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## Editor's Welcome

Karen McGarry, Editor-in-Chief

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This past summer, I took over the role of Editor-in-Chief of JUE from Dr. Martha Radice. For many reasons, I am honoured to be taking over the editorial responsibilities for JUE. In an increasingly neoliberal environment where there is significant pressure for both academics and students to expedite research publications, undergraduate students often face fewer research opportunities and increasing competition to acquire suitable, high-quality outlets for publication. For the past 11 years, JUE has provided undergraduate student authors the opportunity to obtain critical, peer reviewed feedback from top scholars who serve as JUE Editorial Board members, to engage in the recursive writing process, and to publish their original, ethnographic research. This ultimately helps mentor talented students through the process of peer review and publication, and it instils in students a sense of pride and confidence in their work.

This past year, we received unprecedented numbers of high-quality manuscripts, resulting in the publication of this third issue (11.3) with seven original papers by undergraduate students. I am pleased to see that the journal is reaching a broad, interdisciplinary demographic of students and academics, and I hope that it continues to provide students with a steppingstone toward their future careers and other ambitions.

I am immensely grateful for the mentorship and patience of Dr. Radice while I served as a Co-Editor this past year. Dr. Radice was the Editor-in-Chief of JUE for six years and will continue with JUE as a Co-Editor until the summer of 2022. A special thank you as well to JUE's Founding Editor, Dr. Jason Patch, and for the editorial assistance of Brianna Kelly and Bryce Anderson, who are both graduate students at Dalhousie University. Lastly, thank you to the members of our Senior Editorial Board for your hard work and commitment to this journal.

This final issue of the eleventh season of *The Journal for Undergraduate Ethnography* opens with Hanna Maria Burhoff's exploration of perceptions of race and racism in a German school. In her interviews with teachers at a high school branded as one of Germany's "schools without racism," she examines the link between anti-racism and racism, arguing that anti-racist branding does not necessarily result in the dismantling of underlying racist structures or attitudes. Emily Cowart conducted participant observation and interviews with teachers, students, and school administrators at a rural elementary school in the southern United States to explore the challenges and complexities of implementing personalized learning in schools. Kathryn Gerry draws upon her fieldwork experiences in Kerala, India to study the gendered effects of worker migration

to the Gulf region. She argues that migration fuels women's status and is a catalyst for changing perceptions of gender. Maria Schrupp's fieldwork among Venezuelan migrants examines their contradictory emotions and attitudes toward the state as they relocate to Chile and begin to experience daily life in Santiago. Through an analysis of the illness narratives of three Ethiopian immigrant women, Meklit Daniel argues that the sharing of narratives provides women with a sense of control and agency over their bodies and identities. Drawing upon the work of Foucault, Zachary Gallin's fieldwork in a Jordanian HIV prevention NGO examines how the notion of biopower operates within the context of many partnerships with international donors from developed, wealthy nations. Finally, Megan Greenhalgh combines an autoethnographic approach with interviews to explore the bodily experiences of individuals with food allergies in the U.K. Focusing specifically on individuals who carry adrenaline auto-injectors (AAI), she highlights how AAI becomes integral to the management of their condition and to bodily perceptions.

Best Wishes,  
Karen McGarry  
November 2021

## School Without Racism? How White Teachers in Germany Practice Anti-Racism

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### ABSTRACT

This qualitative study investigates how white teachers at a German Catholic comprehensive school conceptualize issues of “race” and racism in the context of being a “School without Racism – School with Courage” (SOR-SMC). By collecting signatures and exhibiting yearly projects, more than 3,300 schools in Germany brand their school to be “without racism”. I found the branding of my researched school to be a form of “anti-racialism” that opposed “race” and racism as concepts but did not tackle any underlying racist structures (Goldberg 2009, 10). The teachers I interviewed took the SOR-SMC branding for granted and assumed that the school was racism-free. They thereby engaged in silent racism and reproduced racist connotations and structures without challenging them (Trepagnier 2001). Being anti-racist is not accomplished by declaring a school as racism-free. Instead, white teachers need to understand that anti-racism involves a deeper engagement with the structures that keep “racial” inequality in place (Goldberg 2009, 10).

**Keywords:** whiteness; racism; critical race theory; identity; Germany; education

There are no schools without racism (yet). But together we can change this. By looking closely instead of looking away. And by recognizing that a label might be a (good) beginning but is not yet enough to eliminate a social problem. (Ogette 2016, 111)

With these words, the German anti-racism activist and educator Tupoka Ogette (2016) questioned the potential of the *Schule ohne Rassismus – Schule mit Courage* or “School without Racism – School with Courage” (SOR-SMC) branding. The above quote is from her book “Exit Racism”, a guide for white people to understand and unlearn racism as it is engrained in German society. Ogette (2016) emphasized that no matter the branding of the school, schools are still shaped and impacted by structural and institutional racism. Therefore, she warned that anti-racism needs to involve more than just a label. Otherwise, participating schools run the risk of ignoring the issue instead of tackling it.

More than 3,300 schools in Germany are branded as SOR-SMC (Aktion Courage e.V. n.d.-b). Signs at their entrances and yearly projects highlight the schools’ opposition to racism. The concept behind SOR-SMC can be traced back to the German registered association *Aktion Courage e.V.* (Action Courage). It was initiated in 1995 as a response to violent forms of racism that arose in Germany in the 1990s, whereby people of color in various German cities were killed. The racist murders created a pogrom-like atmosphere in Germany which was characterized by right-wing extremists (Fuchs and Frey 2010). Consequently, the initiators of the SOR-SMC project saw a need to “overcome intolerance and hatred” at German schools (Aktion Courage e.V. n.d.-c, n.p.).

Lately, the violent presence of racism in Germany was highlighted by racist acts such as the terrorist attack in Hanau in February 2020 where nine people of color were killed, or the attempted mass murder of Jews in Halle (Saale) in 2019 (Kaschel 2020). In its institutionalized form, racism is visible in the labor market through lower employment rates of people “with a migration background” as well as through their reported experiences of “racial” discrimination (ENAR European Network Against Racism 2017). But already in early education, students of a lower social class and students “with a migration background” are systemically inclined to graduate with lower degrees from German schools (Klemm 2007; Wellgraf 2014). Knowing about this institutional discrimination, I was interested in understanding how white teachers make sense of their role and responsibility at a German school that brands itself to be “without racism”.

I chose the Happiness School (a pseudonym), a Catholic secondary school in a city in West Germany, as the subject of this study. Its unique status as private school allows for a specific selection of students that fit the pedagogical profile as defined by the Catholic diocese. The Happiness School has a Catholic orientation and focuses on an open and peaceful learning environment to distinguish its profile from public schools. This exacerbates the students’ demographic homogeneity, making it a particularly interesting case to study the teachers’ sense of their roles and responsibilities. Since 2013, the school has branded itself as a “School without Racism – School with Courage” and exhibits yearly projects to maintain this status. To understand how the white teachers at the Happiness School make sense of being a SOR-SMC, the guiding question of my research was: How do white teachers at a German Catholic comprehensive school conceptualize issues of “race” and racism in the context of being a “School without Racism - School with Courage” (SOR-SMC)? To explore this issue, I interviewed nine white teachers at the Happiness School and contextualized their experiences within the European discourse on “race” and racism.

Before going further, I need to explain some of the terminology of “race” that I am using. I use quotation marks around the word “race”, to

emphasize that it is a social construction, an “abstract signifier for separating human groups socially, politically and economically” (Lentin 2008, 490). I use “people of color” throughout the paper to describe “all members of racialized and marginalized communities” that experience oppression through the dominant white culture (Ha 2009, n.p.). Finally, the phrase “with a migration background” is common in German to describe people who are perceived as non-German and non-white. An exact translation of the German “*mit Migrationshintergrund*” would be “with migration background”.

In this article, I begin by explaining my theoretical framework of structural and institutional racism, the European discourse on “race” and racism, and critical whiteness at schools. Next, I introduce the Happiness School and explain my methodology. The analysis has three components. First, I reevaluate the consequences of branding a “School without Racism – School with Courage”. Secondly, I reflect upon the teachers’ approach to “race” and their perceptions of students of color. Thirdly, I address the teachers’ relationship to whiteness and their responsibility as white educators. Finally, I discuss the main contradictions that I found.

## Anti-Racialism vs. Anti-Racism

To understand the branding “School *without* Racism”, it is important to differentiate between “anti-racialism” and “anti-racism” (Goldberg 2009). While the latter is an opposition to conditions of “racial” inequality and includes the risk and willingness to give up on societal structures that perpetuate marginalization, “anti-racialism” is the opposition to “a concept, a name, a category, a categorization” (Goldberg 2009, 10). “Anti-racialism” therefore is the superficial critique of racism, without any clear indication on how to challenge a racist system. It criticizes an essentialist argument about “race”, without interrogating institutionalized and structural forms of racism as they are manifested in society. “Anti-racialism” erases “race” from the discourse “without addressing the legacy, the roots, the scars of racism’s histories, the weights of race” (Goldberg 2009, 21).

The European conceptualization of racism is illustrative of anti-racialism. The Holocaust was taken as the marking point and an antithesis to European modernity, while a prevention of its repetition was emphasized (Goldberg 2006). In the attempt to overcome Europe’s cruel and racist past, “race” disappeared from the public discourse and racism was pushed to the periphery (Lentin 2008; Müller 2011). As such, racism was framed as an issue that occurred outside of Europe, something only other societies struggled with (Goldberg 2006). With this silence about “race” it was assumed that any structural discrimination based on “race” would also disappear (Lentin 2008). This, however, is a form of anti-racialism, where the concept of “race” was erased only to be replaced by “culture”, “ethnicity” or “background”, all of which maintain a racist structure.

Despite the silence about “race”, European identity is based on a “racialized” ideal of “whiteness” (El-Tayeb 2011). “Racial” differences are created, and minorities are framed as the Other, the non-European. In the German context, this is visible through the association of Germanness with whiteness (Müller 2011). Furthermore, even in a context that promotes “racial” equality, differences can be emphasized so as to problematize them. In her qualitative study on diversity in the workplace, which she frames as “ethnic”, van den Broek (2014) described mechanisms that distorted white people’s perception and that rendered ethnical differences as “bad”. She thereby highlighted the dichotomy between the wish for diversity on the one hand, and the preference for sameness on the other. Ultimately, van den Broek’s study showed how the ideology of “racial” equality can be upheld in the European context, even when people perpetuate the idea of a “racialized” Other.

## Critical Whiteness Studies

Critical whiteness studies investigates the position of white people in a racist system that serves their advantage. Frankenberg (1993) emphasized that although whiteness is seen as a neutral category and goes unnoticed, “race” nevertheless shapes the lives of white people as members of a racist system. The first comprehensive work that introduced a critical

perspective on the white subject and emphasized the contributions of artists and academics of color in Germany was published by Eggers et al. (2005). However, the authors emphasized that the topic had not reached the German public discourse. White Germans still tend to have an old perception of whiteness as associated with Nazis and white supremacy (Müller 2011, 620).

Critical whiteness scholars such as Robin DiAngelo (2016) and Barbara Applebaum (2004) highlighted the importance of the classroom as a place of confrontation with issues of “race” and racism. They addressed white teachers’ and students’ difficulties in understanding and explaining racism. Picower (2009) also found that due to white privilege, the teachers’ “racialized” position can go unnoticed. Instead, white teachers reinforce a racist discourse through emotional, ideological and performative strategies such as expressing fear in situations with students of color. This especially affects students of color negatively as it maintains “racial” inequality. Consequently, Picower (2009) emphasized the importance of critical race education for white teachers because of their responsibility as educators.

German schoolbooks perpetuate a racist discourse that reinforces stereotypes (Apraku 2017; Marmer and Sow 2015) while teachers “with a migration background” report experiences of exclusion and discrimination at German schools (Fereidooni 2016). These are only two examples of the institutionalization of racism at schools. Institutionalized discrimination based on “race” presupposes that the schools’ organizational structures legitimize certain racist knowledge and practices (Gomolla and Radtke 2009). Often these are subtle and engrained in the organization’s mechanics so that individual members are unaware of them. As various studies have shown, German schools produce “racial” differences and exacerbate the segregation of students in primary schools (Gomolla and Radtke 2009; Radtke 2007). Through a specific pedagogical profile, schools can additionally attract and select certain students, leading to an increased homogeneity of their school community (Radtke 2007). As members of the school as an institution, teachers contribute to the legitimization of

racist practices. It therefore appears crucial to investigate whether white teachers at a private SOR-SMC are reflective of the racist structures at their school and to analyze how they make sense of their responsibility as educators.

## The Happiness School

The school I studied is located in a city in North-Rhine-Westphalia, Germany. In 2018, the percentage of people ‘with a migration background’ resembled roughly the national average of 26% (Bundesamt für Migration und Flüchtlinge 2019). The city is politically shaped by the Christian Democratic Union (CDU), and its social composition is impacted by the university. The Happiness School is a Catholic comprehensive secondary school, integrating the three traditional secondary school tracks of the German educational system in one institution. It was the first and until recently the only comprehensive school in this city, founded in 1969, and it has a very prestigious reputation, leading to disproportionately more applications than open spots for new students. As a private Catholic school, the Happiness School can form a unique pedagogical profile and attract and select specific staff and students. Consequently, the homogeneity of “race”, social background, religious orientation, and performance of the students is intensified. In 2019/2020, 3.5% of the students had a non-German citizenship, which is below the city-wide average of 10% but gives no clear indication on the number of students of color, since nationality is not an indication of “race”. It was a general assumption among the teachers that the majority of the students and staff at the Happiness School were white. The Happiness School requests no tuition fees, but instead benefits from the financial support of the diocese that offers more opportunities than public schools can.

## Methodology

This qualitative, exploratory study aimed to understand how white teachers at a German Catholic comprehensive school conceptualize issues of “race” and racism in the context of being a “School without Racism – School with Courage” (SOR-SMC). I chose a critical paradigm to deconstruct how the teachers make sense of their social position and responsibility in regard to racism (Hesse-Biber and Leavy 2006). To

collect rich, in-depth accounts of the teachers' perspectives, I utilized semi-structured interviews (Gray 2014; Hesse-Biber and Leavy 2006). The results provide an account of situated knowledge, which is shaped by the sociopolitical position of the interviewees and is therefore specific to the context (Hesse-Biber and Leavy 2006).

I contacted all employees who were teaching at least one of the three subjects: History, Social Sciences/Politics, or English at the Happiness School via email. This purposive sampling yielded nine participants, including two teachers who were involved in the SOR-SMC project. To preserve their anonymity, I changed the teachers' names. All teachers self-identified as white Germans. There were four men and five women, and their ages ranged between 29 and 65 years. Some participants had only recently started working at the Happiness School, while one had been around since the 1980s.

The interviews took place via Skype, by phone or in person and lasted between 45 and 80 minutes. I asked questions about the teachers' experiences of racism at the school and in Germany, their understanding of the SOR-SMC label and projects, and their views on critical whiteness. With the interviewees' consent, I audiotaped and transcribed their answers. I focused on the spoken words, but also included stumbling, laughter and other verbal signs. To interpret and analyze the data, I made use of coding and memo writing in line with a "thematic analysis" (Gray 2014). Starting with open coding using the software ATLAS.ti (Version 8.4.2 Mac), I looked for similarities and ambiguities across the transcripts. Through memo writing I could express the connections among the emerging codes, formulate them more analytically, and begin with the interpretation of the data (Hesse-Biber and Leavy 2006). This process was significantly informed by already established theories, thereby ensuring the reliability of my interpretation. Based on the memos, I developed a number of main themes which are presented in the remainder of this paper as the research results.

As a white German who grew up in a city with similar demographics, I could share certain

experiences with the interviewees and experienced how "race" and racism were approached at a German school in a predominantly white environment. While I could comprehend the teachers' standpoint, I could also distance myself from it. Over the past three years I lived in the Netherlands and enjoyed university education about critical race theory and whiteness studies. I could therefore recount many experiences that the interviewees mentioned as my own, but my academic position allowed me to interpret them differently. At times, I shared my analysis of the situation and gave an account of how I understood racism or whiteness, making my position as researcher involved, rather than neutral (Frankenberg 1993, 30).

I now discuss my findings within the context of five themes. I first address the teachers' binary understanding of racism. Secondly, I discuss the perception of the SOR-SMC branding as presupposition. The third and fourth part illustrate how the interviewed teachers perpetuate a racist discourse in two specific ways: when they address "race", and when they talk about students of color. Finally, I evaluate the teachers' relation to whiteness and their responsibility as white educators.



Figure 1: The 'School without Racism – School with Courage' sign at the Happiness School's entrance. Photo by author, 2020.

## On the Good Side of the Binary: "Every School Must Have That"

The Happiness School attained the "award" (*Auszeichnung*), as the initiating teacher

Mrs. Kessler phrased it, of being a SOR-SMC in 2013. This was celebrated with a ceremonial act in which a sign was mounted at the school's entrance (Figure 1). Its status was also referenced on the school's website. As the oldest teacher, Mr. Lindemann, who was involved in the school's Holocaust memorial excursions and various projects concerning discrimination, told me, they are proud of the accomplishment:

Well, we've certainly deserved it [to be a "School without Racism"]. We've certainly deserved it. Basically, every school should have it, because it's not only the projects (laughs) that ... take up the topic. Basically, our everyday awareness is what this label stands for.

By saying "every school should have that" Lindemann argued that the positioning as a "School without Racism" is a necessity. He thereby emphasized his understanding of racism as bad and illustrated Trepagnier's (2001) argument that in dominant discourse, people differentiate between being racist and being not racist. Being racist is connected to individual, intended, and conscious actions, and therefore renders racist people as bad people (DiAngelo 2016). By understanding racism in these limited terms, being not-racist becomes the "default category," while racist actions are condemned (Trepagnier 2001, 142).

Lindemann's argument corresponds to the Western ideal of a tolerant and non-racist society (Lentin 2008). The dominant discourses in Europe uphold the modern values of equality and democracy as unique to the continent and thereby render any association with present racism as incompatible. Consequently, as can be exemplified by the above quotation, it is seen as self-evident to position oneself as non-racist in a "post-racial" society that has seemingly overcome racism (Lentin 2008). This perception aligns with a core concept behind SOR-SMC. The more than 3,300 "Schools without Racism" in Germany are required to collect signatures of at least 70% of the affiliated employees and students and subject their schools to the three pillars of the project: To develop sustainable projects against discrimination, to openly deal with discriminating acts and statements, and to

exhibit at least one project a year concerning discrimination, especially racism. Thus, racism is portrayed as a conscious, voluntary but bad act executed by individuals. Only in cases of overt racism, students and teachers are advised to intervene (Aktion Courage e.V. n.d.-a).

This self-perception of the Happiness School as a "good" "School without Racism" is further shaped by the Christian profile of the school. When I asked Mrs. Döring, who recently started organizing the SOR-SMC projects, why the white students are so shocked to see or hear about racism she said that "most of the parents I met here are just very, very open people, who just in the end actually say that 'I want to treat every person as he deserves to be treated'. That sounds so big somehow, but who actually practice this Christian principle of altruism in some way". Unconsciously, Döring described the parents of the *white* children who "treat every person as he deserves to be treated." This implies a power hierarchy that renders white people as superior to people of color, who are perceived as the Other. The emphasis that the white parents "actually" practice what Döring understood to be principles of altruism highlights their moral superiority. But her understanding of altruism presupposes a judgement on the children's deservingness. Although well-intended, Döring reproduced "racial" inequality with her statement and highlighted the intersection of whiteness with Christianity (Arndt 2005).

It was a general assumption among the teachers that the majority of the students and staff at the Happiness School were white. But many justified this with being a Catholic school, which reinforced the perceived link between Christianity and whiteness that excludes many communities of Christian people of color. In 2015, the Happiness School voluntarily started to accept children who had recently fled to Germany. Some teachers believed that the school consequently showed a great diversity and was "very colorful" which reinforces the idea of Germanness as whiteness and renders people of color as "not-German-looking" (Ming-Bao 2000, 175). The decision to accept the "international children" as they are called at the school was phrased as a humanitarian, "very generous" act by Mr. Richter, a teacher for Social Sciences, History and Economics. By

calling them “refugee children” Richter further fed into the European discourse of rescuing the fleeing people that implies colonial power relations (Danewid 2017). Although the Happiness School is not explicitly bound to accept only Catholic students, the authority over the acceptance or refusal of children applied specifically to children that fell outside the norm of being white, Christian, and German students.

## **Branding as Presupposition: Becoming a ‘School with Courage’**

The SOR-SMC project positions itself against any form of “discrimination, especially racism” (Aktion Courage e.V. n.d.-a, n.p.). The teachers at the Happiness School, too, conflated racism with prejudice and different forms of discrimination, such as homophobia. The second part of the SOR-SMC slogan, “School with Courage”, was only added by the umbrella association in 2001 (Aktion Courage e.V. n.d.-b). Yet, by adopting a not-racist stance as the status quo, the latter part of the label became the focus of the Happiness School:

We were of the opinion that there is no racism as such at our school. (...) We have put the emphasis on ‘School with Courage’ and have looked at what possibilities we have at our school to draw attention to something. (...) We said that if we were to make this a topic, or yes, I wanted to, or the idea was: what is racism, everyday racism, or where do we encounter racism in books, in storybooks, in any kind of characters. Whether we would wake up sleeping dogs, and basically make it a topic if it is none.

