' reputations for technical mentorship and business acumen. Simultaneously, dentists often view dental team reforms as attacks their profession, whether symbolic threats to the "cultural authority" (Epstein 1995) of what amounts to dentistry's monopoly of the top of a technical and moral hierarchy, or the earliest steps toward the pluralization of the profession and attendant threats of competition of lower-cost care; indeed, these two concerns are often considered as entwined threats to dentists' status as elites.

Accordingly, organized dentistry has shaped attempts at reforms, primarily by maintaining a stronghold over their governance. Not only has the ADA effectively lobbied both states and national legislatures to limit the types and circumstances of dental team members' duties, but they have also obliged the approval of such changes to state practices boards that are, in all but two states, comprised primarily of dentists. While dental hygienists and dental assisting have had some success navigating this restrictive policy and practice environment, another proposal to add a safety net dental team member that is modeled on an international norm, the dental therapist, has twice been foreclosed by organized dentistry. Currently, however, in light of increased attention to dental disparities in the United States and dentistry's failure to address the problem, the dental therapy profession seeing a successful revival.

Dental therapy was incubated in New Zealand in 1921 as a way to serve elementary school children, and has operated there in this framework ever since. Trained in two-to-four year technical programs and supervised by public health service dentists, often through remote consultation, dental therapists (DTs) now work in almost 60 countries (Nash et al. 2012). Dental therapists' duties sit at the intersection between the prevention orientation of dental hygiene and

some simple but irreversible procedures common to basic dentistry: triaging and stabilizing existing disease, including, in some cases, drilling out minor decay and filling it with temporary materials, and performing simple extractions while also facilitating a referral to a community dentist for a longer-term restorative solution as well as other procedures beyond DTs' level of training and licensure (Edelstein 2010; McKinnon 2007). In many countries DTs practice only in institutional settings, such as schools, homes for the aged, or the equivalent of community health centers in locations where private care also exists. Indeed, their work centers on the very populations that dentists have not, historically, reached: low-income, racial or ethnic minority, rural, or otherwise marginalized people. A prolific literature on DTs attests to their safety and high quality (e.g. Phillips and Shaefer 2013; see Nash et al. 2012 for a comprehensive review of the literature). They also rate highly on patient satisfaction which, like dental hygienists, often surpasses that of dentists, an outcome which many analysts attribute to the "cultural recognition" between patients and DTs, who are often recruited from the communities they serve, with the explicit goal of returning following training (Nash et al. 2012, Wetterhall et al. 2010; see Shaw 2008 for a critique of the concept of cultural recognition). Together with the reduced costs associated with performing basic procedures instead of the more advanced "high tech" procedures that have become the norm in private practice, and the financial sources of their work which is often in the public sector, this recruitment model also helps explain dental therapy's cost-effectiveness. The short duration of DTs' training, coupled with their professional status as community-based technicians as opposed to elites – not to mention, their social status as women, racial and ethnic minorities, and rural populations – serves to command a significantly lower rate of pay than dentists, though commonly on-par with or slightly above dental hygienists (CITE).

A significant proportion of the evidence on DTs' safety, quality, and cost-effectiveness comes from research conducted in the United States during the late 1940s and 1970s. Yet DTs have not practiced here until recently. Why? At least one explanation follows from an overall assessment of the dental marketplace: These were two eras in which the ADA was trying to determine the appropriate market saturation of private practice dentists, as routine dental care was becoming increasingly mainstreamed and, for those privileged enough to have insurance, a covered benefit. Accordingly, the dental establishment opened more dental schools and enlarged cohorts only to find that this move oversaturated the proportion, per-patient, of service-providers who could not be maintained at the rate of pay they expected and, thus, training was again contracted. Based on concern over the threat of competition of a mid-level provider who the ADA assumed would have autonomous yearnings, organized dentistry initiated campaigns of fear-mongering over safety and quality, a tactic that advocates understood as a thinly-veiled attempt to constrain market pluralization but that was persuasive to the general public and policymakers; the proposals were foreclosed.