With the first sentence, Kessler already presupposed that the school is racism-free, which inhibits any further engagement with racism as an institutional and structural issue. It illustrates silent racism, when racist connotations and structures remain unchallenged (Trepagnier 2001). Declaring it to be a ‘School without Racism’ proclaims absolute innocence and discharges the white teachers and students from an interrogation of their own position in a racist system. Instead, Kessler believed that by not addressing racism, they would prevent its reinforcement which is illustrative of the European silence on

‘race’ (Lentin 2008). Kessler told me that through travelling, especially on the African continent, she realized the problems associated with racism, which is why she was so passionate about the project. She used to go to bookstores and tell the staff about racist depictions in children’s books. And recently, before our interview, she had been to a talk about everyday racism given by a Black journalist. As other teachers reported, there were very few individual instances of antisemitic jokes and one verbal attack against a girl of color. But the teachers dealt with them individually and usually found that the students had no bad intentions so that they were soon perceived to be resolved. Hence, the SOR-SMC branding still positions the school on the ‘good’ side of the binary, by claiming they are not racist (Trepagnier 2001). Once the schools commit themselves to be a SOR-SMC, there is no controlling mechanism that could reinsure that the school remains ‘racism-free.’

It seems contradictory that the school consciously decided not to address racism. That presupposes that racism is not understood in its structural form. Otherwise, no school could be seen as operating outside a system that institutionally and structurally perpetuates racism. The choice not to talk about racism is a privilege for white people who can perceive an engagement with racism as a voluntary act (McIntyre 1997). However, it shapes the lives of white people as well, and a discussion of it should not be an option, but a necessity (Frankenberg 1993). Unaware of this interpretation, Kessler emphasized her perceived detachment from racism:

... that we also did smaller projects for us that dealt less with racism but with things that were dear to our hearts. We did a day of politeness. Where we talked about manners. We put up posters everywhere. We really took a look at the old school again – etiquette. Which parts of it make sense, which do not? We implemented a day of silence because noise is an issue here.

The quote indicates that racism, different from a day of politeness or silence, does not lie close to the hearts of the white teachers (and students). From a position of white privilege, Kessler assumed the universality of her

perspective by talking about “projects for us” who are not affected by racism. She thereby neglected to acknowledge her advantaged position in a system built on ‘racial’ inequality and presented herself as unaware of students’ experiences of racism. Being anti-racist is seen as enough to position themselves as a ‘good’ school. Through various practices, the school’s image of being ‘good’ and non-racist was upheld, whereby a deeper confrontation with its racist conditions was prevented. As the next section will show, especially because the systemic and institutional forms of racism were not challenged, the teachers at the Happiness School perpetuated a racist discourse.

### **Talking about “Race”: “For Me, They’re Just the Children”**

During the first interviews, I assumed that the interviewees would know the terms *People of Color* (PoC) and *Schwarze Deutsche* (Black Germans) as they are used as self-designation in the German language, but they did not use either one. I then changed my strategy and asked the teachers whether they were familiar with the terms. Some teachers were familiar, while others had not heard the terminologies before. I only explained my understanding of the terms to the teachers unfamiliar with them, but retrospectively, I could have initiated a discussion about language with every teacher. Although I referred to “People of Color”, the interviewees responded by saying colored people (*Farbige*), dark-skinned, black-skinned, “Colored People”, or most frequently, “people with a migration background”. However, the two teachers to whom I explained how and why I use “People of Color” appreciated the discussion and adapted to use the terminology for the remainder of the interview. Mrs. Krause, teacher for English and Social Sciences, showed reflection on her own lack of awareness and admitted that it is indeed important to keep up with the terminology to not discriminate against anyone. She further intended to “bring it up again” to create awareness through non-discriminatory language, which showed the need to talk about the social construction of “races” as it is assumingly not done until yet. It indicates an insecurity about the use of language which arose out of the intention to be not-racist (Hondius 2014).

The interview with Mr. Neumann, one of the youngest teachers and a Happiness alumnus, illustrates the ambiguities of the terminology that was used for people of color. I asked him whether he had observed anything remarkable among the students concerning stereotypes, discrimination, or bullying, and he replied that, “I now teach many very, very high-performing classes, [and] I must say, there is simply a very large proportion of children without a migration background, and I believe that it [discrimination] is really less common there.” Neumann associated the small number of people “with a migration background” with the absence of racism, which he defined as individual, mean-intended actions against people of color rather than structural racism (DiAngelo 2016; Trepagnier 2001). The quote further indicates a direct link between “very, very high-performing classes” and the absence of students “with a migration background”. Asked about this potential link, Neumann confirmed and said, although one cannot generalize, children who recently fled to Germany are in a different position than someone who was born in that city and whose parents are doctors and lawyers. Apparently then, for Neumann, children “with a migration background” are not German, have a recent refugee history, and their parents lack prestigious occupations.

In dominant discourses, the phrase “with a migration background” is used for people of color generally, disregarding whether they recently migrated or whether their families have lived in Germany since generations. I asked Neumann if, from his perspective, a person of color who was born in Germany to a well-off family would also be considered a child “with a migration background”:

Ah, that’s a good question (...) I really don’t like to make such distinctions, so who is from where and so on, for me they’re just the children (laughs). (...) I think if they were born in Germany and their parents both speak German, they don’t have a migration background, or, they don’t have one anymore, do they? That’s really difficult to differentiate. And actually, it is just so that, that I actually do not need it, only if you think about, it is already difficult right?

Neumann thus revealed the contradictions of the terminology. "With a migration background" is one of the "alternatives to racial and racist-sounding words" in the German language that are used to circumvent "race" (Hondius 2014, 275). However, it indicates an "implicit temporariness", thereby rendering people of color as the "racialized" Other who do not belong (Müller 2011, 627). Neumann used the terminology to prevent the implication of "races", which he "actually do[es] not need." Nevertheless, the teacher's direct association of academically high-performance students with "no migration background" illustrates his perception of differences among the children. It is therefore important to reflect upon the implications of such Othering terms. Neumann's example shows that the students are clearly not "just the children."

### **Talking about Students of Color: Cultural Assumptions**

In the abstract, teachers like Mr. Richter believe in the ideal of cultural equality as a "very big gain." However, I found that their perceptions were biased by cultural expectations that solely focused on the students' difference. Echoing van den Broek's (2014) findings, the teachers emphasized the importance of cultural diversity. Yet they practiced exclusion through the limited and distorted interpretations of their observations that reaffirmed dominant European discourses on the "racialized" Others (El-Tayeb 2011). Their views were shaped by "perceptual distortion" and "selective perception" that gave only a fragmented view of the situation (van den Broek 2014).

When I asked Mr. Richter about the students of color at the school, he said that the image of "international children" has become increasingly normal: "However, also with all the difficulties. We as teachers notice that of course other cultures have also come to the school with children from other regions of the world, and so the things that were taken for granted in the past can no longer be taken for granted." Richter thereby implied that the German culture is homogeneous and is opposed to cultures from outside. With the example of one Syrian boy as a "problem student", Richter conflated culture, "race", and nationality. The

particular boy showed disrespect for a female teacher who is a nun, which Richter interpreted by the cultural differences that the international student presumably had. His interpretation might be accurate. It is, however, significant that when I asked him about people of color at the school, his first association was "problematic" "international children", who brought different cultures and religions and deviant behavior that were incompatible with the assumed German standard. Later in the interview, Richter admitted some awareness of his own racist attitudes that he had towards Muslims:

I don't think it's right either, that modern women should wear a headscarf like that, yes, it always seems to me, like such a gesture of submission, that they represent themselves like this in the public. So, there I am sometimes shocked by myself, how I, how quickly I am with judgments.

That there were sentiments among the teachers especially about the presumably Muslim students is illustrative of dominant European discourses surrounding "race". El-Tayeb (2011) discussed how Muslim cultures are perceived as the antithesis to the European culture, an assumption that is deeply ingrained with the apparent gender inequality among Muslims. The headscarf is seen as the ultimate symbol of cultural difference, resembling "silenced, oppressed women living in parallel societies" (El-Tayeb 2011, 83). Although Richter proceeded to reflect upon his own biases, the assumption of cultural incompatibility is still underlying his interpretation of the Syrian boy's behavior as well as his understanding of the headscarf. The cultural discourse on the "European Others" places issues of gender inequality outside of Europe (El-Tayeb 2011). There were only a few girls at the Happiness School wearing headscarves, yet this provoked an internal debate and resulted in a minimum age rule for them to prevent "that the students pressure each other to wear these symbols." Certainly, the religious affiliation of the school impacted the school's discussion of Islam, but the implemented rule can still be understood as a form of patronization that interprets the wearing of a headscarf as bad.

Asked about the segregating behavior of the students, Mrs. Kessler, the initiating teacher of the SOR-SMC project, discussed group formation in the context of the international classrooms. These were installed in German secondary schools to accommodate students who had recently migrated to Germany and needed additional support to adapt to the new language and environment (Ministerium für Schule und Bildung des Landes Nordrhein-Westfalen n.d.). Kessler was especially outspoken about the Syrian students, presumed to be the majority in the international classroom, whom the school started to accept in 2015:

That is such a *Verclanisierung* (clan in the making). They gang up and form a pretty powerful force over other students because they really stick together, I've noticed that and forwarded it to the responsible teacher [who is organizing the SOR-SMC projects] so that you don't get a two-class society or school.

With the use of a neologism that indicated the clan character of the students, Kessler interpreted the group as having a collective power. She perceived the situation from the perspective of the majority white students against the collective of the Syrian students. To "gang up" has very derogatory and negative connotations, expressing the lack of empathy that Kessler had for them. It also implied that it is a big group of students, which Kessler supported by describing them as executing a "pretty powerful force." She assumed the group character of the international classroom was a threat to the white students.

While Kessler offered one interpretation that made her scared and worried, there are other possibilities. Tatum's (1997) explanation of why black students tend to group together in a school context is very different. She argued that it is an act of empowerment and mutual support among students who have had similar experiences of discrimination. The Syrian students that Kessler mentioned recently migrated to Germany and took the same class; as such, it seems natural that they hung out together during breaks. Wellgraf (2014) also discussed how students find collective strategies that can be perceived as violent and

dangerous, but these must be understood in the context of the "racial" and classist misrecognition that they experience.

Mrs. Kessler did not consider any of these alternative explanations. Instead, she proceeded to report the group formation to the SOR-SMC teacher, implying that something should be done about the Syrian students sticking together too closely. That Kessler interpreted the group of students in a specific way is indicative of "perceptual distortion" (van den Broek 2014). She focused on cultural difference as a possible threat, which rendered any alternative interpretation as invalid. Her fear of a "two-class society or school" became a self-fulfilling prophecy because Kessler already differentiated between two groups of students as outsiders and insiders.

## The Teachers' Role and Responsibility: "The Little Word 'White'"

The previous section demonstrated the problems associated with branding a school to be *without* racism and illustrated ways in which institutionalized and subtle forms of racism were perpetuated at the Happiness School. While the SOR-SMC label was seen as an accomplishment, and the non-racist standing of the school as a necessity, the question arises as to how the teachers made sense of their role and responsibility as white teachers. Consequently, this section deals with the teachers' relationship to their whiteness.

Although the teachers found alternative racist and not racist-sounding words to talk about people of color, they were even more hesitant to talk about whiteness. When asked how he conceptualized "whiteness", Mr. Richter said:

I wouldn't use it too, because there will definitely be someone sitting in the class who feels excluded and who thinks, oh, I somehow belong to some tolerated minority here (...) and I'm trying to tell them that, trying to tell them no, there are no human races. This is a racist invention. And in that context, I'd rather not use the little word 'white'.

Richter opposed an essentialist argument about “race” by arguing that “there are no human races,” which he was eager to teach the students. To circumvent racist connotations, he employed a color-evasive strategy (Frankenberg 1993, 139). Richter saw his own whiteness as neutral and invisible. He also used the German diminutive for “word” (*Wörtchen*), which I translated to “little word”, to belittle the word “white”, thereby diminishing its significance as a social position in a racist society (Frankenberg 1993). His opposition to an essentialist argument had good intentions. He perceived whiteness as corresponding to white supremacy which he rejected as exclusionary (Müller 2011, 620). Instead of questioning why that could be the case, and thereby challenging any underlying racist structures, Richter was silent about whiteness. Although “racial” colorblindness is often seen as strategy to avoid essentialist racism, it reinforces white complicity because it does not address “racial” inequality (Frankenberg 1993, 145). With his response, Richter evaded the acknowledgement of his white privilege.

Most teachers had never thought critically about their whiteness before. Mr. Neumann said that he only recently realized that his class was comprised solely of white German students: “otherwise, I find it actually quite nice in everyday life, that you don’t have to pay attention to it, or that, I think if you don’t realize anymore, whether one is black or white, that’s the right way. But that it is simply normal. That’s what you want to achieve.” With the intention that “race” should not matter, Neumann expressed his wish for “racial” colorblindness as “the right way.” This is, however, contradictory, since he claimed it should be normal to have a diversity of “races”, yet one should not notice if every single student was white. In an all-white German context, Neumann felt that “race” did not matter and he applied this to the general structure of “everyday life.” He thus assumed that his white position was universal, implying that if whites experienced their “race” as insignificant then this must be true for everyone (DiAngelo 2016, 176). Such a claim denies the experiences of exclusion and structural racism that people of color face because they are not white. While in a racist system whiteness can go unnoticed, Neumann

had previously pointed out his perception of how those “with a migration background” and low academic performance were interlinked. This contradiction emphasizes the importance of talking about “races” because apparently only whiteness is invisible, while the teachers emphasized the Otherness of people of color.

Mrs. Kessler told me about her travel experiences, and the benefits of whiteness in this context. When asked how this related to her experiences in Germany, she said:

So here I wouldn’t know that I have an advantage now [as a white person]. I see it rather the other way around, that probably in conversations with colored people (*sic*) it would become apparent that they have a disadvantage. But I don’t see the advantage now. I see it more on the African continent as a white person. Or in India or in other countries.

By focusing on disadvantaged positions of people of color, Kessler maintained her position as “race”-neutral (Frankenberg 1993). Whether the “racial” inequality is phrased as advantage or disadvantage is a matter of perspective, but a different emphasis can disguise the “racialized” position of white people. That being white is an “unearned advantage” (McIntosh 1989, 11) in Germany remained invisible to Kessler especially because she rendered being white as the default category. Additionally, by comparing the situation to racism in other countries, Kessler downplayed the significance of racism in Germany and posed it as a problem that happens elsewhere. This is illustrative of Europe’s denial of racism (Goldberg 2006), wherein colonialism is perceived as a problem external to Europe, which renders any problematization of its continuities in modern Europe impossible (Goldberg 2006). Kessler could refuse her responsibility as a white teacher because of the privileges she enjoyed. Racism in Germany therefore remained a problem for people of color in particular (Frankenberg 1993, 6).

The teachers’ positions on whiteness must be understood as a spectrum. There is, for example, Mrs. Böhmer, who grew up in the German Democratic Republic and was involved in the school’s excursions to the memorial site of Auschwitz. At the time of the interview, she

was reading the book "Exit Racism" by Tupoka Ogette (2016) from whom I have taken the opening quote. She admitted that she learnt new aspects from the book, which she intended to integrate into her lessons. Böhmer further told me how she contextualized the German colonial past with class discussions of monuments and the history of the local zoo, as well as everyday examples of racism. However, she also admitted that she was more aware of racism because of her own experiences of discrimination as an East German woman in the West.

After I made explicit that critical whiteness is concerned with the position and responsibility of white people in a racist system, Mr. Freitag broadened his perception of this responsibility to ensuring values of democracy and tolerance in general:

But that now, that I would somehow have to take responsibility in the school, certainly in the sense of integration, or just massively oppose certain things, regardless of whether it is now bullying or ra-, or a form of racism, is actually self-evident. But I would not reduce that to just being white.

Freitag highlighted that in a global context he was aware of his privileges linked to wealth and political security. By conflating whiteness with a general global responsibility, a critical reflection on racism within Europe was again evaded. Specifically, he did not understand critical whiteness in the context of institutionalized and structural racism at the school. Rather, he perceived his responsibility as an abstract awareness, whereby concrete local interactions and structures remained unchallenged.

At this point, it is important to emphasize that the teachers were not defensive of their positions. Instead, throughout all the interviews, the teachers allowed me to offer my understanding of the situation and were open for a discussion. After having explained to her what critical whiteness entailed, Mrs. Krause said the following:

Otherwise, I wouldn't say that this whiteness is directly addressed in class, or at least (...) if, then these are probably conversations that simply result from a conversation with the students in class. But I wouldn't say that this

is directly really being incorporated into our planned lessons, it might be something that could actually be extended. At least that's how I would perceive it personally.

Krause demonstrated reflection on her individual perception, but also on the lack of anti-racist education that the school is providing. She showed her concern about the topic and a willingness to achieve an anti-racist education.

## Conclusion

In this case study, I have shown how a school that brands itself to be a "School *without* Racism" still perpetuated discrimination based on "race" through various practices. As Ogette (2016, 111) argued, "There are no schools without racism (yet)." In this regard, the SOR-SMC branding of the Happiness School seems to be counterproductive since it propagated anti-racism that opposed "race" as a construct but did not tackle any underlying racist structures (Goldberg 2009, 10). The teachers I interviewed took the SOR-SMC branding for granted and assumed that the school was racism-free. They thereby engaged in silent racism and reproduced racist connotations and structures without challenging them (Trepagnier 2001).

The contradiction between the SOR-SMC branding and the teachers' perceptions and practices became especially clear when analyzing the school's position towards the "international children". Several teachers perceived the students of color at the school as non-German, lagging behind, and bringing along incompatible cultures. These individual accounts gave an indication on how "Germanness", whiteness, and Christianity appeared to be interlinked. Because they assumed their school to be not-racist, the teachers perpetuated a racist discourse. Being unaware of their white privilege, the teachers evaded a confrontation with their responsibility as white educators.

The results of this study have certain limitations. I reduced the sample size to only nine teachers at a Catholic comprehensive school in a conservative, predominately white city in West Germany. The selection of the teachers was limited to their involvement with

the SOR-SMC branding and the subjects English, History, and Social Sciences. Except for one meeting in person, the interviews were limited to videocalls. This required me to rely on the participants' own reflection of their actions, whereby many aspects of silent racism might have remained unnoticed. Further research should therefore integrate participant observation at the school and inside the classroom. Additionally, this research indicated the intersection of different social categories such as "race", class, and religion. For the future, it would be beneficial to focus on an intersectional perspective to provide a multilayered account on discrimination at German schools.

Taking the SOR-SMC branding seriously would imply "looking closely instead of looking away" (Ogette 2016, 111). Teachers have a crucial role in combatting the institutionalization of racism at German schools. Therefore, white teachers need to understand that talking about racism is not a choice but a necessity, and the SOR-SMC branding could be a good starting point. Being anti-racist is not accomplished by declaring a school as racism-free. Instead, anti-racism involves a deeper engagement with the structures that keep "racial" inequality in place (Goldberg 2009, 10). The SOR-SMC project group could be realized as a platform for students of color to find empowerment and for white teachers and students to learn about the institutional and structural dimensions of racism at their school. This could be an important first step in the process of becoming a "School *against* Racism".

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# Implementation of Personalized Learning in a New Charter School

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## ABSTRACT

Personalized Learning (PL) is an educational approach that tailors instruction to the academic needs of each student. Most research on PL focuses on student achievement, technology, and implementation challenges. Little research has been conducted on the actual practices that teachers use to personalize instruction and on students' and teachers' feelings about being in a school that implements PL. I conducted a case study at a recently opened rural elementary charter school in the southern United States, which was implementing PL schoolwide. After attending a professional development workshop on PL hosted by the State Department of Education, I conducted classroom observations in a first-grade and a fifth/sixth-grade classroom. I interviewed the teachers of these classes, the school principal, and three students. Three themes emerged from my analysis of this material, relating to student engagement, teacher behaviors and dispositions, and student outcomes. Overall, I concluded that PL is not a quick or easy transition for a school to make, nor does it involve just changing the curriculum to individualize instruction for students. Personalized Learning requires an adaption of teacher and student mindsets and the development of a school culture that fosters both academic and social-emotional growth among the students.

**Keywords:** teaching; personalized learning; charter school

works in practice and what benefits it can yield when effectively implemented.

## What is Personalized Learning?

While Personalized Learning may be seen as a new approach, Campbell et al. (2007) argue that it is really just constructivist learning based on Vygotsky's social theory in which teachers scaffold instruction for students. They see PL as a collaborative activity between teachers and students, rather than individualized instruction for each student, which, they argue, can only be accomplished through one-on-one tutorials. Although PL can be implemented at all grade levels, Campbell et al. propose that because it involves teachers and students co-producing knowledge, the approach is more suited to older, high-achieving students who are capable of higher order thinking.

Regardless of the grade level in which it is implemented, Personalized Learning has several key features. The RAND Corporation (Pane et al. 2015, 3) report that incorporating separate time for individual student support is common in PL schools, as is allowing students to set their own learning goals (Pane et al. 2015, 50). In a study of middle school teachers' approaches to goal setting, De-Mink et al. (2017) identified a range of approaches to goal-setting among teachers, including: (a) independent design, (b) interest-driven co-design, (c) interest and skill-driven co-design, (d) skill-driven co-design, and (e) selection. In the co-design approaches, the students and teachers collaborate to align their goals to different disciplinary skills. The researchers found that most of these approaches involved connecting learning to students' interests, students actively participating in the design of their learning, and students taking responsibility for their learning. These findings highlight the collaboration between teachers and students that PL fosters.

In order to determine the most common structural elements of Personalized Learning, Olofson et al. (2018) administered a survey to 308 teachers. The results indicated that the most common practices teachers used were whole-group learning, customized learning, personalized assessments, and technology implementation. Other research (for instance,

An approach to teaching and learning that has increased in popularity in recent years is Personalized Learning, in which students advance at their own pace, material is connected to students' interests and experiences, students have both choice and voice within the classroom, and assessments are designed to allow students to demonstrate their learning in a multitude of ways (Murphy, Redding, and Twyman 2016, 57-69). The South Carolina Department of Education (SCDE) established a Personalized Learning (PL) Department three years ago and is now working with 33 districts on implementing this approach. According to the PL Coach from the SCDE, the approach is popular because it gives students a sense of ownership, teaches them responsibility, and empowers them (Catto 2019).

Previous research focuses on the different elements that comprise PL, but little research has been conducted on the practices that teachers use to personalize instruction and set goals for students in the classroom, or how students and teachers feel about being in a school that implements PL. Furthermore, there is virtually no research on why teachers choose to work at a school that implements this approach to learning and teaching. It is important to conduct further research to increase educators' knowledge about particular strategies, the challenges associated with PL, and its benefits for students to fully understand all aspects of its implementation. I conducted a case study of a new school, Thomas Charter School (a pseudonym), which opened in August 2019 as a Personalized Learning school, in order to gather more information about PL from the perspectives of the administrator, teachers, and students. This research will enlighten educators and families on how PL

DeMink-Carthew et al. 2017, 5-8; Schmid and Petko 2019, 79-80) also indicates that the most common structural elements include varied classroom models (customized, or whole-group/small-group where either the entire class is taught together or they are placed into small groups for instruction), technology implementation such as online delivery and digital tools, student choice/interest, and personalized materials and classroom environments, which will be discussed in more detail in my study.

## Research on Personalized Learning

Existing research on Personalized Learning focuses on student achievement, the use of technology, and implementation challenges. In terms of the benefits of PL, it has been found that personalizing not only units of instruction and materials for students but also the classroom environment and learning goals has a positive impact on student achievement. The RAND Corporation examined the ways teachers personalized learning and the effects it had on student achievement (Pane et al. 2015). The researchers conducted site visits, interviewed school administrators, reviewed teacher logs and surveys, administered surveys to teachers and students, and evaluated achievement data from 32 schools that did and did not implement Personalized Learning. They found that after being in a PL school for two years, students showed gains in both math and reading performance in comparison to their peers in non-PL schools. They found that flexible student groupings, learning spaces that supported the models of a personalized classroom, and students discussing data related to their personal learning goals contributed to student achievement (Pane et al. 2015).

Research also indicates positive effects of personalizing even one unit of study. Bernacki and Walkington (2018) personalized four units of algebra for 155 ninth-grade students to examine the impact on student performance and interest in the topic. To personalize the math, the researchers related problems to students' interests and their home or community backgrounds and interviewed students after each unit to assess their interest.

The results indicated that personalizing the units for students triggered greater interest in the subject matter and had positive effects on their achievement in classroom exams.

Technology is a common aspect of Personalized Learning implementation both within the United States and in other countries. Schmid and Petko (2019) administered an online survey to 860 eighth-grade students in 31 schools in Switzerland to determine whether the use of digital technologies for Personalized Learning helped students develop technological skills. The results showed that 86% of the students used a computer in class which shows a strong correlation between PL schools and the use of both technology and technological skills. In another study, the inclusion of technology was found to have a strong positive effect on both students' self-reported digital skills and their positive attitudes towards technology use in the classroom (Lee et al. 2018, 1270-1275).

Lee et al.'s research study (2018) also investigated teachers' technology use and needs in schools that were based on a framework of Personalized Integrated Education System (PIES), a course management system for recordkeeping, planning, and instruction in Personalized Learning schools. The researchers evaluated the survey responses of 245 teachers from 41 schools across the United States that were implementing Personalized Learning. They found that only 12% of teachers had a technology system that integrated the four major aspects of PIES and 21% reported they had no such technology system. Overall, the findings indicated that technology was typically used by teachers for recordkeeping, planning, instruction, and assessments. In a two-year study of 28 Personalized Learning schools, Bingham et al. (2018) conducted interviews, focus groups, observations, and surveys with teachers, administrators, and students to identify challenges, disruptions, and contradictions within schools. The results showed that teachers and administrators experienced similar challenges regarding a lack of available technology. Students reported issues with technology not working correctly or not having the technological skills needed for

the amount of technology use within the classroom.

Although research indicates that Personalized Learning contributes to student achievement (Bernacki and Walkington 2018, 864; Pane et al. 2015, 10-17), challenges with technology, standardized testing, student choice, and teacher preparation can elicit issues for both teachers and students in PL environments. Available technology often does not align with teachers' needs and students often also experience technology issues. Bingham et al. (2018) identified issues that both teachers and students faced, including those associated with internet failure and the absence of backup lesson plan options, online content not aligning with personalized goals, and students not having the requisite digital skills.

In addition, research indicates that teachers experience many challenges in attempting to align their Personalized Learning methods to standardized testing. Results of the RAND Corporation study (Pane et al. 2015) show that teachers thought they should be teaching grade-level content aligned to standardized testing rather than having students working at their own pace. Expectations related to students' performance on standardized tests are a major challenge for both teachers and students in PL schools. In Bingham et al.'s two-year study on 28 schools, most teachers felt that their measurement of success did not align with the standardized tests that outside stakeholders used to evaluate students, and students felt distressed and unprepared for these tests.

Another common challenge that teachers and students face relates to the implementation of choice. Netcoh (2017) conducted 11 classroom observations, as well as individual interviews and focus groups with 80 middle-school students and teachers at a low-socioeconomic status (SES) and culturally mixed school in Vermont. He found that students and teachers struggled over the structure of choice and control within the class. The students often felt that they should have more unconstrained choices in their academic programs, yet the teachers wanted to be more involved to ensure academic rigor. In contrast, in Bingham and Dimandja's (2017) study, students often felt overwhelmed by the amount

of choice they had, and at the same time, teachers struggled to structure learning environments and projects because the students had so much choice.

Teacher preparation and expertise are imperative for any classroom to run smoothly. Moreover, an improperly prepared teacher who is unsure of effective strategies to use in a Personalized Learning classroom can face numerous challenges (Bingham et al. 2018, 481-482). In a three-year case study, Bingham and Dimandja (2017) examined teachers' experiences implementing PL at a low-SES charter high school. The researchers interviewed 17 teachers, six administrators, and the CEO of the charter school's management organization. They also observed teachers in their classrooms and evaluated artifacts such as the parent/student handbook, grant documents, and class websites. Overall, teachers reported that consistency in the use and evaluation of student data was key to effective instruction and student success. The most significant finding, however, was related to the length of time teachers had been in the field. Teachers who had fewer years of experience had different struggles with technology and the pressures of accountability than teachers with more experience. In particular, this study uncovered a disconnect between what preservice teachers were taught regarding the delivery of an exemplary lesson and the PL model of a lesson. Teachers in their first years of teaching were likely not only to set standards and goals, but also to dictate what each lesson would entail, what the students would be doing, what they learned, and how they would be assessed. In PL, however, students are supposed to have choices even to the extent of picking the standards they are working on, their learning goals and objectives, and the methods of assessing them.

Previous research has focused on student achievement, the use of technology, and challenges within Personalized Learning school environments. The main challenges that have been identified in the research relate to technology use, teacher preparation, student choice, measurement of student success, student accountability, and standardized testing. Notwithstanding these findings,

research on PL is limited as it is still a relatively new approach. The research that I report in this article helps extend this body of research through a case study of a new school in its first year of implementing Personalized Learning.

## Methods

Before beginning this study, I obtained approval from Presbyterian College's Institutional Review Board (IRB). I then obtained consent from the principal of the school, the two teachers of the classrooms in which I conducted my study, and, later, the students I interviewed as well as their parents/guardians.

I conducted this study on a school campus in a rural southern U.S. city. The school had been shut down in 2007 and reopened in 2019 as a charter school. Thomas Charter School currently serves 154 students from Kindergarten to sixth grade, with intentions of adding additional grade levels in the upcoming years. Of the 154 students who attend the school, 32% are minorities (African American, Hispanic, and Mixed ethnicities) and 53% receive either free or reduced-price lunch. There are 31 students who receive special education services and there are no students who are English Language Learners.

Before collecting data for my study, I attended a Personalized Learning professional development workshop facilitated by a trainer from The Ohio State University where I was able to interact with teachers and administrators from different school districts who were new to Personalized Learning. I also had the opportunity to informally interview the Personalized Learning Coach from the South Carolina Department of Education (SDCE) about different aspects of the Personalized Learning method and the districts the SCDE was currently working with.

My next step involved conducting classroom observations in two teachers' classrooms. I observed four hours in a first-grade classroom and seven hours in a fifth/sixth-grade Math and Science classroom. While observing, I took notes on the different aspects of Personalized Learning I saw being incorporated in the classroom, based on my review of literature and components described in the Professional Development workshop.

I then conducted interviews with six participants: the school principal, two classroom teachers, and three students (to whom I refer by pseudonyms in this article). The principal, Dr. Watson, had been a principal for 10 years, but this was his first year at Thomas Charter School. Mrs. Caldwell was a first-grade teacher who had been teaching for nine years, mostly as a Montessori teacher. Mrs. Mason was the fifth/sixth-grade Math/Science teacher and she had been teaching for 16 years. She recommended the three students (two in sixth grade and one in fifth grade) that I interviewed. Two of the students were White and the third was African American. Two students were male and one was female. The students varied in academic ability and had attended different schools previously. The teacher recommended these three students not only because of the diversity they represented in terms of their gender, race, and academic abilities, but also because they were vocal students who had demonstrated an ability to articulate their opinions in the classroom.

The interviews and the observations took place during the 80 hours I spent at Thomas Charter School as part of one of the field experience requirements for my preservice education program. I created three different interview guides for the principal, teachers, and students, basing my questions on previous research findings, the professional development workshop, and my classroom observations. Each audio-recorded interview lasted around 30 minutes. I transcribed the interviews verbatim within two days of conducting the interviews. In order to identify common themes among the participants, I read through all transcripts as a whole using a system of open coding described by Creswell and Poth (2018). For example, the students, teachers, and principal all referenced students' "motivation" and "choice." I combined these codes, and others, such as "ownership" and "student interests," to create the theme of "student engagement."

One way that researchers can increase the validity of their findings in qualitative research is through data triangulation (Denzin and Lincoln, 2011). In this study, I used multiple

sources of data including observations, interviews, and a literature review to corroborate my findings. In this way, I was able to triangulate my findings. For example, I corroborated the information that teachers, students, and the principal shared with me through their interviews by conducting classroom observations. Moreover, through the interviews I was also able to find support for the information provided at the professional development workshop I attended on Personalized Learning. For instance, one of the benefits presented at this workshop was the use of student choice. In the interviews, teachers provided specific examples of how the choices they gave students were beneficial and conducive to learning. Through my classroom observations, I was able to confirm this information by seeing the scope of choices students were given and students' engagement while learning.

Acknowledging the researcher's perspective, experience, and biases can help to increase the credibility of qualitative analysis (Patton, 1990). Therefore, it is important for me to acknowledge the shift in my thinking about Personalized Learning throughout the research process. As a preservice teacher candidate, I had minimal teaching experience. My firsthand experience with Personalized Learning occurred during 80 hours of practicum fieldwork at Thomas Charter School, during which time I conducted this study. Subsequently, I completed a 15-week student teaching experience in the same classroom at Thomas Charter School, providing me greater insight into the practice of Personalized Learning and allowing my position to shift. When Personalized Learning was first explained to me prior to my field experience, I believed it to be an exceptional idea but was highly skeptical of how it would realistically work within a classroom. I saw the benefits of meeting students where they were academically; however, due to the difficulties I envisioned of individualizing instruction and fostering student ownership of learning, I was hesitant to trust that the approach would be beneficial for all students and teachers. Initially, I thought it involved teaching each student at the academic level they were on, rather than the grade level

they were in, which I did not think would be feasible.

However, as I spent time in the field and got to witness students' academic growth, I recognized that my initial conceptualization of Personalized Learning was inaccurate. Students were, in fact, taught material based on the grade level they were in. However, the teacher used specific methods to make the work manageable for students who were academically below grade level, such as presenting the content in smaller chunks and decreasing the quantity of work they had to do. These modifications allowed students to progress at their own pace on grade-level standards. I witnessed students whose academic growth increased by more than two grade levels in one academic year. Therefore, my initial skepticism about Personalized Learning gradually faded throughout my time in the field. I saw not only how it was implemented in a way that was manageable for the teacher, but also how students benefited from the individualized approach.

## Participants' Previous School Experiences

Participants' previous experiences of school clearly influenced how they experienced and felt about Personalized Learning. Each of the students interviewed went to a different school before coming to Thomas Charter School, yet they all reported similar experiences with bullying, academic achievement, and ineffective teachers. Bryan, in particular, noted that there was one "mean kid" in his class who constantly caused problems for him, yet the teachers' discipline was not effective in stopping the behavior. He shared that he was often bullied and made fun of at his old school for not being able to read as well as other students. Similarly, Dedrick claimed that his peers would "smack talk" him and were rarely kind to him. Lauren also experienced bullying and witnessed many fights at her old school. Each of these students said that the teachers and principals were strict, yet not consistent or effective with their disciplining of students, so the bullying would always continue. The students also told me that learning at their old school was not enjoyable. They said that they rarely used technology, test-

taking was never fun, the academic objectives were too hard, and all students got the same work. Moreover, teachers would not provide as much help as they needed when they were struggling. These students all stated that they did not like and did not want to attend their old schools, in contrast to how they felt now with regards to Thomas Charter School. It should be noted that due to students' previous negative school experiences, their fondness for Thomas Charter School may not have been as much a result of the Personalized Learning approach itself, as of the sense of community promoted by teachers who appeared to be genuinely invested in their learning.

The two teachers I interviewed had different experiences of, yet similar beliefs about Personalized Learning. For instance, the 1st-grade teacher claimed that her background as a Montessori teacher for three different grade levels was well-suited to the Personalized Learning approach. In contrast, the fifth/sixth-grade teacher claimed that at her previous school she was not allowed to "follow the child" as required in Montessori and Personalized Learning; in fact, she felt that she could not devote time to students who were struggling in her classroom. Although both teachers had different prior background experience as teachers, they both fully supported the idea of Personalized Learning to help students reach or exceed the expectations associated with the grade level they were in.

The principal, Dr. Watson, had worked in education for 21 years, serving as a principal for nine years and an assistant principal for three years prior to that. This was his tenth year as a principal and his first year at Thomas Charter School and his first year implementing a Personalized Learning approach. Dr. Watson's prior schools were low-income with a high population of the students below-grade level. It is likely that his experience with needing to meet so many students at their own academic level at his previous schools led him to take a central role in implementing Personalized Learning as a school-wide approach.

In my analysis of interview transcripts, three key themes emerged in relation to the research participants' practices and experiences of PL:

student engagement, teacher behaviors and dispositions, and student outcomes.

## Student Engagement

When I asked the principal how he made hiring decisions about teachers, he responded:

One of the things I believe in is, one of the most powerful things is, you can't have personalized learning without student engagement and student engagement is a very, very important part of our school. If you don't have student engagement you don't have learning and you don't have skill development. Students have got to learn how to have fun, so one of the things we did, I asked teachers, asked all candidates to submit a three-minute video and they had to discuss why they became a teacher, what student engagement meant to them, and how they could implement personalized learning in the classroom.

Both the students and teachers indicated that one of the biggest ways that teachers engaged students in learning was through choice. The first-grade teacher, Mrs. Caldwell, discussed how she had transitioned from whole-group learning at the beginning of the year to "station rotation" where the students were split into groups and rotated around the room to complete different activities selected from choice boards (graphic organizers that presented options for how students could learn a concept). For example, students could choose the order of the lessons they completed or the activities they completed. In addition, she personalized the choice boards by giving fewer choices to students who had difficulty choosing from too many options. She noted that students were a lot more focused and got more accomplished since she had begun implementing the choice boards.

The fifth/sixth-grade teacher, Mrs. Mason, used choice in a similar way. Her students were given choice boards and were allowed to choose their "learning pathways," which was the way they chose to learn a particular unit or standard. Unlike Mrs. Caldwell, Mrs. Mason faced challenges because all of her students were in their first year at Thomas Charter School, and as they had transferred from traditional schools, they were not used to taking

control of their learning. Mrs. Mason found herself having to coach students to help them understand why they needed to challenge themselves and how they would grow because of their choices. She stated that the most effective method was to use “baby-steps” in modeling how to make choices.

Along with the Personalized Learning concept of choice comes a great deal of accountability. Students discussed how they set academic goals with the guidance of their teachers, then monitored the completion of their goals, and shared their progress with their teachers. This process allowed students to gain a sense of ownership over their learning. Bryan explained that students were supposed to “teach themselves” and help each other while working in groups, which enabled them to take responsibility for their learning.

Reflecting on the sense of ownership that students displayed in the classroom, Mrs. Caldwell stated, “I think it is that ownership that they have and what they’re choosing to do and it just makes it a better experience for them – that’s what I’ve seen with the transition in just these 14 weeks, they are happier and better-working kids.” The three students also noted that they liked learning this way. Dedrick enjoyed the challenge because he could be pushed to learn at a higher grade-level than he was currently in. Lauren said that she appreciated the amount of coaching and guidance the teachers provided and the way they incorporated fun activities into learning:

The way Miss Mason teaches math is like, whenever we take tests it’s kind of online and how she has, like, you’ll do something kind of non-fun and then you kind of do something fun after it. I kinda like that and I kinda like how she’ll tie something fun in with it to keep us occupied, like a lot of times we’ll take tests on Prodigy [an online game-based math program] and I like it because you’re having fun battling the monsters but you’re doing the questions anyway.

In sum, the students noticed that teachers were making an effort to engage them in learning, and from the teachers’ perspectives, student engagement was central to both the functioning of the classroom and student achievement.

## Teacher Behaviors and Dispositions

All teachers at Thomas Charter School had to learn about, and adapt to, the Personalized Learning approach. The teachers were trained in PL for 40 hours over the summer prior to school starting. A central component of PL involves teachers making the effort to tailor instruction to students’ different levels in the class. Dedrick said that teachers individualized quizzes and gave students different work to see what students had mastered and what they were capable of. He also explained that teachers paid attention to each student’s needs and tried to get them on grade level if they were below the required standards. Lauren described how teachers went around the room assisting students and described PL in the following way:

It is like when people have different abilities, like some people run fast and some people run slow, some people run in completely different ways, if you run in completely different ways, Miss Mason and Miss Harrison will give out different work or help people in different ways.

As a teacher, Mrs. Caldwell’s view of PL supported Lauren’s definition by incorporating her commitment to teaching a student no matter how long it took. Mrs. Mason expressed the importance of meeting students at their level to build a foundation of knowledge before they could meet the standards that the state required of them. She stated that her focus was coaching students to keep meeting higher goals so that they would be ready to earn the credits they need to graduate from high school.

Both teachers used short whole-group instruction and choice boards and worked with students in groups to implement Personalized Learning. They used the data they gained from their assessments to tailor the work for students’ individual needs. They took the time to plan their groupings based on students’ different ability levels. For station rotations, the teachers normally grouped students by similar achievement levels, but if they were learning a new topic, they made sure that there was at least one higher-level student in each group. The teachers also worked individually with

students to get them on their age-related grade level. The extra time and effort it took to individualize work to this extent demonstrated that the teachers were committed to helping students make progress towards increasingly higher goals.

Both Mrs. Caldwell and Mrs. Mason commented that in a Personalized Learning school, students were not viewed as a number as they were in other schools. Mrs. Caldwell described the appeal for parents of Thomas Charter School in the following way:

I know our schools aren't huge around here but they're still very large and the way our education accountability system is set up, it's a big numbers game, and so I feel like the stress put on students and teachers is significant, and I think an opportunity to come where the atmosphere is smaller, so it's more of a community, and your child is seen, like seen as a child and not a number or score or another one to get through... I don't think that all of them [parents] truly understand it [Personalized Learning] but I think that they know it's a good thing for their child because it tailors the learning experience for their child. And some students who come here have had a hard time keeping up with the pace that's been given to them in previous years, and some students are ready to go above and beyond that, and so I think just the opportunity to meet with a child's needs is a big draw-in for parents.

Mrs. Caldwell suggested that the reason parents chose to send their child to Thomas Charter School was because it was a smaller school where students would not only be given more individual attention but would be viewed in an entirely different way. She explained that instead of each child just being another student that passes through the teacher's class, they are given the ability to move at a pace that works for them, whether that be going slower and getting extra help, or moving ahead to challenge themselves more.

## Student Outcomes

The happiness and pride students felt in themselves and their academic achievements appeared to be the most significant student

outcome of Personalized Learning. All three students claimed that the way they learned at Thomas Charter School was more enjoyable than at their previous schools, especially due to the greater amount of group work that they were given. The students also appreciated having peers who were willing to help each other and not bully one another. Lauren specifically liked that each student was able to get what they wanted out of a lesson because the teachers at Thomas Charter School attempted to include fun in their learning.