Ten year ago, however, the dental therapy concept was successfully revived when a constituent group of the semi-sovereign bodies Indian Health Service & Bureau of Indian Affairs, successfully agitated to address, through dental team reform, what amounted to a crisis among its children, a per-capita caries rate near 70%. The Alaska Native Tribal Health Consortium (ANTHC), initially in collaboration with colleagues in New Zealand and, later, with the University of Washington's program in community dentistry has, in the last decade, trained twenty-five locally recruited dental therapists to deliver basic care to approximately 40,000 Alaska Native people who live in remote villages that would otherwise be almost completely isolated from dental care; new cohorts enter the two-year training program every other year

(DENTEX Nd.). The project has persisted in large part through the sizeable evidence base it developed (e.g. Bolin 2008, Wetterhall et al 2010) as well as an ever-increasing amount of public attention and endorsement, not least by the American Dental Hygienists Association, the Association of Public Health Dentistry, the American Public Health Association, and a number of popular presses. Galvanized also by the U.S. Surgeon General's first ever report on oral health disparities in 2001 (USDHHS 2001), as well as the success of some other advocacy to reform dental policy, such as the inclusion of dental benefits in CHIP legislation in 1997, the Alaska program also won, quickly, the support of a contingent of powerful funders who began to outline a strategy to implement dental therapy in the U.S more broadly (Nash and Nagel 2005, Potter 2014). The first dental therapy program aimed at a "general" underserved population, as opposed to only members of a sovereign Native Nation, was approved by the Minnesota legislature in 2009, and began graduating cohorts of trainees in 2012 and placing them in community-based settings where they serve low-income children and adults. While studies of Minnesota's DTs are only preliminary, their results are consistent with the evidence from elsewhere in the world: that their safety and quality of care surpass standards, as does patient satisfaction. Meanwhile, one other state (Maine) has approved the introduction of the dental therapist model, with four other states poised to follow suit.

The response of organized dentistry to the recent introduction of dental therapy training programs, and practice, in the U.S. has transpired, as anticipated, around attempts to block or enclose it. Interestingly, much of this effort has served to advance dental therapy and pave the way for pluralism in the safety net, if not the mainstream dental marketplace. For example, the Alaskan Dental Association attempted to force the closure of the dental therapy program through legal action, an effort supported by the American Dental Association of which it is a constituent

chapter. This move was not only unsuccessful within the local judiciary but it also garnered the attention of the Federal Trade Commission, which argued against dental professional monopolism and, instead, for the opening of the marketplace so long as evidence affirmed dental therapy's safety. Sensing the public appetite for dental team expansion that focused on community outreach, as in the perceived "soft skills" of dental therapists, the ADA countered with its own "extender" proposal, the Community Dental Health Worker, modeled on the community public health worker concept but intended to coordinate patients into traditional models of care. With questions remaining, however, as to how this proposal would be financed, given that many of its duties would be non-reimbursable through insurance, it has been slow to get off the ground. Extremely late in the writing of this dissertation, however, a major shift in the ADA's stance on dental therapy occurred: The Commission on Dental Accreditation (CODA), a subsidiary of the ADA which sets guidelines, policies, and procedures for dental education, announced its publication of standards for the training of dental therapists in the United States.

The impact of dental therapists on oral health, both at the individual level among lowincome and other marginalized people as well at the collective level on the prevalence of disease
remains to be seen. On the one hand, the introduction of dental therapy in the US context nearly
a hundred years after it started becoming a norm elsewhere, where it has made a substantial
contribution to the reduction of individual pain and suffering and some communities'
disproportionate burden, suggests enormous promise for the potential impact on the US. On the
other hand, at least a few of its perils may already be anticipated, namely how it may advance the
model of health care in a neoliberal milieu by which the dental safety net is already
characterized. For example, it may serve to further entrench a hierarchical system of care in
which private practice dentistry and the advanced techniques employed may increasingly

become the domains of only people of means, and only the most basic of procedures remain available to people of middle or low income. The techniques of argumentation through which dental therapy has been made palatable to some dentists leverage an extension of their position at the top of the dental hierarchy (Williard and Fauteux 2011), indeed a likely eventuality for dental therapists' patients who need advanced care. In this way, dental therapists can actually be seen as serving to bolster organized dentistry's practices of carving off mundane tasks for "lesser skilled" colleagues and reserving the more interesting work for themselves, as among dental therapists tasks are facilitating patients' entry into advance care as needed. Accordingly, dental therapists have been posited as potential "money makers" for dentists, in the model of dental hygiene, another argument which serves to evince how support for dental therapy may not only fail to responsibilize professional dentistry to its social obligation but may also contribute to the further entrenchment of a dental professional hierarchy in which the financial and status rewards accrue upwards. Indeed, ironically, one of the arguments for dental therapy that best leverages a model of dental pluralism as a method of socially responsibility is, at its core, a capitalist one: that the market ideal of competition, when enacted through the pluralization of dental care, may drive fairness in both quality and pricing (Potter 2014).