Mrs. Mason discussed several instances where she saw how much students enjoyed school because of the sense of community that had been developed. She described how students had developed new attitudes towards school:

The difference I've seen is the kids want to come to school now when they used to not care about coming to school. We had a student whose dad picked them up early and he cried because he didn't want to leave, so I was like, 'oh my gosh, his dad is here and he's crying - what's wrong? This is going to be terrible,' and he was like, 'I don't want to leave,' and I was like, 'wait, dad is picking you up to go get food,' and he was like, 'I don't want to leave because we had a house [classroom] party.' I mean it is very motivating and encouraging and engaging. It's a cool place to be if you're a kid, I mean it's fun.

Mrs. Mason relayed this incident as an example of how students felt about the PL environment at Thomas Charter School. There was a sense of community that helped students feel part of their school in a way they had not felt in their previous schools. To a large extent, this community was established through the PL practices that helped students feel confident about themselves and their abilities. For example, Mrs. Mason used a computer program to have the students work on different tasks. If they were struggling, the program would give them the names of three different students who had already mastered that concept. The program randomly picks the three names and does not necessarily pick the highest-level students. Mrs. Mason described a particular situation in which a student who was

typically on the higher end of the academic spectrum, asked another student, Bryan, who was on the lower end, for help. The other students, including the student who asked Bryan for help, gave Bryan compliments on his work. Bryan was very excited to be in this position as he was not used to being considered “smart.” Mrs. Mason described how Bryan became highly motivated in his work after this exchange. In other words, the positive environment that Thomas Charter School had established fostered confidence in students and enthusiasm for learning. When discussing changes in the students since being at Thomas, the principal exclaimed, “I mean it’s amazing – we have kids that love school, want to be at school that have never in their life ever wanted to go to school.”

Student outcomes also came in the measurable form of academic progress and grades. For instance, Lauren explained that at her old school, her lowest grade was in Social Studies, and now, it was one of her highest grades. Moreover, Mrs. Mason described a student who started the year on a first-grade level and was now on a third-grade level. She felt that if she had students gaining two years in her class, she would be able to eventually fill their academic gaps and get them up to their grade level. Mrs. Mason also stated that although long-term achievements were difficult to see now, she predicted significant achievements for students in the future:

I think the school has to implement it for a long time before you see the major achievements. ... I want to see these first-graders all the way through sixth grade and I think the achievement is going to be amazing... I have seen within my class, I've seen more students proud of themselves than they've ever been and making their own goals.

Mrs. Mason had noted immediate improvement in student achievement, especially in regards to how the students felt about their academic performance and gaining a sense of ownership. She also predicted that while it may take time to develop, PL would get these students up to grade level, and that significant achievements would be apparent in the future. When I asked the principal how PL may be beneficial for

students after they graduate, he stated that companies believe in the concept of PL and have put money into this new trend because it fosters ownership and allows students to reach their full potential. Furthermore, he claimed that companies will be more inclined to support this method of education in the future, stating:

I think Personalized Learning is a new trend and the new way because it shows more productivity in learning and making the grade and also developing a product in a lot of companies. The Bill and Melinda Gates Foundation supports Personalized Learning, a lot of Fortune 500 companies are big on Personalized Learning because they've seen the impact that it has on them [students].

Based on research that he had conducted, the principal claimed that students who attend Personalized Learning schools will be more prepared for the work world in the future. He predicted that because major companies are supporting this approach and want to employ people who have a sense of ownership in their work, Personalized Learning will become a growing trend within schools.

## **Teacher and Student Perspectives of PL Strengths and Weaknesses**

One of the most significant implications of this study into Personalized Learning in a new school is that the whole culture of the school needs to adapt to this approach. Teachers must adopt a new mindset about teaching and learning and must be willing to help each student by creating a supportive and caring classroom environment. Mrs. Mason, whose son attended Thomas Charter School, described the culture of the school from the perspective of a teacher and a parent:

It's such a loving culture, like welcoming, you know what I'm saying? It just feels I don't know, it's comfort, it's comfort, I feel safe bringing my child here every day, like I know he's loved every single day in this building. He's not just a number, he's not gonna be forgotten about, even though he's not the greatest student he's not gonna be overlooked – he's going to be taken care of. So I think we have, especially sixth grade, we have a huge opposite spectrum – we have

some that are super, super high and we have some that are really, really low, so I think both sets of parents want their child challenged or want their child cared for. Like, do something for my child – just don't leave them behind, do something for my child but don't let them sit there bored.

Mrs. Mason passionately described her love of the culture that had developed, which fostered love and support for her child. Moreover, she stated that Personalized Learning met parents' desire to have their children, no matter their level of academic achievement, be supported and challenged at school. Mrs. Mason gave an example of the impact of the school's culture she had seen on a child. One of her students, who had never enjoyed or been very good at math, was now excited and making gains in his work. He even commented to her about how nice it felt to have teachers that cared about him and cared about helping him succeed in math.

Both Mrs. Caldwell and Mrs. Mason modified the amount of work for specific students according to their ability levels. Mrs. Mason explained that she liked having flexible groups so that she could move students to different groups based on the unit, lesson, or task they were completing that day. The everchanging groups showed students that while one student may have already mastered a certain skill when they had not, the following week, they may be the one who had mastered a difficult skill while the other students needed more assistance. Thus, the school culture of accepting and normalizing differences in ability among the students was reinforced.

In discussing the positive feelings teachers and students had towards Personalized Learning at Thomas Charter School, it is also important to acknowledge other factors that may have contributed to their satisfaction. For example, because the school was a new school, there was a lot of excitement in the community, particularly among parents who wanted to get their children into the school. Due to the high demand, the school had to implement a lottery system to select students. Getting into Thomas Charter School therefore became a privilege for the select few. It is worth pointing out the contradiction between the Personalized

Learning approach of "customizing" education for individual students and the marketization of education that creates competition in access (Campbell et al. 2007).

In terms of students' positive experiences, all students came to Thomas from different schools and were therefore in the same position of being eager to make new friends; it was also a chance for everyone to have a fresh start. In addition, because of the small scale of the school, with only one class per grade, it was very easy to build a sense of community. These situations were particularly meaningful for students who had been bullied at their previous schools. Similarly, teachers who applied to teach at Thomas were actively seeking teaching opportunities in a different school environment, which could in itself have increased their level of contentment in a new school.

The school was not without its challenges of course, some of which were associated with a newly implemented commitment to PL. One of the main challenges teachers faced was associated with giving students so much choice in the classroom. Not only did this require different forms of accountability for work that students completed, it also required having to motivate students to push and challenge themselves beyond the minimum amount of work. The principal noted that some students did not want the freedom that Personalized Learning afforded them. Rather, they wanted to be fully guided and told what to do and how to do things. Teachers also described struggling with the work that Personalized Learning required, notably the challenges in implementing whole-group learning due to the many different levels that students were on. They also described not having enough materials to draw from, particularly for higher level students. These students were often not able to advance because they were waiting for materials. Teachers also discussed the need for improving the communication of student achievement and the standards the students were working on with families. For example, if a student had an A in the class, this did not mean they had an A in sixth-grade standards; they had an A in the standards they personally were working on, which were based on their ability level.

## Conclusion

Personalized Learning is not an approach to learning that can be easily implemented with the inclusion of student choice, goal setting, and individualizing instruction. Personalized Learning must also involve the development of a school culture that fosters a new mindset about learning for both students and teachers. Students need to acquire a mindset where they take ownership of their learning, challenge themselves, and monitor their progress toward self-made goals. Teachers need to adapt their mindset to be invested in meeting each student at their level, modifying the amount of work for students while also paying attention to standards, addressing students' different ability levels, and guiding students' transition from relying on instruction from the teacher to taking ownership of their learning.

These changes are at the heart of Personalized Learning and have been reported in other research. Campbell et al. (2007) noted in their study of PL in the U.K. that school values were developed around:

learning behaviour, respecting differences in views, taking account of student voice, and the importance of self-motivation for learning. This set of values was the underpinning infrastructure of the personalised pedagogy, and without their influence on the attitudes and behaviour of teachers and students in classrooms it is probable that the pedagogy would collapse. (153)

Although Personalized Learning aligns with the positive outcomes discussed, it is possible that the beneficial outcomes identified in the school are due to underlying factors such as the school culture and organizational structure that both the administration and teachers have committed to, rather than to the implementation of PL itself. Having both the administration and teachers commit to the idea and implementation of PL can most certainly influence the outcomes of the approach. The culture that developed at Thomas Charter School was described as a loving and safe, a place where students were not overlooked. A big emphasis was placed on having fun while learning in order to engage students and

promote positive academic and social-emotional development. The students I interviewed credited the school culture at Thomas Charter School as the reason they no longer got bullied and why they looked forward to attending school. They enjoyed school because they had peers who were willing to help them, and they did not struggle academically anymore because they were doing work at their own level and receiving help from their teachers. Overall, it was clear that Personalized Learning involved much more than personalizing instruction for students. It involved creating an entirely new school culture focused on supporting students and cultivating students' academic and social-emotional growth.

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# “We Become Capable of Handling Everything”: Gender and Gulf Migration in Kerala, South India

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## ABSTRACT

Women have a uniquely gendered experience with worker migration from Kerala, South India to the Gulf, a phenomenon which touches virtually every household in this state. Drawing on ethnographic fieldwork in Kerala, this article examines the intersections of gender and migration; I argue that migration fuels significant social change in terms of gender expectations and the role of women as economic agents. My fieldwork reveals that women work abroad due to personal circumstances and to conform to local ideas about modernity. Migrants' wives also experience increased autonomy in their daily lives. These two categories of women, migrant women and the wives of male migrants, are attuned to others' perceptions of their roles vis-à-vis migration. Despite occasional negative feedback, women report that they are empowered by worker migration. This project builds on scholarship examining the status of women in Kerala (Eapen and Kodoth 2003), the experiences of migrant spouses (Osella 2016), and female Christian nurses' Gulf migration (Percot 2006). I extend this work by analyzing the personal narratives of individual women who work in the Gulf, head their own households in Kerala, and experience stigmatization because of emigration. Finally, I explored the broader implications of migration for the lifestyles and aspirations of women in Kerala.

**Keywords:** migration; South India; gender roles; women's empowerment

Under the cloak of pre-dawn hours, I dressed in a newly purchased *kurta* and walked across the street to join the Hindu priest preparing a housewarming ritual in Kerala, South India. I sat on the lone chaise in the room, still covered in its plastic wrapping, as the priest built a *havan* (fire altar). As the sun began to rise outside, family members trickled into the ceremony. Today's ritual would cleanse the new house of any negative energy and spirits and prepare it to be inhabited. The intricate rites extended until noon, at which point Seema and Shiv, the new homeowners, welcomed and fed their many guests. In addition to its religious significance, the day was also a celebration and display of the couple's material success. As Seema remarked, "Today we are sharing our happiness, so [our guests] are happy."

Seema returned a few days prior from a year of living and working in Saudi Arabia as a nurse. She wanted to be present for the housewarming of her and her husband's newly constructed home, which was funded in part by her toils in the Gulf. She confided in me that building their own home had been a dream for her and her husband for the past five years. When I asked if the house was what she had pictured, Seema declared, "I finished what I dreamed."

Seema is one of many Malayali (i.e., Malayalam-speaking persons from Kerala) women who migrate for employment and with whom I spent time while conducting fieldwork on the pervasive phenomenon of worker migration from this South Indian state to the Gulf. Relationships with migration are decisively gendered in Kerala, as evidenced by Malayali women's experiences, whether as family members of migrants or those who migrate themselves, in contrast to those of Malayali

men. Seema's narrative demonstrates the possibilities for various forms of material, personal, and professional success that migration opens up for women. Furthermore, her narrative prompts questions about how other women in less advantageous situations have navigated this terrain. Malayali women have a unique set of gendered relationships with migration, including a resulting increased autonomy, agency, and independence for them, while men typically migrate to fulfill their gendered duty as a household provider. Drawing on one month of intensive participant observation and fifty-five semi-structured interviews ranging from thirty minutes to three hours which were recorded in Kerala in the summer of 2019, I argue that Seema and other women like her fit into a broader pattern whereby outmigration is catalyzing significant social change in terms of gender roles and expectations. More specifically, I contend that women are empowered through migration both in terms of economic agency, as they earn salaries abroad, and in terms of personal agency as they increasingly head households and assume new responsibilities at home in the absence of their husbands.

## **Kerala, Migration, and Gender**

This article builds on existing scholarship that examines the status of women in Kerala, the experiences of migrant spouses, and female Christian nurses' Gulf migration. Women's relationships to migration have overwhelming been framed negatively and in terms of their menfolk's absence. Mridul Eapen and Praveena Kodoth (2003), for example, highlight the discrepancy between Malayali women's supposed high social status and their relative lack of economic autonomy and decision-making and note that migration-related marital tensions may produce mental health challenges for women. In a study of female Christian nurses, Marie Percot (2006) argues that individualistic aspirations fuel both the desire for a nuclear family model, in contrast to the traditional extended family, and a novel approach to migration where the Gulf is viewed as a stepping-stone for migration to the West. Most recently, Caroline Osella (2016) has critiqued and complicated the somewhat unidimensional picture of Malayali women that

emerges in the academic literature, where they are characterized as the “Gulf wife.” This trope is a gloss for a lonely woman who is rendered helpless by her husband’s absence. My own scholarship extends the literature in new directions by analyzing the nuanced narratives of individual women who take on various roles by virtue of migration, whether that means going to work in the Gulf themselves or assuming responsibility for managing their households in Kerala. While many of these women experience success, some experience various forms of gendered stigmatization. Unsurprisingly, these divergent experiences can be linked to key variables, such as class and education differentials, as well as access to resources. My work places these women’s narratives in conversation with those of their male counterparts, who frame migration experiences and community reactions to women’s roles through their own lenses. In contrast to the existing scholarship, the narratives from Hindu, Muslim, and Christian men and women that I recorded highlight women’s self-articulations about the value of their economic and social contributions as well as men’s assessments of these activities, and prompt me to analyze recent shifts in the roles and agency of women.

Since the 1990s, the gendered dimensions of Kerala outmigration have not been stable, but rather have shifted as the number of female emigrants has increased and perceptions of women’s roles have changed. In 1998, about 10% of all migrant workers from Kerala to any destination within India or internationally were women (Zachariah, Mathew, and Rajan 2003, 315). By 2004, 17% of Kerala’s migrant workers were women (Percot and Rajan 2007, 319). The increase in migration was especially rapid for those migrating to the Gulf. The migration rate for women increased by 143% between 1999 and 2004, growing from 127,000 to 309,000, whereas the migration growth rate was only 24% for men in the same time period (Percot and Rajan 2007, 319). The two most common professions for migrant women included working as housemaids and nurses (Percot and Rajan 2007, 320). Prior to this escalation in women’s migration, most scholarship depicted the relationship between migration and women as being characterized by their experience as

abandoned wives who were seemingly lonely or incapable. In her research on the impact of male migration on women, Leela Gulati (1993) describes wives facing handicaps as being dependent on their community for support and requiring more education to assume new responsibilities associated with children’s education, health care, and finances. Some scholars described the most prominent effect stemming from migration as the separation of wives from their husbands (Zachariah, Mathew, and Rajan 2003, 321). Despite the reality that some women were migrating, the rhetoric remained focused on their status as wives now living apart from their husbands. In a survey conducted in 2003 and focused solely on Gulf wives, scholars characterized women remaining in Kerala and separated from their husbands as highly educated but mostly engaged in household activities (Zachariah, Mathew, and Rajan 2003, 326–27). Furthermore, these women were described as having to overcome the “adverse consequences” of loneliness and added responsibilities (Zachariah, Mathew, and Rajan 2003, 329), effectively casting their experiences in a negative light. While women’s experiences might have initially aligned more closely with the “lonely Gulf wife” model, as women’s migration became more widespread and socially acceptable, the number and kinds of opportunities shifted and grew; these conditions allowed their experiences to become more complex and edge towards empowerment.

Indeed, my fieldwork participants reported that “in the old days” and “before” women did not migrate often and were mostly housewives. Additionally, many people in Kerala explained that migration used to be advantageous for men to participate in because it elevated their marriage prospects. They argued, however, that migration no longer positively affected marriage prospects, perhaps because of changing dynamics due to the increase in female migration. The characterization of women and migration experiences in the media, such as in movies and songs, has also been focused on sorrowful, lonely wives. For example, Gulf-themed “letter songs,” which are revivals of an older generation of songs relating letters between “lonely, love-lorn” wives and their migrant husbands, became popular at the

turn of the century (Kurien 2002, 72). Participants explained that these media representations of migration highlighted and dramatized husbands abandoning their wives for the Gulf, while the women who remained in Kerala felt hopeless and longed for their men to return. The lived realities of the women I encountered during my fieldwork contrasts with media depictions of the spouses of emigrants, participants' descriptions of their past experiences of migration, and existing scholarship, suggesting that the phenomenon I witnessed is a part of a recent shift in the gendered expectations and experiences of Gulf migration.

The negative framing of female migration is not specific to Kerala, but surfaces in other academic research on Indian female migrants. Radhika Kanchana (2016), for example, focuses on an exploration of India's paternalistic emigration policy for women, which restricts female migration for the supposed safety of migrants. It is based on the argument that migration leaves women vulnerable to exploitation. This policy privileges protecting women "by citing the practical 'realities'" of exploitation rather than focusing on empowering them, ultimately restricting female's access to the benefits of migration (Kanchana 2016, 100). In other parts of South Asia, pervasive associations between female emigration and exploitation incite similarly restrictive politics. Tom O'Neill (2001, 153) details this phenomenon in Nepal whereby policies that are intended to "rescue" female emigrants ultimately increase instances of trafficking by limiting legitimate migration opportunities. Despite these examples, female migration is not exclusively presented as negative phenomenon throughout academic scholarship. For example, C.Y. Thangarajah (2003) examines Sri Lankan women's experiences of migration to the Middle East and highlights their feelings of empowerment that stem from their migration experiences. The women integrate Islamic religious practices learned during their tenures abroad to "successful(ly) [negotiate] and [recast] their roles" and empower themselves (141). Women's migration to the Gulf, regardless of its framing, is evidently not confined to Kerala. Migration in contexts across India and South Asia are salient

because the influence of Gulf migration is as widespread as the migration itself, affecting individuals across the region. Women are thus likely experiencing these shifts in gendered ways, empowering them personally and economically to varying degrees in Kerala, India, and South Asia.

## **Ethnographic Encounters and Exchanges**

As an American undergraduate researcher, I arrived in Kerala in the summer of 2019 as a relative outsider to the local community where I would base myself during my fieldwork. However, I had assiduously prepared myself by reading relevant scholarly literature, spending four months living and studying in Northern India, and utilizing my mentor's decades-old relationships and ties to Kerala. Building on the foundation of my mentor's networks significantly shaped my project, as it enabled me to identify a translator and meaningfully immerse myself in the communities where I conducted my research project. For the duration of my fieldwork, I lived in the homes of the friends and family of my translator, Sahil, a 24-year-old Hindu man whom my mentor has known since he was a child. I elected to work with Sahil because of his English fluency, familiarity with ethnographic research, and his intimate knowledge of fieldwork locations in his home state of Kerala. I traveled to three regions with Sahil to access a cross-section of religions representative of Kerala's remarkable diversity. The state is significantly more religiously diverse than the rest of India. According to India's 2011 census, Kerala's population is 55% Hindu, 27% Muslim, and 18% Christian, reflecting numbers for minority religions that are well above the national averages (Government of India Ministry of Home Affairs 2011a). The corresponding national averages are 80% Hindu, 14% Muslim, 2% Christian, and 4% other religions according to the 2011 census. Elsewhere I have explored themes grounded in this religious diversity, examined the multireligious landscapes of Kerala and the Gulf, and analyzed the relationship between the two in order to argue that shifts in the multireligious landscape in Kerala are ambivalent in nature (Gerry 2021).

In these communities, Sahil and I conducted open-ended interviews with the friends and family of Gulf migrants and engaged in field visits to religious and social spaces. The migrants themselves worked in a range of professions including as drivers, construction workers, housemaids, nurses, sales professionals, tailors, and business owners. All of my research participants were adults, with the youngest being an 18-year-old child of a migrant and the oldest a 64-year-old ex-migrant worker. Sahil and I recorded each interview and then spent our evenings transcribing and translating them. Pseudonyms were assigned to anonymize my interlocutors.

Working closely with Sahil provided a window into one set of Malayali perspectives, as he helped me bridge my outsider standpoint with his and others' insider points of view. Collaborating with him and translating interviews within the context of a homestay situation added several additional interpretative lenses to this project, as family members, visitors, and others would often interject their own understandings of the relationships between religious communities, India's political climate, and the experiences of religious minorities in Kerala as we worked. This parallel body of commentary contextualized my interviews by revealing unrehearsed reactions and inter-community understandings and perceptions. To augment the narratives we were recording, Sahil and I ventured into the surrounding communities to observe architecture and styles of dress in order to develop a fuller understanding of the Gulf influence. As detailed below, combining this community observation with participants' narratives revealed tangible markers of social change and the influence of migration in women's dress. We also analyzed social media during our free time and used this analysis to raise new questions in our interviews about innovative forms and usages of social media to understand the ways in which Gulf ideas penetrate local communities virtually. These processes allowed me to identify and appreciate the ubiquitous influence of the Gulf in the everyday lives of Malayalis. In addition to the everyday effects of Gulf migration—initially almost invisible but truly pervasive once I learned how to refocus my gaze and isolate

them—special events like Seema's housewarming offered a unique opportunity to observe a significant life cycle ritual made possible, in part, by Gulf money. Throughout my fieldwork I developed my ethnographic sensibilities to become attuned to the dynamics of everyday situations and to learn from the micro-moments that are crucial to ethnographic research.

As Heike Moser and Paul Younger (2013, 137) note, Kerala's distinct social makeup is a key factor making it suitable for ethnographic research surveying religious landscape. Moreover, since Gulf worker migration touches virtually every household in the state, Kerala was an exceedingly rich location for my fieldwork. The 2018 Kerala Migration Survey, for example, found that 67% of households had at least one member living in a Gulf state (Rajan 2018). Migration from Kerala took hold in the 1950s amid the growing demand for manual labor in Gulf construction, surged in the 1970s and 1980s with the growth of the oil industry, and later extended into professional fields, including medicine, sales, and technology (Gardner 2011; Miller 1992). In addition to being studied because of its unique migration patterns, Kerala has drawn attention because of its "model state" identity: it has the nation's highest literacy rate as well as the lowest rates for infant mortality, maternal mortality, and fertility (Government of India Ministry of Home Affairs 2011b; Government of India Ministry of Home Affairs 2013). However, Kerala's high social development indicators rest on a weak economic base, with the state's unemployment rate registering at double the national average (Eapen and Kodoth 2003; *The Lede* 2019). Moreover, this positive characterization of a "model state" notwithstanding, I continued to have questions about the quality of life for women in Kerala, particularly in terms of social roles and relations. Given this backdrop, my fieldwork sought to answer questions concerning the extent to which women experience and self-report empowerment and agency and to what degree they might experience certain types of gendered stigmatization because of their relationships with migration. Here I use the term "empowered" to signal women's own expressions of increased agency, confidence,

and capability as they take on new roles vis-à-vis migration. While I recognize that this term is context-sensitive and culturally located, I employ it to highlight that I take seriously women's self-perceptions and thus utilize this term located within their self-articulations.

## **Narratives of Social Change**

The narratives of individual women who work in the Gulf illustrate social changes occurring around gender roles and expectations, partially because many Malayali women take jobs in the Gulf in alignment with locally constructed ideas about modernity. Seema, for example, explained to me that “before [her lifetime] girls were not supposed to be sent to far places for studying.” However, because of “modern” ways of thinking—such as allowing girls to obtain high levels of education and travel or live alone for their education or work—prevalent in Kerala today, Seema noted that girls “can make choices [and] have the right to decide what [they] want.” Seema is not a third-party observer of the local situation vis-à-vis gender expectations; rather, in sharing these observations, Seema was effectively telling her own story. She was educated in Kerala and attended school and worked away from home in India before moving to Saudi Arabia to work as a nurse. As such, she is an exemplar of modern values of women's education and independence.

Seema's story illustrates the increased autonomy drawn from worker migration because of her position as an economic agent. Her narrative contrasts sharply with the prevailing portrait of Malayali women in earlier scholarship, which depicts them as subordinate to men due to their relative lack of financial decision-making abilities (Eapen and Kodoth 2003). Seema's profession as a nurse, which requires specialized education, as well as her control of financial resources, signal her social status in Kerala. She breaks the mold of the so-called “Gulf wife,” who is cast as suffering from loneliness and mental distress in the absence of her migrant husband. Instead, as a female migrant who embraces her experience, Seema offers a counterpoint to the Gulf wife stereotype and therefore confirms Caroline and Filippo Osella's (2008) challenges to that trope.

Her narrative thus points to a new reality in which direct migration is one clear pathway for women to attain economic mobility and raise their social status.

Seema's migration decisions were not inspired by the individualistic desires that are often linked to “modern” worldviews. Rather, she dedicated herself to her education, possible only through the financial contributions and support from her extended family, so that she could improve her family's economic status. This pooling of support is part of a broader pattern in contemporary India whereby families merge their resources to amass enough capital to advance the education and career prospects of a specific individual with the understanding that this family member will reciprocate by assisting other family members with future support and benefits (see, for example, Dickey 2002). The collectivist effort of her network ultimately allowed Seema to attain social mobility and success that she hopes to share with her family. According to Seema:

I wasn't born into a high, rich family...So we are low class; they consider [us] like that...I want to make my mommy happy and I want to make her relax...Only for that I wanted to make some money. I want to make my mommy comfortable. She struggled, a lot—I can't say, I don't have words....So for my family and to safeguard my future generation, I don't want my child to struggle like me. And I mainly want to give rest to my mother.

Seema related her story to me while we sat in her new home with her family. They appeared to be financially secure now; her sister is married to a chef who is working in the Gulf and has two happy, healthy children. Seema achieved her initial aim of “settling” her family into a comfortable lifestyle. Their newly constructed house, housewarming ritual, and food choices were all clear indicators of the middle-class status Seema had attained. Now she was looking beyond India and nurturing global ambitions to migrate to Ireland, following the pattern of many Gulf migrants who turn to Europe as a further goal. Seema never planned to remain in the Gulf because she did not find the lifestyle of migration, being separated from her husband, and the culture of Saudi Arabia to

suit her long-term. Instead, she dreamed of migrating to Europe with her husband, as a couple rather than solo, and enjoying the higher salary and Western cultural opportunities available there. Migration to the Gulf for Seema was a crucial step in her journey towards achieving her goals by providing her the opportunity to have substantial economic agency and career development which she could build on with future migration.

Seema's desire for global migration aligns with Percot's (2006) observation that nurses utilize the Gulf as a stepping stone to acquire financial means and experiences that position them well for Western migration. Percot, however, argues that the catalyst for these global ambitions is a shift towards individualistic aspirations in Kerala (48). By contrast, Seema's dreams do not appear to stem from a desire for individual success but are instead more collectivist in nature. Her narrative demonstrates that Seema's priorities are more family-focused than self-focused. Specifically, Seema has concentrated her energy on her mother, evident in her desire to make her mother feel comfortable and settled. Seema's deep love, admiration, and gratitude for her mother became evident in our interview, as well as her desire to repay her mother for struggling to raise and educate her. Seema even expressed a desire to bring her mother with her to Ireland if given the opportunity, so that they could share in her success together. These dreams resonate with the traditional understanding of selfhood propagated by scholars of South Asian society, who identify the widespread existence of collectivist societies. The concept of the "dividual," in contrast to the individual, signals the collective nature of thinking in terms of a community or family (Marriott 1989; Strathern 1988). Karl Smith (2012) extends the selfhood discussion by delineating the "porous" versus "buffered" self, pointing to those who are inherently socially embedded versus those who are guided by self-centered motivations. The notions of joint responsibilities and shared triumphs, as exemplified by Seema's family merging resources to support her academic and professional endeavors, signal the socially embedded and "porous" self that Marriott and Smith identify as prevalent in South Asia. The

trend that Percot (2006) identifies of Christian nurses who dream of migrating to the Gulf first and then on to the West in order to escape familial responsibilities and enjoy their own personal successes aligns with the self-centered motivations of the "buffered" self that is advanced in Smith's analysis. Seema, I argue, represents a hybrid and modern collectivism by possessing a globalized worldview with aspirations beyond India while prioritizing her family and maintaining a socially embedded "porosity" in her relationships. Collectivism, which produced the conditions for Seema's own success, molds her worldview by motivating her to prioritize the needs and goals of her family members. However, her collectivism is clearly influenced by her global ambitions which ultimately drive her to move away from some or all of her extended family members when migrating. Seema's experience thus combines these identities and bridges the gap between a cosmopolitan individual and collective society by being a globally ambitious woman embedded within a collectivist society who maintains commitments to her family.

While Seema's story is characterized by success and ambitions realized, there are less rosy aspects to many women's migration stories. These women's personal circumstances may drive them to work in the Gulf for entirely different reasons than Seema, especially due to economic necessity arising out of poverty. For example, I interviewed a woman in her mid-fifties named Sabirah who worked as a housemaid first in Saudi Arabia and then in the United Arab Emirates. Her migration began over a decade ago after she was forced into the breadwinner position when a decline in her husband's health rendered him unable to work. With her earnings, she was able to arrange the marriages of her daughters and sustain her family at a minimal economic level. Sabirah described how she experienced mental distress, including suicidal thoughts, due to her migration and the subsequent disintegration of family relationships. Despite her precarious situation, however, Sabirah persevered in supporting herself and her family, demonstrating the economic agency attained even in the darkest situations of Gulf migration. Although the two women share in having gained economic agency from their migration

experiences, Sabirah's narrative represents a migration experience distinct from Seema's both because her migration motivation arose from necessity rather than ambition and her financial success was tainted by her declining mental health and family relationships.

Despite Sabirah and Seema's narratives, nearly all of the women I interviewed were wives, shaping the focus of my analysis. It appeared uncommon for Malayali women to travel to the Gulf before marriage. Most families are unwilling to allow their unmarried daughter to travel far without supervision; the pressure to safeguard a young woman's "purity" and reputation in order to protect her marriage prospects persists in India. This pervasive concern over women's honor and propriety manifests in a resistance to single women's migration. Thus, although wives gain agency via their relationships with Gulf migration, their participation hinges upon their husband's choice to leave them behind in Kerala or his approval for them to migrate themselves.

### **Confidence, Economic Agency, and Independence for Migrant Wives**

My fieldwork demonstrates that when males migrate to the Gulf, a range of new opportunities for increased independence and autonomy are available to their wives as these women manage their households and engage in work beyond the domestic sphere. Viyasha, the 23-year-old daughter of a migrant worker, described to me the influences of migration on her family, emphasizing the experience of her mother. Her father began migrating to Dubai for manual labor nearly two decades ago, when Viyasha was just a few months old. Despite her father's extensive tenure in the Gulf, when asked to discuss migration Viyasha focused on her mother and explained: "After [my father] went to the Gulf, my mother took care of everything here." All of the roles that her father had previously held, which are traditional for men to assume, Viyasha's mother adopted overnight. These roles included arranging and directing her children's education, managing the building of a new home for her family, and handling the financial decision-making for their newly acquired Gulf money. Viyasha's mother

did not ease into these new roles effortlessly; rather, according to Viyasha, "she faced a lot of difficulties, but she thought it was her duty, so she suffered." The new roles and responsibilities that arose from her husband's migration transformed Viyasha's mother. She was not always the confident and capable woman that her daughter described: Viyasha explained that "when she was married she was a shy woman," but ultimately "she knows more than my father now" and "takes care of us the most." Viyasha's words paint the picture of a woman emboldened by the increased autonomy migrant wives experience, and her tone of pride in her mother evident throughout the interview indicated her own inspiration and the potential for multi-generational influence.

In a study of a female Hindu ritual healer from South India, Amy L. Allocco (2013) explores the ways that individual women may provide new models for other women and cause them to reimagine what is possible for their own lives. She argues that Valliyammal, the healer, "may enlarge the realm of gender possibilities and open up alternative gender ideologies for...many women (and men)" (107). She argues further that by providing what Jayati Lal calls "counternarratives," or life experiences that counter the traditional gender roles and expectations for women, Valliyammal effectively provides a new model of the female experience to "enlarge the social imaginary" (106). In this way, women like Valliyammal, Seema, and others I interviewed offer new life-scripts for the roles of women in Kerala through the examples of their own experiences and "counternarratives." This influence was evident in Viyasha's aspirations as she was studying for a Master of Commerce degree and making plans for a professional career. Viyasha, like her mother, desired the responsibilities that accompanied independence.

Viyasha and her mother exemplify the bond produced by shared intergenerational relationships with migration. Such relationships formed vis-à-vis family members' migration are common in Kerala. As the mother of three children whose lives have all been touched by migration, Seema's mother, Mala, is a prime example. Her eldest daughter, Seema, and her

son, Shardool, have both migrated to the Gulf for work and her youngest daughter, Saakshi, is married to a chef who works in the United Arab Emirates. Saakshi has a daughter and son both under the age of three and is herself only twenty-four. Thus, while Saakshi's husband is working abroad, Mala has stepped in and moved into her daughter's house in northern Kerala to help with managing the children and household duties. Mala, of course, has her own home, spouse, and domestic responsibilities, but she chose to make a sacrifice by staying at Saakshi's home to assist her daughter. Her choice fits into the aforementioned pattern of a collectivist society, as Mala privileged her daughter's needs, happiness, and success above her own. Mala admitted that while she felt the negative effect of leaving her own life behind by moving to Saakshi's village and being away from her home and husband, she explained that she willingly made this sacrifice for her children. Saakshi's narrative and discourses around Gulf migration demonstrate that individuals, both men and women, are prepared to temporarily forfeit their own desires and make what they regard as short-term sacrifices to help members of their family achieve economic stability and experience success. This sacrifice did not go unnoticed by Saakshi, who explained that she needed her mother's assistance because the increased responsibilities, especially managing children, were difficult for her to handle. Mala demonstrated confidence in the abilities of women to overcome challenges associated with migration, whether it be individuals putting their family members' needs above their own or adopting new roles. Speaking generally, but drawing on her experiences with her family, she related: "We will overcome the problems. When they aren't here, [our men], we take their responsibilities. We are able to do that. When they aren't here, we do everything. So, we get the courage to do it." Without hesitation, Mala reported that she and Saakshi were able to jointly manage the household without any problems and observed her daughter gaining independence through the process.

In addition to woman-headed households, migrants' wives also gain economic agency by venturing outside of the domestic sphere to enter the workforce in Kerala. Numerous

twenty-something wives I interviewed had jobs with a range of time commitments outside of their homes. One example is Prerana, a 29-year-old Hindu, who works as a technician in a medical laboratory. She also engages in other activities outside of the home to enrich her days. She shared, "After my job I will go to music class and stitching class. I feel like music is a way of meditation." Prerana filled her day with work and activities to stay "busy" in her husband's absence. In an article from the early 2000s, the Osellas (2006, 583) described an opposite trend of "re-gendering ... Kerala's modernity" and projected standards of modernity on women by bringing them into the household whereby families in Kerala desired for their women to transition from manual workers to housewives as a marker of becoming more modern. Families yearned for their women to be housewives to display status within their communities, because women remaining within the domestic private sphere demonstrated economic stability. The gendered valorization of women becoming housewives was derived from the bourgeois ideal of the "lady of the inside" (Osella and Osella 2000b, 42). This ideal resonated as an ambition with Malayali families because it starkly contrasts with many of their realities at the time, which demanded women to engage in manual labor, such as farming, to aid in supporting the family. Beyond gendered expectations, there is also a "gendered distinction between different kinds of spaces" in Kerala, such as those divided along the lines of private and public spheres (Thiranagama 2019, 325). These distinctions emerge clearly around sociality, as it is socially acceptable for men to gather in nearly any public space while women are confined to a "private-public" space existing within the bounds of their homes and neighborhood (Thiranagama 2019, 325-26). According to these traditional gender distinctions, migrant wives would not typically be expected or encouraged to leave their private sphere (Osella and Osella 2000a). Prerana's experience contrasts with both of these distinctions in that she engaged in the public sphere for both her work and her hobbies.

Through technology, Prerana has been able to stay connected with her husband in the six years that have passed since he began

migrating. Although she reported being lonely in her husband's absence, she also defied the stereotype of the abandoned Gulf wife by finding personal efficacy within her changed circumstances in his absence. According to Prerana:

We feel sad now, but we become capable. [Other] wives don't go out and they are lazy. Like when going to the bank, they think they don't know how and can't do it ... That is how it is for wives with husbands who do everything. Sometimes we miss [our husbands]. Sometimes we go with [other wives] and they say, "I don't know how to do that." It is all done by their husbands. So we feel jealousy towards them. We think about how our husbands are not here. But we become capable of handling everything.

Prerana does not head her own household and lives with her mother-in-law, but she evidently is changed by her roles vis-à-vis migration because she wields increased agency and autonomy. Although she sometimes misses her husband or is envious of women with husbands living at home, these feelings do not inhibit her ability to learn how to successfully manage new responsibilities and perform previously unfamiliar roles. Women sometimes draw on the support of or reside with their extended families so as to not compromise their respectability. However, they can assume increased decision-making ability in the absence of their husbands and through activities such as overseeing or supervising agriculture work and handling marriage arrangements and other life-cycle rites. Migrants' wives who remain in Kerala thus experience agency by leading their households and their lives, often with the support of their female family members, while their husbands migrate.

Nearly all of the women I interviewed were wives, shaping the focus of my analysis. It was uncommon for Malayali women to travel to the Gulf before marriage. Most families are unwilling to allow their unmarried daughter to travel far without supervision; the pressure to safeguard a young woman's "purity" and reputation in order to protect her marriage prospects persists in India. This pervasive concern over women's honor and propriety

manifests in a resistance to single women's migration. Thus, although wives gain agency via their relationships with Gulf migration, their participation hinges upon their husband's choice to leave them behind in Kerala or his approval for them to migrate themselves.

## Community Response

In close-knit communities within Kerala in the age of globalization, aspiration, and competition, individuals are often hyper-aware of others' evaluations of their own and their family's conduct, especially given the collectivist tendencies of Indian society. Malayali women are particularly attuned to others' perceptions of their roles vis-à-vis migration, which may range from respect and admiration to jealousy and disdain. Sabirah faced stigma throughout her career as a migrant; her sons did not appreciate the sacrifices she made for their family and instead rejected their mother for abandoning them. In an emotional moment, Sabirah detailed her eventual split with her sons, stating, "I went abroad because of our problems... because I needed to take care of them and their marriages...[but] they are not willing to [understand] that...They keep blaming me." Furthermore, she explained that people within her community often react negatively to female Gulf migrants, questioning them and any success they achieve more regularly than people would scrutinize their male counterparts. The stigma surrounding women's migration is rooted in an affinity for and valorization of traditional family structures, evident in the persisting belief that a household cannot function when the woman is abroad as well as the tendency to pass judgment on female migrants for neglecting their familial duties.

Some women, however, claimed that negative migration stereotypes are outmoded and a thing of the past. Seema's experience directly contrasts with Sabirah's: Seema argued that although people were previously unwelcoming to the idea of women migrating for work, today people are more educated and understand that men and women desire comparable job experiences. Thus, she believes people's attitudes have changed to accept migrant women workers. Seema and Sabirah's

divergent experiences point to their disparate economic and social statuses as well as the different attitudes that prevailed during the periods when they were migrating. Seema being accepted as a worker within her community and her worldview reveals her own education and economic stability. Although her husband is employed in a coveted position in Kerala as a government worker, it was only because of her second income that her family was able to engage in additional discretionary spending such as constructing their new home. Seema's migration was thus not the result of *destitution* but rather was catalyzed by economic and globally facing *ambition*. Sabirah, on the other hand, was the main breadwinner for her family and engaged in unskilled labor out of sheer necessity. She also began working during a time when fewer women were migrating and were doing so for lower-waged and lower-status jobs. My fieldwork confirms Sharika Thiranagama's (2019, 314–315) insight that people remain contained to their social circles by enacting their lives in their localities, or their "private-publics." Although Sabirah's migration began in a time period with different standards for women's work and independence, the stigmatization she faced persists into her reality today. Within her community, Sabirah was anomalous and surrounded by people who did not share the more educated and accepting worldview which Seema encountered. The narratives of Sabirah and Seema highlight the differential of experience by class and education. I contend women existing in both of these socio-economic spheres gain empowerment—whether autonomy and increased economic independence in the case of Sabirah or personal and professional success for Seema—commensurate with their social circles, education, and class contexts.

As the spouse remaining in Kerala, Seema's husband Shiv was conscious of negative community opinions surrounding his wife's migration but he was unconcerned by them. Shiv explained that he was aware of some people who would gossip about his family situation because his wife was the one migrating rather than him. Indeed, their situation, where the woman was engaged in migration while her husband remained in

Kerala, is somewhat unique: of my fifty-five interviews, I only have four examples of this gendered pattern. Although the number of women migrating I encountered was low, I expect that Seema and those like her are on the leading edge of a growing trend as many young wives expressed willingness to migrate to the Gulf if they could obtain a suitable job. Shiv noted that any community whispers about Seema likely centered around her working abroad so that their family could earn *more* money in addition to Shiv's government job salary. Others in the community may gossip about a migrating wife, but simultaneously respect her efforts and her hard work. Community chatter can thus both be understood as jealous and admiring. Moreover, the opinions of outsiders were not important to Shiv because, according to him, "we know each other, and other families know [us]...I'm not concerned by others." While Shiv was not personally worried and instead was proud of his wife and her work, his ability to disregard comments is not perhaps unsurprising because as a man he has the privilege to be less concerned with others' perceptions. It is also plausible that their family faced less stigmatization since Shiv held his own respected government position, signaling their socio-economic status and reflecting Seema's ability to migrate based on her ambitions. The negative evaluations may then prevail not for Seema and Shiv, but within communities who undertake migration out of economic precarity and necessity.

Seema's mother, Mala, concurred that Seema's experience was not that of a typical Malayali wife. She explained that "in Kerala, after marriage a woman will stay in her home... it is different for Seema." However, she denied that people gossiped about Seema. Despite leading a different life, Mala was proud of her daughter's work and believed others in the community shared this admiration and respect. Mala herself seemed to espouse relatively progressive ideals about her daughter's migration, noting that Seema worked in Saudi Arabia for her family's stability and control over her life. It was apparent Mala recognized Seema's migration as being a means to reach her ultimate life goals and thus worthy of

drawing any potential censure from her community.