## Making Dental Reform Happen: The View from Virginia

In the previous sections, I described three general types of reform that have been proposed in order to increase low-income adults' access to dental care: Medicaid reform, with an emphasis on expansionism; dental practice reform, with an emphasis on the loosening of restrictions on large group practices managed by a non-clinician; and dental teamwork reform, with an emphasis on the introduction of semi-autonomous dental therapists. Which, if any, of these proposals might be implemented in Virginia? Which is best suited for the far southwest

region of the state? Building from my knowledge of the health reform climate in the state, I conduct a thought experiment to respond to these questions.

As suggested by the vignette that closed Chapter 4, as well as the nods made throughout this dissertation to the dental reform efforts of oral health advocates throughout the state who represent sectors ranging from organized dentistry to public health and beyond, there is a tenacious and diverse community of advocates, myself included, working to bring about oral health equity in the state. Indeed, the Virginia Oral Health Coalition (VaOHC), on whose Board of Directors I now sit, is a nationally recognized leader in the oral health movement, whose model and mentorship is highly sought after. Through my engagement with the VaOHC's Legislative Committee, as well as my reading of the grey literature, I have come to better understand the policy climate in which we are working and observed how this group has vetted each of the aforementioned strategies.

As introduced in Chapter 2, Virginia has, historically, been among the country's most conservative climates with respect to public entitlements. For example, only 10% of Virginians under age 65 are insured through Medicaid as compared with 18% nationally (Kaiser 2014). This figure results from the state's stringent inclusion criteria, which categorically excludes "childless adults" and parents who earn more than the income cap on eligibility of *half* the Federal Poverty Level; the state's income eligibility criteria is among the lowest third of all states. One of twenty-two states that turned down the Medicaid expansion option presented by the ACA, Virginia's refutation of the opportunity owed to state leaders' ideological rejection of federal mandates as well as what they argued amounted to unearned "handouts" among the state's most

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<sup>&</sup>lt;sup>114</sup> This is a term used in a number of official settings, for example state lawmakers or policy analysts. I put it in quotations not only to call attention to its official usage but also to note the ways that it indexes heteronormativity, in which the only adults who are legitimized, vis a vis Medicaid eligibility, are those who have procreated.

marginalized residents. As described in Chapter 4, Virginia has also been among the nation's most conservative climates in terms of practice law, restricting opportunities for practice by "allied" and "alternative" health professionals through a multi-pronged legislative approach that includes licensing and qualifications for independent practice as well as the terminology through which professionals who achieve doctoral degrees other than medical degrees may advertise their services. Yet, Virginia's legislative landscape also orients strongly toward free market economics in which the health care industry is considered a major driver of the positive effects of competition, such as quality improvement and cost containment, as well as a contributor to the tax base and as evidence of the entrepreneurialist ethos at work.

As the VaOHC Legislative Committee has determined its agenda each year, it has, with the help of a paid consultant, "read" the legislative landscape in order to determine the best strategy for success. Like advocates in a number of other states, it has taken a step-wise approach to advocating for change, a strategy that has, admittedly, frustrated me because gains would be not only limited but also stratified. However, at least in 2015, this conservative approach also proved meritorious. During the 2015 Legislative Session, a community of advocates spearheaded by the Coalition was able to get extensive dental benefits approved for pregnant women insured by Medicaid, a population whose eligibility extends to 148% of the Federal Poverty Line for the duration of pregnancy and two months post-partum. This move could be critiqued for recreating a heteronormative hierarchy that privileges the reproductive capacity – some would say, the seeming responsibility – of cis-gendered women's bodies as bearers of children, but it also hearkens at least three other areas of import. These include the biological evidence on the reduction of late pregnancy risk that can result from adequate dental care, the epidemiological evidence of the transgenerational effects of pregnant women's dental care in terms of moving

young children into dental clinical settings; and the sociopolitical evidence that the protection of "vulnerable" populations such as women and children can lead, in a step-wise manor, to the extension of benefits to other populations such as people managing systemic disease.