Mala may have been predisposed to support her daughter's pursuits because of their caste background. Their family belongs to the Izhava community, a caste known for its upward social mobility between the nineteenth and twentieth centuries (Moser and Younger 2013, 145). According to the Osellas, in the nineteenth century the caste was made up of "a small landowning and titled elite and a large mass of landless and small tenants who were largely illiterate, considered untouchable, and who eked out a living by manual labor and petty trade" (Osella and Osella 2000b, 8). By the twentieth century, the Izhavas had "expanded their horizons beyond the confines of state and nation" through the pursuit of "social mobility in many social arenas" (Osella and Osella 2000b, 8). The influence of their history of social mobility on the Izhava community today is significant and was clearly evident during my fieldwork. Shathvika, the mother of my translator, sat in a meditative prayer every Friday evening for one hour for the wellbeing of her Izhava neighbors and community. This prayer was inspired by Narayana Guru, a "saintly figure" amongst Izhavas who fought for the dissolution of caste barriers (Moser and Younger 2013, 146). Beyond this weekly prayer at home, I also travelled with my translator to a Narayana Guru temple on multiple occasions to participate in a community prayer and meal. A sense of Izhava identity is threaded through the daily lives of my translator and his family. Moser and Younger (2013, 150-151) contend that Gulf migration allowed for the continuation of the "quest for social mobility that had characterized [Izhavas'] identity since the time of the Narayana Guru." Mala's description of Seema's global pursuits aligned with this understanding of migration for mobility; as she claimed, "[Seema] will be able to do everything by migrating to the Gulf. When we are in India we cannot move forward." Seema's financial and professional advancement is part of a set of objectives that her mother recognizes and supports. It is thus not only young migrants who look beyond India, but also older generations and family members who acknowledge the opportunities that lie abroad in the Gulf.

Although people in Seema's circles spoke positively about her migrating role and discussed her story openly with pride, it can be a more sensitive subject of discussion for other women. I was fortunate enough to speak with numerous women about their experiences vis-à-vis migration. However, nearly all of the interviews with women I conducted were not in private settings. There was always a husband standing behind, a mother-in-law on the couch, or a father in the corner. Even in the rare situations where I found myself otherwise alone with a woman, my male translator was invariably present. Consequently, I venture that these women's voices may have been filtered by their immediate audiences. The interview with Vijasha was one of the unusual instances in which her husband's family gave us privacy and allowed myself, Vijasha, her sister-in-law, and my translator to conduct our interviews alone on the upstairs balcony. As described above, Vijasha proudly shared details about her mother's life as the wife of a migrant. I postulate that Vijasha shared her feelings about her mother's and father's roles in their household openly because of the absence of a family audience. After speaking with Vijasha, I inquired about also interviewing her mother, but this request was initially brushed off and ultimately rejected. Although it is impossible to confirm this, I conjecture that her hesitation resulted from a fear of stigmatization or discomfort with sensitive topics, which may reflect her age and time period of migration. While respondents were not often very explicit about the backlash felt in their communities, I could sense its lurking presence in these moments of hesitation and censoring from women.

## **Conclusion: The Implications of Migration and Influence**

The looming influence of Gulf migration, similarly, could be felt throughout Kerala. It stretched beyond the immediate households of Gulf migrants into the lives of their extended families, the markets and shops in towns and villages, and the imaginations of every Malayali. The nature of my fieldwork—spending night and day living with families in Kerala—shed light on this reality, especially for the family of Sahil. I developed a close bond with Shathvika,

Sahil's mother, despite our language barrier. Every evening she would return home from a long day of work at a local factory and immediately begin housework. However, amidst her cleaning she would find the time to pause in my room, insist on bringing me chai or snacks, inquire about my day, and tease me with the few Malayali phrases I knew. Shathvika held a job at a clothing factory during the weekdays, tended crops on the family plot on the weekends, and performed the household duties of cooking, cleaning, and looking after elderly relatives. Her tireless work signaled to me her dedication to her family and the hopes and dreams she held for them. Shathvika did not engage in this work to pass time, stay busy, or further professional ambitions. Unlike Prerana, she did not leave the house for leisure activities or look for new opportunities to stay busy. Rather, like Sabirah, she labored out of sheer necessity. However, Shathvika's experience is distinct from Sabirah's because although they both act as economic agents, Sabirah also operates as a financial decision-maker as the sole breadwinner for her family while Shathvika's husband remains the designated head-of-household. As a result, the autonomy or increased economic independence often associated with migration thus evaded Shathvika. Evidently, labor for women both as Gulf migrants or in Kerala engenders varying degrees of autonomy and empowerment.

Shathvika's ambitions emerge from a history of Gulf migration in her family and community. Three of her brothers, all of whom I interviewed, and countless other relatives are Gulf migrants. The house in which I stayed was newly constructed, with generous donations from one of her migrating brothers. Sahil remarked to me while we worked one day that the laptop sitting on the desk between us was itself a tangible marker of Gulf money. Their family was directly touched by migration, although they were not migrants themselves. This close proximity to the Gulf, via migrants, fuels a culture of aspiration that drives shifting lifestyles and ambitions. Shathvika comes from a meager background and works industriously to support her family, but she dreams of success for her sons. She prays daily her sons will find employment and explained that once

they had stable jobs and wives, they would build a second story to their house so they could each have their own rooms after marriage. For Shathvika, her community's response to migration is evident in her aspirations for her future and her children, and her assiduous work to attain them.

Travelling through towns and villages, I witnessed the influence of the Gulf in the ways people dressed and through the windows of shops. Respondents reported a marked increase in the number of Muslim women donning *purdah* or *hijab* (various forms of covering and headscarves, respectively), and Sahil claimed they now appeared frequently in stores where they were not seen five or ten years prior. Research participants explained the growing popularity of Gulf-inspired styles as indicators of social and religious trends, including increasingly "modern" styles of dress or increased religiosity. Donning *purdah* or *hijab* can thus be a result of Gulf influence and the head coverings can be considered as cosmopolitan clothing styles. Exclusively Muslim women participate in adopting Gulf clothes styles, but the fashion choice both instigates and is indicative of increased personal religiosity and increasing distance between religious communities. While there are differentials of experiences vis-à-vis Gulf migration by religion (see Gerry 2021), I contend that the empowerment of Malayali women catalyzed by this migration cuts across religious distinctions. Women, whether they migrate themselves or are influenced by friends and family who migrate, thus embody globalized worldviews through the micro-practices of cosmopolitanism evidenced by tangible changes in their dress. Gulf clothing styles and Shathvika's aspirations indicate the strong connections felt by Malayalis across Kerala to other parts of the world. Moser and Younger (2013, 151) highlight the feelings associated with these ties where they observe, "Malayalis today seem prouder than ever of their exposure to the outside world." The perceived and physical global connections cultivated by Gulf migration affects women's life choices, ranging from clothing to professional career to lifestyle and household management, illustrating the pervasive nature of the Gulf influence. The ubiquity and pervasiveness of

the effects of Gulf influence are, I argue, particular to Kerala, where the shifts in gendered expectations and migration experiences are observable among migrants and their families more broadly. The sheer number of Malayali families who are directly touched by Gulf migration means that the Gulf meaningfully influences people throughout the state, seeping into communities, homes, and consciousness at every level.

Malayali women, ranging from migrants themselves to the families of migrants to community members, are becoming empowered through shifts in gender roles and expectations catalyzed by Gulf migration. Women in Kerala are influenced by the expanded range of possibilities the experiences and “counternarratives” of migrant wives and migrating women provide. Consequently, their aspirations and gender expectations are shifting to encompass this widened range of possibilities. Moreover, the personal agency, whether it be through expanded agency, increased autonomy, or growing confidence, of migrant wives increases as they lead households and acquire new roles and responsibilities in Kerala. For female migrants, despite sometimes negative evaluations or backlash, which seem to be indexed to class, women report that they are empowered on the everyday level by worker migration. The women who experience material, personal, and professional success as well as those who are faced with less advantageous circumstances all can garner increased autonomy, agency, and independence by way of their relationship with migration. Indeed, Seema explained that she herself is empowered as a woman in Kerala and felt that she, in her own words, “can make my dreams come true,” whether those are to build her house, support her family, or move around the world on to a European destination.

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# The Affect of the State: Affective Responses to the Bureaucratic State Structures of Migration to Chile

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## ABSTRACT

As human resettlement becomes increasingly frequent, it is crucial to gain a deep understanding of the affective realities of migrants. This article uses qualitative methods such as participant observation and semi-structured interviews to explore the emotions and feelings Venezuelan migrants experience during their relocation to Santiago, Chile. Fieldwork for this project took place between June and August of 2019. During this time, Chile experienced an exponential increase in migrants due to the Venezuelan crisis and a resulting rise in social tensions. This article focuses on Venezuelan migrants' dual affective responses to the state and the bureaucratic processes they encounter as they begin to experience everyday life in Chile. Specifically, I explore narratives concerning the negative emotions experienced by Venezuelan migrants when negotiating with bureaucratic structures, and the positive emotions toward the abstract state that created and ran those structures.

**Keywords:** migration; bureaucracy; Venezuela; Chile

everything familiar is, at its core, emotionally difficult. Relocation and adapting to a new place and society is equally emotionally taxing. Therefore, in order to fully understand migration, it is imperative to study the affect it produces and the implications that emotions have on an individual's choices, understandings of one's relationship to state entities, and the everyday reality of negotiating life as a migrant.

For a wide range of reasons, many people make the hard decision to relocate. Immigrants to a new country must navigate interactions with large structures that are simultaneously abstract and unknown to them, yet deeply intertwined in their daily lives. Migrants' affective responses to the macro and micro level structures involved in the immigration process in Santiago, Chile provide important insight into the reality of migration and the nuances of relationships to the state. These structures often produce immediate frustration for migrants in return for needed security and comfort. These contrasting emotions are constantly in contention for migrants as they settle into their new positions in Chile and begin to grapple with new government entities.

## **The Chilean Migratory Context**

It was not until the return to a democratic state in the late 1990's that Chile experienced a significant level of immigration. Since this time, immigration rates have continued to increase, although the origins of immigrants have changed over time with "growing numbers of Peruvians and Bolivians starting in the 1990s, and Haitians, Colombians, and Venezuelans in the 2000s and 2010s" (Doña-Reveco 2018). Largely due to its relative economic success as well as its perceived sense of social and political stability (Stefoni 2011), Chile quickly became a popular destination for relocation. In fact, "between 2010 and 2015, immigration to Chile grew at a faster rate than anywhere else in Latin America" (Doña-Reveco 2018). Since 2016, migrants began to arrive in unprecedented numbers due to economic and civil turmoil in Venezuela. In March 2018, the Department of Foreign Affairs and Migration was "attending an average of 4,000 people per day, and an estimated 1.1 million people [passed] through their offices" in 2018 (Gobierno de Chile 2018). This influx overwhelmed the government's

**L**ucia, a middle-aged, Venezuelan migrant, was standing at the front of her classroom on the first day of class. She had been a professor for her entire adult life and year after year, she stood in that very spot and looked out at the seats in front of her to see the eager eyes of students looking back. She recalled fondly the days when students would chatter as their new books and notebooks were placed neatly in front of them. But the past year was different, she said. There were no books, no chatter, and, a once filled classroom, now had only four students in it. This was the image that Lucia described to me with difficulty as she reminisced about her home country which she had been forced to leave a short two weeks earlier. She simply could not exist in Venezuela anymore. What she knew how to do was teach, but students could not afford books anymore, in fact, they could not even afford photocopies of books. The few students who were still enrolled frequently missed class because venturing to campus meant putting themselves in danger and they could not work remotely as the internet and phone signals would disappear for days at a time. With no indication that the situation would improve, Lucia felt that she had to leave her country. Choking up as she explained the difficulty of deciding to leave her home, her culture, and her family, she made it clear that she would not have left if she felt she had the option to stay.

Lucia's story is far from unique. The United Nations Department on Economic and Social Affairs estimates that the number of international migrants worldwide was nearly 272 million in 2019 – just under 3% of the total global population (United Nations 2019). As Lucia's story shows, migration is an emotional experience. Making the decision to leave one's home, one's culture, one's family, and

ability to process visa requests and immigration became a popular topic of discussion amongst a polarized Chilean population. During the course of my research, the number of Venezuelans entering the country continued unabated. Consequently, migrants dealt with unparalleled wait times from government institutions when attempting to become regularized - a process which involves seeking a variety of documentation, including a visa, to allow migrants to live, work, and exist in a way that is deemed legal by the government. Additionally, severe unemployment and a growing disdain by Chileans about the increase of migrants targeted at particular racial and ethnic groups, defined many migrant's experiences in Santiago (Ciudad 2019, 2).

The laws that govern immigration to Chile are remnants of the Pinochet dictatorship. The Immigration Act of 1975 is currently in use. It was written in a restrictive era and only a few minor amendments have been made to it (Doña-Reveco 2018). In recent history, Chile has taken a generally welcoming attitude towards migrants under the assumption that the country "needed to repay a debt of solidarity to the rest of the world for having received the half million exiles of Pinochet's dictatorship" (Doña-Reveco and Levingson 2012). However, as migration increases and tensions rise, the antiquated immigration law is far from adequate, and "some argue the law is a relic of the Cold War and dictatorship, viewing immigrants as threats to national security. For others, it leaves too much open to interpretation and facilitates illegal immigration" (Doña-Reveco 2018). The Immigration Act of 1975 gave overwhelming power to the government as it "grants the federal executive (the military junta at the time of ratification) the authority to prohibit entry and deport any individual or group 'for reasons or interests of national security' with complete discretion," thus allotting the government with huge power and authority (Schmidt 2019, 13). Even still, recent rhetoric from the national government has emphasized a need to reduce the number of irregular immigrants in the country (Gobierno de Chile 2018). It has become clear to both proponents and detractors that the Immigration Act of 1975

needs an update (Gobierno de Chile 2018, Doña-Reveco 2018).

According to current Chilean law, a person can enter the country and receive a tourist visa that is valid for up to 90 days. During this time, individuals can apply for a number of visas which remain valid for a longer period of time, allowing them to stay in the country legally past the expiration of the tourist visa. Most commonly, migrants entering from a Mercosur trade nation (Argentina, Brazil, Paraguay, Uruguay, Venezuela, Bolivia, Columbia, Ecuador, Guyana, Peru and Suriname) apply for a temporary visa which is valid for one year, however, visas tied to job contracts and student visas also exist. Once a migrant has resided in the country for two years with temporary visas, they can apply for a definitive visa which is valid for five years, after which they can apply for citizenship (DEM n.d.). Under ideal circumstances, when entering the country, a migrant would apply for and receive a temporary visa before the 90-day period of their tourist visa expiry, thus residing in the country with a valid visa at all times. This ideal, however, is hardly ever reality, especially in the current era of increased migration (United Nations 2019) and is discussed in detail below. Consequently, migrants remain in the country without valid documentation (a status known as "irregular") until they receive their temporary visa. It is important to note that this irregularity is quite different from the illegality or lack of documentation that is discussed in the United States. Migrants who enter the country legally in Chile are at no risk of deportation and can regain a regular legal status by completing a bureaucratic process and paying fines. Migrants must pay a fine for every month spent in Chile without a valid visa. Tourist visas are administered by the border police and temporary visas are administered by the Department of Foreign Affairs and Immigration; this means that a migrant must work with both departments to acquire a temporary, working or student visa. There are a variety of documents, which vary depending on the migrant's country of origin, that migrants need in order to receive a visa. A new policy that went into effect on July 20th, 2019, required all Venezuelan migrants to Chile to receive a temporary, work, or student visa before

entering the country, thus eliminating the option to enter as a tourist. This brief legal and policy framework outlines processes that migrants experience upon resettlement in Chile, yet it is important to understand that Chilean immigration laws are complex and changing. For example, Chile's New Migration Law was drafted, passed both chambers of Congress in August 2019 and implemented in April 2021 (Ministerio del Interior y Seguridad Pública 2019, 2021; Senado de Chile 2020).

## Methods

This project was completed as part of the All College Thesis at the College of Saint Benedict and in collaboration with Dr. Megan Sheehan through a professor-student partnership grant. Additionally, we worked with a Chilean anthropology student, who conducted and transcribed interviews. I conducted qualitative research while living in Santiago, Chile between June and August of 2019. I gathered information through a series of semi-structured interviews with migrants and Chileans. I conducted 13 interviews and drew from a series of 57 interviews conducted by the aforementioned research team. The migrants were contacted through social media, posters, and word-of-mouth. They have been given pseudonyms here to protect their identities. The migrants varied in their origins, but nearly all interviewees had migrated from countries within South America, with the majority recently arrived from Venezuela. All interviews were recorded and transcribed, and translations are my own. Additionally, I drew data from participant observation conducted at an organization located in Santiago, Chile hereafter referred to as the Migration Foundation. At this organization, a team of social workers, lawyers, and volunteers helped migrants find employment and navigate the legal processes involved in becoming a working resident of Chile. My role at the Migration Foundation consisted of working one-on-one with migrants to learn about their employment history and current social situation to best help them secure employment and understand their financial needs. On average, I worked with 15 migrants a day for three days a week and completed field notes for every day spent at the Migration Foundation. Furthermore, while in

Santiago, I lived with a Chilean host family. Through them, I gained insights into Chilean political and social perspectives on migration.

Admittedly, this study was limited in its findings. Ideally, this ethnographic study would have taken place over the course of several years, as opposed to months. This would have led to a more holistic view of immigration in Chile and, perhaps, more confident and concrete findings. Furthermore, while proficient in the Spanish language, I feel I lacked the ability to understand more colloquial and nuanced forms of the language that would be crucial in fully understanding those whom I interviewed. Furthermore, stronger language skills would have created more meaningful relationships between me and the population I sought to understand. Despite these obstacles, I worked diligently to accurately represent the sentiments and views of immigrants and Chileans in Santiago.

## The State

In the process of relocating to a new country, migrants develop a relationship with a second state. This relationship often reflects both a mixture of their old ideas of the state developed in their home countries and ideas formed through encounters with the state in the country of relocation. The state is "both an abstract, macro-level structure and a concrete, microlevel set of institutions," that creates governing and power establishments through bureaucratic structures (Auyero 2012, 6). It is this very distinction that correlates with the occurrence of positive and negative affects among Venezuelan migrants; the abstract, macro level state producing the former and the microlevel bureaucracies producing the latter. A large part of this macro-level structure is the significance that people attribute to it so that it becomes more than the sum of its parts: "the reification of this system [...] takes on 'an overt symbolic identity progressively divorced from practice as an illusory account of practice'" (Mitchell 2006, 169). The state comes to exist in the minds of people through the feelings produced in their everyday interactions with it. Akhil Gupta argues that "the most immediate context for encountering the state is provided by their relationships with government bureaucracies at the local

level" (Gupta 1995, 378). In fact, most states are aware of this and work to foster better relationships through these methods: "they attempt to materialize this contract between citizens and institutions. They are made up of public 'things' such as offices, documents, technocratic procedures and infrastructures that seek to provide the foundation for social relationships with the state" (Bear and Mather 2015, 19). Bureaucracies, as they function as an intermediary link between civilians and the state, are important in how the state is viewed. It is then curious that the Venezuelan migrants with whom I spoke, expressed such contrasting views of individual bureaucracies and the reified state.

Venezuelan migrants were generally grateful towards their new home country and anticipated that the reified state would be instrumental in providing them with a better life. In my interview with Lucia, the Venezuelan professor, she told me: "I believe that the government of Chile has helped a lot, it has supported a lot, and with the boom, the number of Venezuelans that came from 2015 to 2018 was very large, many people." She went on to say that she did not mind that the government had begun to filter the number of immigrants from Venezuela because the Chilean state needed to protect its own country first. Lucia, like many of the Venezuelan migrants I interviewed, saw their experiences with the Chilean state in contrast to the problems of the Venezuelan state. Even if the Chilean bureaucracies caused inconvenience, they were small in comparison with those of the Venezuelan state; consequently, they maintained a positive view of the Chilean state. In another interview, Eduardo, a middle-aged Venezuelan man, said "in reality, they do treat us very well here," right after explaining all the bureaucratic issues he had encountered, proving the migrant's ability to separate their own affective responses to micro and macro level structures. Most Venezuelan migrants shared this perspective, they were empathetic and felt warmth towards the state despite the daily grievances it caused them. In all, these contradictory affective responses are formative in a migrant's opinions of the state which is ultimately crucial to their experience of living a new country.

## Bureaucracy

As individuals migrate and settle in new countries, they often experience bureaucratic processes of relocation. These processes in Chile, due to the increased rates of migration, became particularly intrusive in the lives of migrants during the months when my field research took place. Bureaucracy, and its impact on society, has long been a focus of social science research. In the field of sociology, Max Weber (1921, 89) described bureaucracy as "the means of transforming social action into rationally organized action." Bureaucratic structures are a way for the state to create order in a given population. The concept of bureaucracy has developed greatly from Weber's initial definition and now has connotations far beyond a management technique. Current work on bureaucracy recognizes the amorphous and hazy modes through which bureaucracies present themselves to a given society (Auyero 2012, Bear and Mather 2015, Gupta 1995). The processes, people, and ideas that are deemed "bureaucratic" are often blurred: "the elusiveness of the boundary between state and society, [is not] a problem of conceptual precision but a clue to the nature of the phenomena" (Mitchell 1999, 170). The less society knows about bureaucracies, the less power the former has over the latter. This power dynamic is not necessarily the product of intentional maliciousness on behalf of bureaucratic structures, but a result of attempts to govern large bodies of people, especially during rapidly changing times such as those present in Chile during the summer of 2019. As members of society deal "with state bureaucracies, they have to patiently comply with the seemingly arbitrary, ambiguous, and always changing state requirements" (Auyero 2012, 9). Additionally, it is important to view the dual nature of bureaucracies. On one hand, they are abstract, ambiguous, large-scale structures. On the other hand, "bureaucracies and bureaucratic encounters are affective. They produce and are produced by emotion, self-interest, social networks and much more" (Tuckett 2015, 114). They are dually abstract and intensely personal. As migrants encounter bureaucratic structures, they can

experience a wide range of emotions, both positive and negative, which frame their time in Chile and shape their relation to the Chilean state.

One of the most consistent ways in which immigrants in Santiago experience bureaucracies is through the process of waiting. In order to become a legal citizen with a definitive visa who can work and live in Chile, migrants have to go through several procedures, most of which involve them filling out paperwork, sending it to a government office, either via physical mail or email, and then awaiting response. There is essentially nothing that a migrant can do to speed up this course of action and the wait can often leave migrants in limbo between legal statuses, complicating nearly all other aspects of their lives from employment to housing. Waiting, especially in circumstances when the awaited documents will provide ease of life, is a “temporal process in and through which political subordination is reproduced” (Auyero 2012, 2). Waiting is generally an action ripe with status and autonomy; those who have power infrequently wait for anything. Contrarily, those with less power and who must wait, live in a state of uncertainty and lack authority. This waiting period is full of emotions both towards the waiting itself and the larger entities responsible for the waiting. The waiting itself produces negative emotions, however, the arrival of what is being waited for, often brings joy and relief, thus producing conflicting and complicated affective responses.

Migrants must wait for many things. In their new society, they have little power, autonomy, information, or cultural capital, and thus, they wait. It was part of my role at the Migration Foundation to help migrants navigate the required visa processes in Chile. It is important to note that the duration of these waits was unprecedentedly long and they continued to lengthen even in the short period in which I completed my field research. The entire process of getting a temporary visa had once taken roughly six weeks to complete from start to finish; however, I regularly had migrants tell me that they had to wait five or six months to have the initial meeting with Department of Foreign Affairs and Migration. In the time when

migrants were waiting for this visa, after the expiration of their tourist visa, they would have to pay a fine for residing in the country without a legal visa. Camila, a Venezuelan woman in her sixties, stated that the Department of Foreign Affairs and Migration “is very slow, very slow. I imagine it is because of the current demand, they are not as automatic, I do not know. I know that there are many migrants at the moment and this could generate delay.” She went on to say that her “documents were already at the Department of Foreign Affairs, but they take too much time, too much time and, sadly, you have to wait, you have to wait.” Camila was clearly upset about the length of time her visa application was taking to process. The very process of attempting to become a regular citizen made her and many other migrants irregular while they waited for their visas to process. Migrants grumbled at this complication as it was a financial burden and existing outside of the law brought fear to their daily lives. However, because this process has become reified, migrants felt that there was no other option but to acquiesce. This aspect of bureaucracy was further complicated by the fact that most migrants also found themselves waiting for a job. Many migrants chose Santiago based on the city’s economic opportunities, but the unemployment rate was around 7% even for Chileans who had connections and the appropriate cultural knowledge (INE 2019). Therefore, paying the fine for being irregular is often a great encumbrance on the migrants which adds additional worries to an already difficult situation. Migrants expressed strong negative emotions towards these bureaucratic structures, yet they endured them for the positive outcomes.

Additional bureaucratic entities that migrants encounter are the laws that govern them. It is an unfortunate reality that “migrants must grapple with ambiguous and arbitrary laws that shift across space and time” (Tuckett 2015, 114). This theme was a reality during my field research between June and August of 2019 in Chile. As previously mentioned, the Department of Foreign Affairs and Migration made a change in policy that went into effect on July 20th, 2019, insisting that Venezuelans apply for temporary visas before entering Chile (Ministerio del Interior y Seguridad Pública

2019). The changes in policy created confusion for the migrants. On the days leading up to July 20th, there was an increase of migrants seeking legal help from the lawyers at the Migration Foundation and asking questions regarding their immigration status. Their confusion and fear were palpable. Although I usually only helped with finding employment, several migrants asked me questions about immigration laws and where they could find more information. For example, one woman asked me several questions about her own regularization process and then a similar set of questions for her daughter. She took very detailed notes as she attempted to understand all the things that she needed to do. Earlier in fieldwork, this ambience of panic did not exist. The new policy also purposefully instilled ambiguity, allowing individual officers to make decisions about the length of the tourist visas. I began seeing migrants who had tourist visas that were only valid for a single day, again, forcing them to reside in the country irregularly. Because Venezuelans had to acquire visas prior to entry, their reliance upon their collapsed government for paperwork, like background checks, further limited their ability to legally enter Chile. Lucia, the Venezuelan professor, said she "intended to get a democratic (temporary) visa," but she explained that "it was very difficult. So, [she] had to travel as a tourist, and just two days after [she] arrived is when they changed the law where they allow the tourist visa." This policy was specifically targeted at Venezuelans, which would seemingly garner resentment, but migrant reactions were often quite different. Despite the frustrations of the bureaucratic processes themselves, migrants continued to speak of how grateful they were to be received by this larger, abstract entity that they referred to as the Chilean government or state. They accounted for any delays or changes to the augmentation of immigration to Chile. Eduardo, for example, noted that migrants were "coming in masses" and expressed that he was not surprised or angry that the visa process was taking so long, although he did admit that the wait was quite frustrating. While at times some migrants appeared frustrated with the changing laws, they were rarely angry with the state for making those changes because they

understood that the influx of migrants was overwhelming the bureaucratic entities of the Chilean State.

While Venezuelan migrants expressed the contradictory views of the state and its bureaucracies, migrants who relocated from other countries had different affective responses. The interactions that these migrants have with the Chilean Border Police are often the first contact migrants have with their second state and these interactions can be incredibly affective. For example, one young man whom I helped at the Migration Foundation expressed this sentiment. He recounted that he had migrated from Peru and when he entered the country, the police at the border told him that he would need to return two days later to get a tourist visa. Yet when he returned two days later, the police refused to see him and so he was left without a visa. It was nearly a month after this occurred when I spoke to the young man, but he was still upset about the incident. He spoke in an exasperated tone and raised his voice appearing to try to catch the attention of the other migrants in the room so that they would share in his frustration. This man's view of the Chilean governing process was formed almost immediately as he entered the country and those frustrations towards the state lingered as we spoke nearly a month later. This young man's experience provides evidence that the trend of migrants holding negative affect towards bureaucracy and positive affect towards the state tends to be inapplicable beyond the demographic of Venezuelan migrants. Another woman, Julieta, shared her story of passing through the border from Peru to Chile and her resulting emotions towards the bureaucracies and state of Chile. She explained how she took a bus to cross the border. When she reached border control, the Chilean Border Police told everyone to disembark from the bus and to leave their belongings. Julieta emotionally recalled that she "did not know what was happening." She explained that the police then split the group into two, telling one group that they could continue their journey and the others that they could not. Julieta was in the group that was not allowed to pass. She said that the police did not even look at her passport or other documents, that they made distinctions among migrants based on

appearances alone. Julieta concluded that the border police “treated us like shit.” She was undoubtedly angry with the bureaucracies and the apparent injustice incurred at the border. These examples are some of the most extreme and these migrants hold a view of the state bureaucracies that is significantly worse and more skeptical than the other migrants with whom I spoke. However, their narratives are valuable in their ability to illuminate the process of producing negative affect. It is their fear, their frustration, and their confusion that constructs lasting views of the state, at both the macro and micro levels. These stories are reminders that migration is not an abstract idea, but a lived, emotional experience.

## Conclusions

On October 18, just two months after I left Chile, the country erupted into either social disorder or a social awakening depending on perspective. Protests started in response to an increase in the cost of public transportation in Santiago -- the fourth within a year (Bunyan 2019). However, the demonstrations soon spread across the country. More than one million protestors took to the streets (BBC News Mundo 2019) in the week following the price increase and found themselves facing “police firing rubber bullets, tear gas and water cannons” (Bunyan 2019). The drastic response from the population was not only in response to public transportation costs but also “rising living costs, low wages and one of the worst rates of inequality in Latin America [...] Chile has the highest rate of income inequality among a group of 35 of the world’s wealthiest nations” (Bunyan 2019). Rising tensions surrounding migration, with wide support from both perspectives, certainly contributed to the issue as well. Immigrants, many fleeing the crisis in Venezuela and in economic distress, contributed the drastic inequality and put a lot of pressure on a job market that was already suffering unemployment. In fact, on October 18th, the very day that the protests began, a Santiago newspaper published an article claiming that 51% of the Chilean population thought that immigration is bad for the country (Molina 2019). This came as somewhat unsurprising news as, a week before I left Chile, there had been an anti-immigrant protest in the

center of Santiago. Several Chilean nationalists were marching through the streets wearing Chilean flags, yet this did not last long as an even larger opposing group soon arrived and things began getting violent. This growing anti-immigrant sentiment often made the claim that migrants were stealing their jobs and that they were changing the general atmosphere of the city. Contrarily, a study found that the foreign-born population of Chile is primarily economic (working) migrants and across all skill levels, migrants are working in positions that they are overqualified for, suggesting they are of value to the Chilean economy (Aldunate et al. 2019, 1). Essentially, Chileans are severely divided on their response to the surge in migration.

It is difficult to imagine that these social disruptions have made wait times even worse for migrants, many of whom have made great sacrifices to get to Chile. There is one last emotion that needs to be discussed with migration, one that supersedes all of the conflicting emotions that migrants feel towards the bureaucracies and the reified state. This emotion is heartbreak. The one emotion that I heard more commonly than any of those that I previously discussed is the destructive sorrow that one feels in leaving their home, family, friends, and culture behind. As Eduardo poetically put it, “I did not like to leave my land because it is difficult to put everything in one suitcase, all of your customs, your friends, your family, your style of life as well [...] to start from zero is not easy, to start from zero is not easy.” In all this discussion of structures and policies, it is imperative to remember the distress many migrants have gone through, to recognize and understand their situation, and work to make their situation better. Emotions are a powerful tool in creating empathy and sparking progress. If the life of an immigrant in Chile is to improve, it must be done affectively.

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# “A good conversation is better than a good bed”: How Migration Impacts Meanings of Health among Chronically Ill Ethiopian Immigrant Women

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## ABSTRACT

Narratives reinstate meaning to the body and mind, especially after major life events like migration and illness. To better understand the interplay between migration status and narrative practices, I examine the functions and meanings of illness narratives among three Ethiopian immigrant women living with chronic illnesses. I investigate how these accounts impact the ways in which my interviewees identify and understand themselves in relation to their illnesses. The core of this article is divided into three sections—Stigma, Frustration, and Faith—each conveying my interlocutors’ migration and chronic illness experiences as well as the liberating and constraining effects of storytelling. Collectively, these themes highlight the agentive aspects of illness narratives that help chronically ill Ethiopian immigrant women assert control over their bodies and identities as they strive toward bettering their health.

**Keywords:** chronic illness; illness narratives; migrant health; women’s health; Ethiopia

## Introduction: To Take Control by Sharing the Truth

On a chilly Sunday evening in January of 2020, Almaz and I attended the local Wollo Association's Christmas celebration. The Wollo Association is a social club established to connect and support Ethiopian immigrants living in the Washington, D.C. metropolitan area with origins in the northeastern Wollo province. As Almaz and I entered the packed venue, we were greeted by familiar sights, sounds, and scents. Near the entrance to the left was a group of giggling children playing with each other. Three women were busily reheating wot (stew), replenishing a platter of injera (sour fermented flatbread), and brewing shai (tea) and bunna (coffee) in the kitchen in front of us. And in between these two spaces was the living room, filled with the rest of the association members. They were dressed in their best traditional attire and sat in a circle, surrounding a pile of shiny presents for the White Elephant game. Almaz quickly joined a friend while I, alone and without a seat, squeezed myself next to two other people on a two-person couch.

The association meeting officially commenced once bunna and shai were served. The club's president stood up at the edge of the living room and made several announcements in Amharic, the lingua franca of Ethiopia. He reminded the members to review their contact information on the attendance sheet being passed around the room and to pay their membership dues before leaving the meeting. Then, he asked for everyone's attention: "We have a returning member with us today, and she would like to say a few words for us." A middle-aged woman seated not far away from me arose shyly, holding her right hand. In

Amharic, she introduced herself in a gentle yet nervous voice:

Hi everyone, my name is Rahel. I used to participate in the Wollo meetings, but I stopped coming to the last few meetings because of my right hand. I don't know why, but about four months ago, my right hand began to hurt every night around 12 a.m. I had trouble sleeping, but I feel better now. I know I missed a lot of meetings, but I want to rejoin this association. I promise to pay my past dues. I hope you all will allow me to join again.

Rahel sat down. The room was silent. Everyone had sympathetic looks on their faces. "Thank you for speaking, Rahel," interrupted the association president. "Don't worry about anything. The board will discuss how we can help you pay the past dues. Just enjoy tonight's festivities." A few minutes later, the party's mood lightened with the start of White Elephant. While the guests playfully bickered over the presents, I noticed Rahel in deep conversation with the people around her. It seemed that her problems were solved, and she was welcomed back into the association. Yet, I noticed her spacing out as the members danced to traditional Wollo music for the rest of the night. It appeared as if Rahel was processing what she had just done—narrate her pain and suffering.

Rahel's disengagement from the Wollo Association draws attention to how cultural beliefs affect sick individuals' responses toward their health conditions. Within Ethiopian culture, a notion of pride—that is, a set of culturally specific ideas that emphasizes independence and self-sufficiency—is vital. This belief becomes particularly important for Ethiopian immigrants, who are adjusting to unfamiliar environments in their countries of resettlement and who must assert their success in a new land for their family members, compatriots, and fellow immigrants. Personal struggles like illness become stigmatized issues that are not openly discussed among Ethiopian community members. Instead, these individuals enact a performance, appearing to be healthy when, in reality, this cultural expectation prevents Ethiopians in need from getting help. Ethiopian social clubs are established to help

immigrants hold onto remnants of home while providing financial, emotional, and spiritual support for those in strenuous circumstances. But for Rahel, the Wollo Association did not fulfill this purpose. She withdrew from the organization due to the cultural shame and fear engendered by her chronic pain. When Rahel explained her absence to the association, her bodily movements, like lowering her head and clutching her ached hand, conveyed Rahel's humiliation in revealing her weakness. At a glance, this behavior appears defeatist, but I contend that Rahel was carrying out an empowering act. She was finding the words to capture her illness experience. Constructing this narrative was an important step that helped Rahel heal. She was rebuilding her relationship with the association members, gaining control over her life narrative and telling her truth (Frank 1995, xii).

This article draws upon my undergraduate senior honors thesis in which I ethnographically examined the chronic illness experiences of Ethiopian immigrant women living in the Washington, D.C. metropolitan area. My fieldwork lasted from January 2019 to January 2020. I collected the life histories of five chronically ill Ethiopian immigrant women, conducted twelve semi-structured interviews with local Ethiopian women and men, and interned at a local immigrant health clinic. An emphasis on life history helped me develop rapport with my interlocutors through multiple visits. This approach provided these women—my “primary interlocutors”—greater control over the interview process. I have relatives who reside in the D.C. metropolitan area and so I gathered many of my informants with their help through snowball sampling. Snowball sampling is a nonrandom method that could lead to nonresponse bias or a selection of respondents who constitute a distinct social network. But as an outsider to the D.C. Ethiopian diaspora community, this approach was crucial for me to get “inside” my study population (Beaman 2017). Rather than being “controlled away,” my participants’ distinct characteristics are “understood, developed, and incorporated” throughout my analysis (Beaman 2017, 126).

I also identified interviewees by attending local Ethiopian community events. Most of my interviews were conducted in English and Amharic at my interlocutors’ places of residence. If more convenient, some of these conversations were held over the phone. In this article, I have transcribed my interlocutors’ responses as spoken rather than “correcting” them to standard English. Additionally, I conducted semi-structured interviews with local Ethiopian residents to understand how blood, fictive, and ethnic kinships affect chronic illness care. These informants included Ethiopian women and men, who ranged in profession, age, and years of residence in the U.S. I have changed all of my interlocutors’ names in my study to protect their privacy. Lastly, I interned at a local immigrant medical clinic, where I shadowed different health personnel and conducted a needs assessment on the center’s health promotions program. Through this clinical perspective, I was able to better comprehend and build upon my interlocutors’ illness accounts.

In this article, I examine the functions and meanings of illness narratives among three of my primary interlocutors to better understand the interplay between migration and narrative practices. I investigate how these accounts impact the ways in which my interviewees identify and understand themselves in relation to their illnesses. However, I do not simply describe my participants’ narratives. Rather, I add the impact of social networks to these stories because illness narratives change when shared with different audiences. Indeed, the accounts included in this article are interpreted through my perspective as a second-generation Ethiopian American woman, yet my goal is to demonstrate the liberating and constraining aspects of storytelling among my interlocutors.

The core of this paper is divided into three sections—Stigma, Frustration, and Faith. Each section begins with a vignette about one of my interlocutors and subsequently analyzes this account. In Stigma, I examine Genet’s nearly fatal struggle with disclosing her diabetes status to her family. Understanding the stigma around her disclosure contextualizes the social worlds Genet must navigate to make sense of her illness. Frustration explores Haset’s resentment

toward her diagnosis of hypothyroidism. Although Haset felt physically well, empirical data disregarded her perspective, drawing attention to the contentious division between “objective” and “subjective” health measurements. The focus of Faith is Almaz’s mixed response to her diabetes diagnosis. Although she mostly adheres to her treatment, Almaz relies on her Ethiopian Orthodox Christian faith to explicate her illness and to maintain hope about her future well-being, thus pointing to the fraught relationship between biomedical and cultural views of health. Altogether, these themes highlight the agentive aspects of illness narratives that help chronically ill Ethiopian immigrant women assert control over their bodies and identities as they strive towards bettering their health.

## **Habesha People in the U.S.: How Migration Affects Social Networks**

With an estimated 256,032 residents, first-generation Ethiopian immigrants are the second largest African immigrant group in the U.S. after Nigerians (US Census 2019a; Migration Policy Institute 2014). Nearly 60% of first-generation Ethiopian immigrants arrived in the U.S. after 2000, but their first significant wave of resettlement occurred during the 1980s and 1990s (Migration Policy Institute 2014). These decades were turbulent times in Ethiopian history as the country withstood an oppressive political regime, a civil war, and severe food shortages. Consequently, many Ethiopians sought refuge in nearby Sudan, Djibouti, Somalia, and Kenya while others relocated to Europe, North America, and Australia. In the U.S., about 1,000 Ethiopians were resettled annually between 1981 and 1993 (Capps, McCabe, and Fix 2014).

Of importance at this time, tens of thousands of Eritreans left their homeland due to the Eritrean War of Independence (ca. 1961-1991). Prior to Eritrea’s secession from Ethiopia, the exact number of Eritreans in the U.S. was unknown as they were counted as Ethiopian nationals. But as of 2019, there are about 49,355 Eritreans living in the U.S. (US Census 2019a). Despite Eritrea’s separation, Eritreans and Ethiopians are often referred to collectively

as Habesha, a word that has been generally embraced within the Eritrean and Ethiopian diaspora. These deeply rooted cultural connections have influenced where Habesha immigrants live in the U.S.

The Habesha diaspora is distributed widely across the U.S. Most first-generation Eritrean immigrants reside in southern California with an estimated population of 9,156 in the entire state (US Census 2019b). The greater Washington, D.C. area has the largest Ethiopian immigrant population in the U.S. with about 35,000 first-generation Ethiopian immigrants (Migration Policy Institute 2014). D.C. is a cosmopolitan city, yet it is considered more manageable in size, living costs, and traffic than other major U.S. cities, like New York, Los Angeles, and Chicago. As Jill Wilson and Shelly Habecker (2008) write in “The Lure of the Capital City,” the development of immigrant enclaves attracts new migrants to established educational, religious, and cultural institutions (cf. Massey 1990). The social networks within these communities become fortified and enlarged “through transnational activities organized around a variety of ethnic, national, political, and religious affiliations and identifications” (Wilson and Habecker 2008, 444). Altogether, these connections critically shape immigrants’ health.

Studies have demonstrated that people with high levels of social support have lower risks of mortality than those who have weaker support networks (Wright 2016; cf. Berkman and Syme 1979; Cohen, Gottlieb, and Underwood 2000). Further, positive social support can reinforce healthy behaviors while negative social aid can deter healthy behavioral changes (Wright 2016; cf. Revenson et al. 1991; Goldsmith 2004). Accordingly, individuals’ health outcomes depend not simply on their physiology and actions but also on their physical environment and the behaviors of people around them (Smith and Christakis 2008). Some studies indicate the entangled sociocultural, psychological, and environmental factors that shape people’s social networks and subsequently health (Wright 2016). These phenomena are most drastic for immigrants whose social networks are also fractured by relocation.

Migration affects the robustness of immigrants' social networks. This process puts immigrants' kinship relations to the test as some immigrants cannot visit or bring their family and friends to their destination countries (Brettell 2008). These issues are further complicated with the addition of chronic medical issues. Chronic illnesses not only encompass the daily experiences of pain and suffering; they integrate into sick people's lives, becoming inseparable from their life histories and worlds. Adjusting to and making sense of such profound changes are difficult, but illness narratives help reinstate order to everyday life.