A significant component of the success of efforts to expand Medicaid to provide dental benefits to pregnant women in Virginia was the timing, relative to state political leadership. After years of leadership under a socially conservative Governor who some accounts characterized as hostile to public entitlements, in 2014 a socially progressive Governor was elected by a narrow margin on a platform that included, among other things, Medicaid expansion. With a Lieutenant Governor who was a medical doctor known for his volunteerism at health charity events, not least the RAM at Wise, as well as the election of progressive legislators in a number of key districts, the state seemed well-poised to legislate its way to improvements in oral health, as well as overall health. Another aspect that was considered crucial to success was the coalitionbuilding through which the proposed legislation was negotiated. For months prior to lobbying efforts, the proposal was vetted by health economists, consultants familiar with Medicaid, social services personnel, payers, and representatives of the Virginia Dental Association to ensure that it would be evaluated as sound with regard to economic impact, strategies for implementation, and the politics of professionalism. As a "low stakes" proposal, public dental benefits for pregnant women earned general agreement from all, although negotiations around specific aspects reflect the politics at play. Expensive restorations like implants and porcelain veneers were excluded from coverage, for example, for concern that inclusion might "incentivize" poor women to become pregnant for the sake of vanity, a rationale that echoes the more generalized negative stereotypes that have long been associated with public entitlements. The duration of coverage also required the Coalition to compromise. Whereas during initial legislation

development, the duration of service was proposed to extend to six months post-partum – to acknowledge such factors as the duration of time between conception, awareness of pregnancy, and enrollment in Medicaid, as well as the clinical necessity of multiple appointments to address some dental problems like persistent decay or modest restorations and the arduous process that can be involved to find a provider who accepts Medicaid – in the end the legislation was approved with a conclusion of the benefits two months post-partum. This concession aggrieved, particularly, the many advocates who were, themselves, parents, so knew first-hand how the challenges of parenting a newborn might inhibit utilization during the first two months postpartum. Since implementation in March 2015, utilization data gleaned from Mediciad reimbursement filings has been modest. Although 45,000 women are projected to be eligible for the benefit, fewer than 200 have signed up for it and even fewer have used it. Data on the geographic distribution of sign-up and utilization is not available at present, though there is discussion that it centers around locations where community health workers outreach to pregnant women, particularly those who do not speak English, is known to be robust (that is, the state's urban areas in the center and north).

The case of the dental pregnancy benefit is instructive when considering the proposed solutions reviewed above, not least because it was selected as the strategy of emphasis above and beyond the strategies named here, all of which were deemed too political to be successful. The coalition-building and collaborative legislative efforts of a variety of stakeholders, ranging from uninsured patient populations to payers who want to earn income by implementing Medicaid managed care, is currently coalescing around general Medicaid expansionism, leveraging momentum around the ACA, in which dental benefits would be considered, for adults, of secondary priority, at best. Oral health advocates in Virginia cite, here, the opportunity to build

social capital among advocates of more generalized Medicaid expansion by supporting their primary agenda during a year when that of oral health advocates doesn't have a clear step-wise direction in which to go: It is argued, probably correctly, that overall Medicaid expansion will lay a long-term foundation for the introduction of adult dental benefits, and that concurrently legislators will grow weary of extending adult dental Medicaid to another "step-wise" population, for example diabetics, until they observe the outcomes of implementation with pregnant women.

# **Discussion**

Indeed, the perception of an uneven uptake of public dental benefits among pregnant women, stratified by not only geographic region generally but also areas where infrastructures exist to help women sign up, is likely to be reflected in utilization data as well. As evinced in this dissertation, an imagined adult dental Medicaid of the present or future, whether that of pregnant women or general populations, is unlikely to achieve success without dental providers with whom to use it. That is, without dental practices, whether private or in dedicated safety net settings such as Community Health Centers, who accept Medicaid as payment. Accordingly, to be successful, any effort to increase oral health equity by extending public benefits must also address ways to increase dental practices' acceptance of this benefit, likely through some combination of improved reimbursement rates and bureaucratic processes such as speed of preauthorization of services; an increase in the distribution of dental clinicians in the regions with the lowest patient:provider ratios; and efforts, for example social norming and mentorship, to increase the percentage of dentists who not only claim to accept Medicaid, but who actively prioritize it in their payer mix. As this dissertation and other evidence demonstrates how lowincome patients' attempts to obtain and utilize public entitlements can actually serve to disentitle

them (Lopez 2005, see also Castaneda et al 2010), creating the supports to ensure utilization is critical to the success of any solutions that leverage extensions of a stratified neoliberal marketplace vis a vis the extension of public benefits.

In the case of far southwest Virginia, this means considerable effort to bring new providers to the region. While the security of care for residents who live on the region's periphery can be predicted in the neighboring states to which they already travel to obtain their children's care, residents in the center of the region may be in continual fear of not be being able to locate any dentist, much less one who accepts dental benefits. As states constantly look to cut under-utilized services in order to meet the budget demands of solvency required each year, a dental benefit that goes under-utilized is at considerable risk of elimination. This perpetual cycle, in which budget-minded legislators believe that the non-utilization is a problem with patient need or desire rather than with provider availability or acceptance – the same argument advanced by the oral health advocate who I met at the DentaQuest Foundation regional convening – is the risk that most concerns oral health advocates about the recently passed Medicaid benefit for pregnant women. It also represents, to me, the biggest threat to the permanence, or even longevity, of a more widespread dental Medicaid imaginary that hasn't even come to fruition yet.

Considering how Medicaid expansion, with an assumption of a future in which adult dental benefits are added, might best be implemented can return attention to the other two proposals described in this chapter. While distinct proposals whose areas of overlap I address below, each is framed very clearly in regard to how they interface with public dental benefits. As already described, large group practices are able to support a larger proportion of publicly insured patients on their roster due to a variety of strategies, for example strong case management and tight appointment booking; the centralization of administrative, marketing,

booking, and other non-clinical functions; the leveraging of disease reduction among existing patients in order to increase volume in the recruitment of new patients; and the cultivation of relationships with payers, also supported by volume, such that reimbursement claims are treated expeditiously. Although it is not known whether recent dental school graduates are flocking to large group practices *because* of the emphasis of many of these practices on Medicaid-insured patients, or *in spite of it*, the fact that large group practices are a steady and increasingly desirable destination for the newest generation of dentists bodes well for the ability of publicly insured dental patients to access care. Concurrently, however, the popularity of state laws restricting the ownership of dental practices by non-DMDs also comprises a threat to the breadth of their potential.

Like 46 other states, dental practices in Virginia must be owned by a dentist and cannot be affiliated with "commercial or mercantile" endeavor. Professional dentistry has been extremely successful at regulating its own industry, through influence on practice boards and legislation. Thus, this restriction is unlikely to change without industry-wide reform, itself also unlikely at a moment when the ADA cites concerns over presumed threats of competition posed by corporate practice; while dentists' concerns over the safety, adequacy, and appropriateness of corporate care does benefit patients, these claims can also mask anxiety over threats to dentists' income and position at the top of the dental team hierarchy. Moreover, the Virginia Supreme Court confirmed in 2007 that the owner of dental practices must be an individual who maintains current licensure. Thus, at present, opportunities for large group practice whose business aspects are managed by a centralized CEO who might be able to maximize Medicaid productivity by drawing on business practices gleaned outside of traditional training are low. Even if the opportunity for large group practice by non-dentists opened in Virginia – or if licensed dentist

owners of large group practices sought to locate in the region – challenges in recruiting dentists would likely still be prohibitive to success. Dentists I met during fieldwork told me repeatedly of the challenges of recruiting even one recent graduate to whom to sell their practice. Dental graduate statistics on location after graduation evince how recruiting even one or two dentists to the region poses an enormous challenge, much less recruiting enough dentists to stabilize a large group practice; conversely, however, it is possible that a large group practice could provide the social support that many dentists claim is lacking in the region. In addition, unlike the transportability of dental Medicaid benefits to neighboring states where nearby larger towns may improve their likelihood of usability, neither Tennessee nor West Virginia permit dental company ownership by non-dentists. Kentucky, reachable comparatively easily by residents of the region who live in the farthest west areas and widely cited as an exemplar of Medicaid expansion including dental benefits under the ACA-fomented plan Kynect, does permit the ownership of dental practices by non-dentists. Ironically, then, if Medicaid expansion does take place in Virginia, those residents of far southwest Virginia with the best opportunity to use them may be the ones considered the most geographically marginalized: the residents of far far southwest Virginia.

#### Conclusion: Contradictions in the pursuit of oral health equity

In this chapter, I have considered three increasingly popular approaches to increase access to dental care and, by extension, increase opportunity for oral health equity: dental Medicaid expansion, group dental practices, and the introduction of dental therapists. I have considered the opportunities and challenges of implementing each in my fieldsite, in particular drawing on the example of how dental policy reform is accomplished in Virginia. In conducting

this assessment, I have made summary observations, most of which focus on the contradictory qualities that characterize efforts to increase oral health equity.

Foremost, it must be observed that dental care access and, thus, oral health equity, writ large is dependent on the dental industry. Whether influencing legislation to shape licensure, business norms, and other necessities of legal dental practice, the dental industry perpetuates a norm of self-regulation. Paradoxically, while such structural determinations of care leverage the perceived benefits of the late neoliberal marketplace, for example establishing payment as a feefor-service norm or freeing dentists to practice in the locations of their preference rather than facilitating their entry into underserved markets, they also seek to limit competition, often in service of ensuring dentists' social status and income.

Yet these reforms also depend, profoundly, on the individual actions of licensed dentists. Even in an environment in which Medicaid is expanded, dental therapy is implemented, and practice ownership by a non-dentist is permitted, an individual dentist must still be willing to treat an underserved person. For example, a Medicaid beneficiary referred to a large group practice for treatments beyond the domain of the dental therapist must still be integrated into care through one final synchronization of effort – the dentist's, which, based on the example of stigmatized exclusion presented in Chapter 3, still suggest that more change is needed: specifically, change in the perspectives of many dentists on their patients. How do we go about engaging organized dentistry in its social obligation? The answer is not clear.

# CHAPTER 6: HOW A DECAYED, MISSING, AND FILLED DENTAL SAFETY NET PERPETUATES STRATIFIED DENTAL SUFFERING

In this dissertation I have examined the twinned marginalities of dental disparities in the United States, the *presence* of disease and the *absence* of care, through the lens of the dental safety net in far southwest Virginia. I have shown how dental disparities constitute not merely a biological problem but sociopolitical, moral, and ontological problems as well, from questions about who is responsible for the prevention and treatment of disease to disputes about what health care services are characterized as "essential" and who is permitted to deliver them.

Drawing on the experiences of patients, dental providers, and oral health advocates I have characterized the complex, fragile, and fragmented network of treatment opportunities for low-income families as, borrowing from a crude classificatory scheme used to evaluate teeth, *decayed, missing*, and *filled*.

I have shown how, as a public good enacted through and entwined with private interests, the dental safety net exemplifies a neoliberal model of health care that, paradoxically, creates new patient exclusions even as it attempts to reduce others. For example, policy reform that conflates "access" with public insurance coverage fails to account for the unusability of such entitlements, as many dentists choose to not accept public benefit. Such free market measures protect *provider* choice, while at the same time limiting those of patients. Simultaneously beneficiaries are obligated, by a public imaginary that reduces the origin of dental disease to personal responsibility and individual behavior, to persist in attempting to use public entitlements despite their constant exclusions from care – and to attest to their tenacity – lest their dental decay be otherwise interpreted as failures of self-care. Through such governance, at the intersection of moral, sociopolitical, and biological concerns, this neoliberal dental safety net does not merely *fail* to relieve the suffering of marginalized people but also can *produce* it.

Concurrently, it also places providers in fraught relations in which they wind up advancing certain interests in everyday clinical practice while advocating the opposite institutionally. For example, dentists seek to maximize dental team productivity by distributing ever-more tasks within their immediate clinical domains while also limiting structural reform that could authorize mid-level providers to provide these same services semi-autonomously in safety net settings. Examining these topics within Appalachia, a region whose residents have not only come to symbolize dental disparities in the American imaginary but whose historic vilification centers on broader notions about the care and conduct of the body, has allowed me to consider how dentition serves to index ideologies of race and class, as well as their relationships with beauty, dignity, and health care deservingness.

The *decayed* condition of the dental safety net, and how it perpetuates suffering, is exemplified the stories of Renata and Janie presented in Chapter 3. Together, their experiences lend support to the well-documented observation that the presence of dental disease often evinces the absence of care. They also show that the inverse is true: That marginalized patients who bear evidence of untreated dental decay are routinely excluded from care as a result of their stigmatized identities. Despite Renata and Janie's best attempts exercise their public dental benefits and, thus, the health care consumer identities obligated by market-based approaches to care, they find themselves excluded from it. The extremely limited opportunities for care within the public system leave Renata with two versions of the same impoverished option: full mouth extractions at the hands of a dentist who denigrates her, or one whose declining skill places her at physical risk. For Janie, as for over half of Medicaid-insured families nationwide, suffering derives not only from her dental condition but also from dentists' categorical exclusion of publicly insured people. While the extreme limitations of adult dental benefits in half of states

are a common source of lament among advocates who work, as discussed in Chapter 5, to see them expand, the unusability of children's public dental entitlements – comprehensive by federal mandate, at least on paper – demonstrates how degraded, how decayed this approach is. Which is better: Knowing that there is no benefit from which to be excluded, as in the case of adults, or the "false hope" (Castañeda et al 2010) of being excluded through dentists' rejection of a public entitlement or, in the case of many families, the vilified identity it is taken to represent?

The decayed quality of the dental safety net also shapes providers' experiences as well, for example those of the dental public health pilot team I studied and their encounter with a particularly heart-wrenching young boy, recounted in Chapter 4. For the public health dental hygienist and assistant, decayed is the capacity of a temporary grant-funded endeavor to allow them to adequately address the boy's needs, for example by providing case management services and persisting in locating a local private practice dentist who would treat him, in lieu of the clinical dental services that the public health department used to provide. The example shared in this dissertation was not unique was not alone. Among a patient population whose need for clinical treatment far outweighed staff's ability to secure it, the pilot inadvertently failed to serve many of the patients who most needed its attention. This failure, what I read as programmatic decay, occurred for not only the dental team's inability to identify willing dentists, but also for statutory restrictions on team members' independent exercise of leadership and clinical judgment. For the children for whom the available on-site technologies were clinically indicated, children whose oral health was adequate to qualify for services like fluoride varnish and dental sealants, these services offer valuable assistance toward the prevention of initial incidence of disease. But for children whose existing decay must be remediated before these topical agents could be applied – for example, using treatments that in Minnesota, among Alaskan Native

populations, and in over fifty countries around the world could be provided by a semiautonomous mid-level provider such as a Dental Therapist – the pilot further exacerbated dental inequality as those children often went without any services beyond their initial screening.

The absence of such opportunities for trained dental mid-levels to provide services through the pilot that are elsewhere considered standard provides insight into how the dental safety net in far southwest Virginia is *missing*, or better described as an absence than a presence. So, too, does the closure of the two public health dental clinics and two community clinics that occurred between my formative research and the conclusion of fieldwork. The constitution of adult public dental benefits, too, reveals two other necessities missing from the dental safety net: coverage of a spectrum of services that is clinically and socially adequate and the mechanisms, vis a vis the commitment of organized dentistry, to make benefits usable. Underlying these absences, and evinced in Chapter 5, is the absence of another necessity the dental safety net, one key to its reform: adequate political capital for advocates to affect change in light of the vigilance and resourcefulness of organized dentistry, specifically the American Dental Association (ADA).

One other topic examined in this dissertation provides insight into how the dental safety net indexes the quality of *missing* in other way: the sense of being an idea. Here, the story of Tanya, which opens Chapter 3, is instructive. Effectively homebound due to her advanced medical problems and self-shaming over her advanced decay, Tanya knows that the only dental safety net opportunity that exists for her, the RAM whose attendance by Jeff opens this dissertation, is out of reach. Unlike Jeff, she is not physically capable of an arduous and physical-demanding journey to wait for care that was in no way guaranteed. Thus, the hope of ever having her dental needs addressed is missing from her system of belief.

Jeff's attendance at RAM provides insight into how the dental safety net is *filled*, like a cavitated tooth or a canaled dental root, with manufactured solutions of variable standards and longevity. The RAM, the temporary health fair where Jeff received care, and the MOM, the independent charitable effort responsible for dental services there, were both developed as temporary solutions to the problem of health care inequality in America. While it would have been naïve, on the part of each event's founder, to think that the unequal access to services that they hoped to reduce would be resolved soon after their founding, in 1985 and 2001 respectively, organizers also told me that they did not expect demand to grow as exponentially as it has. Despite adding volunteer capacity over time and opening up new events in the region, the limitations of charity care are being felt: increasing numbers of patients are turned away every year and, as described in Chapter 4, a provider backlash to the events may threaten to inhibit their capacity to expand further. If the policy efforts described in Chapter 5 and advocated by oral health stakeholders do take hold in the arenas of both political reform and professional dentistry there would likely still be demand for donated health services. For example, even an embrace by private practices of an expanded adult dental Medicaid benefit or semi-autonomous mid-level providers placed in safety net settings might exclude childless adults or parents whose is too high a percentage of the Federal Poverty level to qualify them for publicly provided insurance or sliding scale feeds, but is still inadequate to purchase dental benefits or dental services through the private marketplace. Moreover as local dentists have observed of RAM, as described in Chapter 4, formerly paying patients have also sought free care there, lending credence to observations of the negative effects of the seeming uncontainability of dental costs on the middle class and privately insured, as well.

Examining patient and provider experiences synthetically provides insight into one of the major themes of analysis: how the dental safety net exemplifies the contradictions of health care governance in a neoliberal milieu. For example reading together Jeff's story, which opens this dissertation, and Janie's in Chapter 3, shows how safety net dental care in a context of extremely limited provisions may be – inadvertently – unequally apportioned based on provider's ideologies about the etiology of dental problems and patients' worthiness of care. Whereas both participants demonstrate accordance with the demands of contemporary medical citizenship by investing tremendous amounts of labor, time, and emotional skill – tenacity, resourcefulness, and self-discipline, for example -- in the face of extremely unwieldy barriers to care, only Jeff's, an arduous journey to have a dental anomaly, rather than decay, treated, bore out; Janey's family, shamed for its markers of existing decay and stigmatized for invoking its public entitlements, is excluded. These paradoxes are also evident in the capriciousness of dental teams, in both the dental regulatory imaginary and in practice. As described in Chapter 4, dental teams were developed in order to maximize productivity while also preserving a hierarchy in which the dentist is, unequivocally, at the top. Yet their movement from laudatory, in private practice settings, to licentious in the policy arena epitomizes what some analysts have argued is the Janus-faced character of contemporary dentistry: how it seeks to maintain a monopoly over the constitution of care despite its veneration of the ideals of free market capitalism, namely competition and independence. The flexible teamwork arrangements prized in private practice, when posited for the dental safety net, are often interpreted by dentists as risks of pluralization and threats to professional hierarchy that must be contained through legislative means.

Examining proposed solutions lends further credence to this critique as some, like

Medicaid expansion, would further entrench the public sector's dependence on the private sector

without any obligation of the private sector to respond in kind. Like the Medicaid provisions already in place, expansionism would involve new ways to responsibilize patients for their own care, an approach whose failure is already demonstrated at present. Other proposals, like Dental Therapists, if enacted only in the public dental marketplace, would threaten to reify not only hierarchical systems of care in which people of means can access a certain set of treatments and low-income people another, but also the social hierarchies that already pervade dentistry, for example in which private practice dentists, historically white men, remain at the top and midlevel staff, historically women and, in the case of Dental Therapists, ethnic minorities, are supervised, albeit remotely, by them. Reading these proposals through the experience of Virginia's most recent policy reform effort, in which low income pregnant women became entitled to a short term dental insurance benefit demonstrates how the governance of morality in the dental safety net extends not merely to patients or providers, but also advocates, who had to chasten the breadth of their aims in light of threats to foreclose efforts.

Dental caries is among the world's most common health problems. It is also among the most easily resolvable, though that wasn't always the case. In <u>The Bluest Eye</u>, her meditation on the violence of racialized poverty in post-Depression America which I quote in the opening of Chapter 3, author Toni Morrison observes of Pauline Breedlove's lost tooth that "even before the little brown speck" – that is, the decay that precedes its breakage – "there must have been the conditions, the setting that would allow it to exist in the first place" (1970:116). The setting that allowed Pauline's dental decay to exist in the first place included a lifetime of isolation, ridicule, and violence, as described in the novel, traumas which drive her escapism into the cinema and voluminous amounts of candy eaten there. These conditions, and their distal effects on dentition have, likewise, been experienced by Tanya, Renata, and Janie, as well many other participants in

my research. Based on the history of oral health in the United States, these conditions also include the lack of clinical and preventive infrastructure – community water fluoridation, for example, or a dental safety net. The same cannot be said of low-income patients today, whose experiences are described in this dissertation. The conditions that underlie their little brown specks center on the exclusions crafted by and through the organization of dental care in the United States. Over sixty years into construction of dental services as a norm of care and "good teeth" as a marker of American life (Hunt 1998, Picard 2009, Thomas 2009), unequal access and, thus, unequal outcomes – clinical outcomes, social outcomes, embodied outcomes – prevail. What can we make of how the stratified distribution of dental disease also unequally distributes pain and suffering across these narratives, ethnographic and fictional, almost a century apart in time?

Dental sociologists Khalid and Quiñonez characterize the current moment as one in which good dentition constitutes not merely an obligation of medical citizenship in a neoliberal health care economy but, moreover, a "social prerogative" (2015, see also Hitchens 2010, Smarsh 2015, Thomas 2009). As this dissertation has shown, this is a perspective also shared by participants in my research who live with the painful awareness that, despite their best attempts, they are more likely to live in what literary scholar James Robert Saunders describes as the "perpetual torment" personified by Pauline (2012). Perhaps ironically, this torment was portrayed to me by many providers and advocates as well, including Evelyn, who cannot find a dentist to treat the schoolchild with advanced decay; Nancy, who tries to help Renata by stepping outside of her scope of practice to assist her formerly-skilled supervisor in his work; and the many, many dentists, both those working in community settings as well as private practitioners who contribute an enormous amount of volunteer or reduced fee time, who spoke to me of their

feelings of depression at the state of dental disparities in the United States today, as well as their feelings of helplessness to enact reform. Will we make oral health equity the next "social prerogative," and privilege the just distribution of basic treatment above maldistribution of care through which social stratification is written onto the faces of low-income people? In the current moment of various health reforms it is tempting to anticipate what next actions toward oral health equity await, but we will have to be patient and see.

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