## **Illness Narratives: Restoring Order to the Self**

Illness narratives are powerful and necessary forms of self-understanding. Medical sociologist Michael Bury (2001, 264) contends that at its fundamental level, storytelling "help[s] sustain and create the fabric of everyday life...[and] repair and restor[e]...meaning." Narratives reinstate meaning to the body, mind, and life, which have all been threatened by illness (Bury 2001, 264). Bury's explication of narratives echoes psychiatrist and medical anthropologist Arthur Kleinman's definition of illness as "conjuring the innately human experience of symptoms and suffering" (1988, 3). Illness also impacts sick individuals and their social networks (Kleinman 1988). In turn, illness narratives have various functions, like making sense of illnesses' origins or conveying cultural notions of pain and suffering (Bury 2001, 263). We must go beyond Bury and Kleinman's structural functionalist views of illness, however, to understand the fluid relationship between illness and narratives.

People have stories about past, present, and future life experiences that are influenced by the body's ability to fulfill certain goals and plans. But as medical sociologist Arthur Frank (1995, 1) writes, new stories are needed when critical illnesses disrupt a sick person's "destination and map" of life. Frank (1995, 55) contends that "self-stories"—in which "the self is being formed in what is [being] told"—help sick people emerge from the "narrative wreckage" with a new sense of direction. Self-stories, and illness narratives more generally, usher

"greater continuity and closure" for their narrators, influencing how people live and understand their truths (Zipes 2012, 127). My research contributes to Frank's notion of illness narratives by conveying what self means and how it is constructed by my interlocutors as immigrant women living with chronic health conditions. It is through this approach that we can understand how personal truths about health arise from within and through social relations.

Each person has chosen and unchosen stories. In *Letting Stories Breathe*, Frank (2010, 25) develops this idea by building upon Pierre Bourdieu's concept of "chosen" and "unchosen choices." Individuals hold socially rooted dispositions that stem from their families' beliefs and behaviors. Since people are not born into families of their choice, unchosen stories inevitably arise within these social environments and shape individuals' identities. Simultaneously, people can decide whether to retell certain stories and how to do so. In the midst of these competing narratives, people grow through personally selected accounts derived from "collection[s] of stories in which a life is formed" (Bourdieu 1984, 49; see also Zipes 2012, 128). For chronically ill immigrants, illness is just one type of significant interruption in their personal narratives. Developing new self-stories can be challenging for immigrants as they navigate through the unfamiliar terms and tropes of their destination countries. Immigrants present chosen stories about their illness experiences, having assessed unchosen narratives that were created in the social environments of their upbringing. Moreover, they weave together multiple frameworks to create their self-stories. Some of these structures relate closely to native cultural beliefs while others align with values upheld in their countries of relocation. In essence, immigrants construct their stories based on continually changing frames of reference. Recognizing the selectivity and fluidity of storytelling underlines that immigrants inhabit multiple worlds and that they are active agents in crafting their life stories.

In all, these perspectives on illness narratives point to the variability of stories. Such differences depend on the narrator's audience

and contexts, indicating the intersubjective nature of illness. As Smith and Christakis (2008, 406) contend, “[p]eople are interconnected, and so their health is interconnected” through biological, social, and environmental factors. These elements have greater significance for immigrants. When migrants enter a new country, their social connections dramatically change as they confront adjustment to a new land. Simultaneously, immigrants learn to share their experiences in new ways and to attain control over meaningful interpretations of their lives.

### **Stigma: When Disclosing a Health Condition is a Decision between Life or Death**

“For Ethiopians, when you have pain, you don’t go to the doctor until the pain doesn’t let you get out of bed!” asserted Genet. She and I were seated next to each other at her dining table. It was my first time meeting Genet, but she openly shared her life experiences in a mix of Amharic and English. For Genet, the combination of uncertainty, stress, and fear contributed to her development of type 2 diabetes. As she indicated in her opening remarks, the anticipated cultural response to pain and suffering among Ethiopians is to ignore these symptoms until they interfere with everyday life functions. Such expectations echo the cultural notion of pride mentioned earlier and how this trait is a performance of strength during personal battles (Hatch 1989).

Genet was born in 1966 in Menjar, a town two hours east of Addis Ababa. She grew up in both cities with her mother, two older brothers, and younger sister. Genet had a “good” life in Ethiopia. But due to Ethiopia’s political instability after the 1991 dissolution of the Marxist Derg, Genet left Ethiopia for Cairo, Egypt, in 1998, where she worked as a nanny for a wealthy Egyptian family. When recalling her time in Egypt, Genet often stared into the distance with a smile on her face: “I was sitter for a boy of a rich family. I took care of him from when he was nine months to seven years. I enjoyed taking care of him. Those experience help me understand what means to be mother. I learned what means to raise, love, and take good care of kids.”

After living in Egypt for seven years, Genet decided to immigrate to the U.S. She “didn’t expect to come to America” because she did not have any relatives living there, but Genet decided to give it a chance. She arrived in Washington, D.C., where there was a community of Ethiopian migrants who had worked in Egypt. Genet applied for asylum, but her application was rejected—the first of many dismissals. Genet described her determination to submit a successful application with her lawyer’s support: “My lawyer encouraged me to apply again and again. He hustle me to reapply for asylum.... Time to time, one year, two years, three, four. It became very exhausting.” About four years into this process, Genet received her work permit, and she began working various service jobs. Six years later in 2015, Genet finally received her permanent residency card. Upon reflection, Genet does not take her immigration status for granted: “This all things in the past, but I’m emotionally hurt. It’s difficult being immigrant whatever it is. Paper doesn’t mean nothing.... I always told myself, ‘I have to do something. I must always try to do something.... I must be patient.’” Genet’s determination paid off, but the emotional scars from this journey affected her physical health.

Genet began experiencing type 2 diabetes symptoms in 2008. At first, she tried to downplay these signs: “When I was developing diabetics, I know some of the symptoms—dry mouth, thirsty. I drank a lot of water. I’m never satisfied with how much water I drank! I ate a lot of sweets and carbs...[but] I denied having diabetics.” When Genet’s friends saw these behavioral changes, they advised her to visit a physician before her health worsened. Eventually, Genet complied and learned of her health status. She was distraught. “I never had this issue before,” recounted Genet with slight desperation in her voice. “I was panicking—my paper, my health. I was upset.” This physiological development was a sign of failure for Genet. Her illness implied that she was not strong enough to withstand the biological and legal problems in her life. At this moment, migration challenges Genet’s ability to deal with her health conditions. Immigrants have higher expectations of their adjustment in their destination countries due to the greater risks of leaving their home countries and supporting

loved ones. Consequently, immigrants like Genet pay a greater price for displaying a front of self-sufficiency to deter serious problems.

Since her diagnosis, Genet has learned that she has power over her health. She asserted, "I can have command over diabetics by watching what I eat, exercising, [and] eating correct, small portions." Genet has to face the everyday realities of living with type 2 diabetes, like checking her blood glucose levels and giving proper insulin injections before each meal. These routines are daily reminders of her chronic illness, and they possess a degree of shame that Genet must overcome internally. When Genet became a permanent resident, she had an easier time coming to terms with her health condition because this legal resolution affirmed her life's "destination and map" (Frank 1995, 1). What Genet had yet to confront, however, was dealing with stigma from her family.

When Genet traveled to Ethiopia to visit her family in 2015, she did not tell them about her health issue until it became a life or death decision. "I didn't want to tell my family that I have diabetics, but I had to," shares Genet. That critical moment arrived when Genet and her mother attended an Ethiopian Orthodox Church service in Menjar. Typically, these ceremonies begin before dawn and end mid-day (Sellasie and Mikael 1970). Attendees go to church without having eaten food, and they break their fast with *dabo* (bread). This ritual became a problem for Genet when she became hungry to the point of almost passing out. Genet described the moment at which she told her mother that she felt faint: "I [told] my mom I was not feeling good because of diabetics. She said, 'Oh, my child! How I can bring you here and hurt you without giving you food?! Let me find you food.' She went to other people and got bits of bread. I ate it and felt better." At that moment, Genet was faced with the decision to disclose her health status. She had to resist the cultural notion of pride within a sacred place, where people exposed their vulnerabilities to God. Genet had not imagined sharing her illness then but doing so saved her life. In fact, this action led her to gain moral support from her family and to educate them about nutritional health.

A central theme in Genet's account is loss of control in both tangible and intangible ways. Before her diagnosis, Genet had trouble getting her residency card. She was obliged to work hard and create a self-sufficient U.S. American life, which financially supported her family in Ethiopia, but Genet did not have command over her legal status in the U.S. In such circumstances, migration contributes to Genet's loss of control over her life. Genet relocates to two different countries, where she must adjust to unfamiliar cultural norms. Genet's ability to create a stable life, specifically in the U.S., depends on her constant flexibility and willpower to attain her permanent residency status. Ultimately, Genet's determination pays off, but she had to endure a decade of not knowing whether she would stay in the U.S. On an interpersonal level, migration impedes Genet's family role. Many immigrants leave their native countries to provide better economic support for their relatives. But for Genet, migration to the U.S. disrupts her ability to fulfill this role. As a daughter, Genet bears a cultural responsibility to assist her family in Ethiopia (Bekele 2018). Genet carries out this duty by sending remittances, but due to her prolonged legal issues, these pressures exacerbate her health and well-being.

Genet's diagnosis also precipitates loss of control over her body. The concept of control is important when examining Genet's experiences because it frames how individuals perceive their lived realities. Control implies a degree of predictability in life; it "does not require self-conscious monitoring" as Frank contends (1995, 30). However, illness engenders unpredictability, restricting everyday freedoms. For Genet, diabetes is another reminder of her body's limitations as an immigrant and a chronically ill woman. But rather than simply bearing uncertainties, illness also compels adjustment to uncontrollability.

Illness signifies adaptation to the crisis of contingency. Frank (1995, 31) defines contingency as the "body's condition of being subject to forces that cannot be controlled." At infancy, people cannot control their bodies, thus burping or spitting at their own pace. But in adulthood, individuals are expected to control their bodily functions. Loss of that

command is perceived as a social failure, and adults are expected to regain this control or to hide that loss effectively (Frank 1995). The latter pressure is more significant for Genet because of the cultural notions of self-pride.

Further, Genet's circumstances underline the tension between notions of individual and social honor. Individual honor assumes that the "agent's focus is primarily inward upon his or her own sense of self-worth. The underlying motivation is to achieve a sense of personal accomplishment or fulfillment, and the individual does so by engaging in activities or exhibiting qualities that are defined by the society as meritorious" (Hatch 1989, 349). Genet demonstrates individual honor by sending remittances to her family. Migration bears personal and interpersonal responsibilities, and Genet's desire for self-sufficiency honors herself and her sacrifices. She creates a meaningful understanding of her life through these deeds.

Such an intrinsic drive clashes with social expectations of honor. Social honor in Ethiopian culture is significantly influenced by the Ethiopian Orthodox Church. Diego Malara and Tom Boylston (2016, 53) argue that life is considered from an asymmetrical relational perspective; that is, "[r]elationships—with family members, institutions, Church, and God—are shaped both by the circumstances of power and by notions of the good (the mercy and protection of God, the love of Mary, the authority of fathers)." Social honor emphasizes selflessness and a type of love that is "unequal and non-reciprocal" (Malara and Boylston 2016, 53). In Genet's life, social honor takes the form of repatriating money despite her legal and health issues. Her resettlement in the U.S. is an extension of her family's journey, and she is expected to provide for her loved ones as a woman. These cultural notions of honor dictate Genet's body to an extent, controlling how she navigates life in the U.S. as a chronically ill immigrant woman. Such assumptions are part of Genet's unchosen stories that are rooted in Ethiopian customs and the challenges engendered by migration.

Illness disrupts people's lives, but illness narratives help address this interruption. According to Frank (1995, 59), illness narratives have two functions—to restore a fragmented

order and to tell the truth about this life change. Genet's story attempts to organize the jarring pieces of her life. In this process, we see her narrative making strides at the eternal return. Philosopher Genevieve Lloyd (1993: 120) interprets this concept conceived by Friedrich Nietzsche as "a matter rather of seeing everything that happens—whether it be grand or unbearably petty—as integral to the being of a self which...could do so only in its entirety." Genet shares the internal and interpersonal struggles of dealing with her health and legal challenges in her story. She addresses stigmatized cultural issues directly, yet to an extent, her openness is confounded by her retrospective position. It has been about twelve years since Genet was diagnosed with type 2 diabetes. She has adjusted to her daily health regimens, and she has accepted her diagnosis. Accordingly, Genet's story conveys a heroic tone, which conveys her triumph over incredible obstacles. Being removed from the past has allowed Genet to better understand her experiences and to craft her own narrative. Her body is no longer "imprisoned" by the emotional challenges brought by diabetes and her immigration status (Frank 1995, 98). Genet is not controlled by the chaos in her life. She has found internal peace.

### **Frustration: A Clash of Biomedical and Personal Narratives**

Haset learned that she had an abnormal thyroid stimulating hormone (TSH) count during her annual physical examination in 2015. "[My doctor] told I have a problem with my thyroid," recounted Haset hesitantly over the phone. "He say, 'This okay. That okay.' And then, 'The thyroid number is high.'" Haset was confused. She had consistently visited her primary care doctor each year, and there was often nothing of significant concern with her health. But now, a numerical discrepancy pointed to a problem. "When I heard the news, I was not—I was not really happy," sighed Haset in frustration. "I thought, the way I feel—I thought 100% healthy. When he tell me [that I have a high TSH count], that make confused. Unhappy." Despite Haset not feeling physically unwell, her physician referred her to an endocrinologist, who conducted more tests. Interestingly, the endocrinologist was also puzzled at Haset's

diagnosed thyroid issues inquiring, “Oh, [are] you really sick? I don’t feel anything. I don’t see anything. There is no swollen.” But because Haset’s TSH count indicated an abnormality, her endocrinologist and primary care physician officially diagnosed her with hypothyroidism, which Haset does not fully accept to this day.

Haset was born on December 13, 1966, outside of Addis Ababa, Ethiopia. As the ninth child of twelve siblings, Haset was raised by her oldest brother, Getachew, who was roughly thirty years older than her. Despite being soft-spoken, Haset laughed heartily at different childhood memories, especially with her neighborhood friends: “There is always to see something. ‘Oh, so and so dress up. Oh, she’s going now. Look, her shoes!’... We always sneaking from the house, going backyard, playing.” Haset’s fond memories, however, were pockets of glee overshadowed by the Derg. Believing she would have a safer life, Getachew sent Haset to Takoma Park, Maryland, in 1988 to live with their brother. Haset worked various service jobs as a senior living facility food server, an airport gift shop cashier, and a gas station clerk. After fifteen years of living in the U.S., during which Haset got married and had three children, she enrolled in a certified nurse assistant (CNA) course. She then began working at a local hospital, which Haset emphasized as “stressful” but also compelling to live healthily.

When Haset returned to her primary care doctor after her hypothyroidism diagnosis, she received a complicated medical regimen: “I start with 25 milligram for three months. He say, ‘Oh, that’s not enough.’ He increase it, fifty milli, and then he see it. I don’t know what happen. He increase it again, seventy-five [micrograms]. I took seventy-five [micrograms] for two, three years.” Haset did not notice major changes with her TSH count as she took the medication, but she felt its side effects. In an irritated voice, Haset recalled, “[T]he side effects is hurt me bad, like losing hair, drying my hair. My throat dry. It just—Skin issue it even cost too.” Haset changed her primary care doctor to another one, who reduced her medication to seventy-five micrograms for three days a week. Yet, Haset still did not feel sick because of the illness, making her believe she was misdiagnosed: “Yeah, my inside say, ‘I thought

it’s wrong diagnose because I don’t have feeling.’ Still I don’t! There is no sickness or anything. It just playing with the number. I just feeling—my feeling, my body. Are they [the physicians] really right? Is there something wrong?” For Haset, the numbers have no meaning without physical symptoms.

Additionally, Haset is frustrated by her diagnosis because she was not properly educated about her health condition. At first, Haset construed her illness as hyperthyroidism based on her childhood observations of this condition. She remembered, “Back home [in Ethiopia], when somebody has thyroid [issues], it’s not really thyroid the way they put here [in the U.S.]. It’s swollen! Somebody neck is swollen. A big gland is coming out.” The physical presence of this illness frightened Haset. People would know that she is sick and stigmatize her appearance. Haset’s worries subsided when her coworkers, who also have hypothyroidism, reassured her with their experiences of living with this illness.

Further, Haset did not realize that hypothyroidism was a chronic condition upon her diagnosis. She asked her doctor, “Is it temporary I’m taking this medicine [sic]?” But he replied, “No, it’s forever!” The idea of forever shocked Haset, which she described as “hit[ting] me in the head.” Haset had assumed that her diagnosis was simply a minor event in her life; she would overcome this challenge and carry on. However, Haset had to grapple with the fact that chronic illness is a long-term adjustment to everyday disruptions in life. Initially, Haset perceived her illness “like a headache. I will get over with this thing.” But throughout her experience with hypothyroidism, Haset realized that her illness “means...a big deal. Thyroid is not [an] easy disease. It’s really bad. It control your—all your body.” Yet, she did not anticipate the side effects of her medication. Hair loss, dry hair, and weight gain all affected key feminine aspects of Haset’s physical appearance, but these changes were deemed trivial by her physician. Altogether, her doctor’s lack of empathy, combined with the influence of biomedical narratives, reinforced Haset’s frustration about her diagnosis.

At the center of Haset’s illness experience is a clash between biomedical and lay illness

narratives. The development of and advancements in hospital medicine has pressured sick individuals to rely on professional biomedical care. Sociologist Talcott Parsons's sick-role theory describes this relationship. Physicians become the spokespeople for patients' diseases, making ill people yield their narratives to disease and medical personnel (Parsons 1991 [1951]). Thus, ill people lose control of their narratives to the powers of medical institutions. When Haset's physician foregrounded her TSH count, Haset lost control of her life to hypothyroidism. Her doctor's medical interpretation overpowered her illness narrative, delegitimizing Haset's personal knowledge about her body with empirical data. While the general expectation is to entrust care to a doctor, the prolonged nature of chronic illnesses generates narratives that question and nullify authoritative discourses. Haset's physician reinforced an underlying concept of the sick-role theory that "physicians are responsible more to professional codes than to individual patients" (Frank 1995, 15). This standard adheres to values upheld by medical institutions, and its "greatest responsibility...is achieved when the professional places adherence to the profession before the particular demands of any individual patient" (Frank 1995, 15). This approach to medical care is accountable to "the factual truth of medical science, the beneficent truth of institutional management in the hospital, and ultimately...biopolitics" (Frank 1995, 15-16).

Haset's frustration, however, highlights lay people's agency in foregrounding their illness perceptions. Parsons's sick-role theory portrays patients as passive individuals who easily submit to physicians' biomedical explanations. This depiction overshadows sick people who resist doctors' restrictions by centering their own daily illness experiences and personal voices. Haset challenges her physicians' biomedical narrative by outwardly questioning the implications of her diagnosis and treatment. Haset eventually adheres to her doctor's medical advice, but this compliance demonstrates that biomedical discourses coexist with lay illness narratives. Both types of narratives occur within the same time and space as well as the same physical body despite

their dissimilarities. Patients juggle these accounts to craft their own physiological, mental, and social treatments.

Haset's account conveys a chaotic narrative. Frank (1995) defines this genre as stories with plots in which life does not get better. Chaotic narratives have a theme of uncontrollability, which is captured through their incoherent storylines or absent happy endings. Haset's narrative partly reflects these elements in how she depicts the sudden emergence of her chronic illness. Haset has a high TSH count out of nowhere, and she is officially diagnosed with hypothyroidism. She does not have control over this disease's duration because she will live with it for the rest of her life. This diagnosis is an abrupt event, interfering with Haset's everyday life, whether it be through taking daily medication or dealing with its physical side effects. In her interview, Haset subtly conveyed her frustration at these bodily changes caused by her medication. They make her feel less of a woman because these side effects impact her physical appearance, and they are another type of interruption, which Haset must internalize. But does Haset perceive her illness as disorderly?

Even though these physical changes happened so quickly for her, Haset makes sense of them through conversations with her coworkers who also have hypothyroidism. These discussions allow her to express the emotions she had masked at the time of her diagnosis, helping Haset combine multiple frames of explanation: "[M]y coworkers—most of them, they have this issue.... I was saying here, 'Why am I having [hypothyroidism]?' I—I thought I eat, uh, a good nutrition. I can get everything. Why this come? [sic] This and that. And then, some of the nurses who has that, they explain to me: 'That [sic] a hormone change going on in your body.'" Haset learned from her colleagues that dry hair and uncontrollable weight gain are common side effects of hypothyroidism medication. One coworker shared in detail with Haset her experience with the illness:

My coworker told me her hair is dry, like the— like a dandruff thing is coming. You can see it. It's beautiful, long hair. You can see when she wash [sic] and let it down. You can

see [the dandruff] on her skin. The dryness is showing. That is the only side effect she had.... And then, gain weight. There is no way to control to lose it, to be like the skinny person. To be like skinny. "It's hard," she said. She couldn't get her old weight.... She told me that. Those two things was [sic] hit her bad because of the medicine she say.... So, those kind [sic] of things make me completely hate the medicine. If I get a chance, I mean, if it is another chance, I wish I can stop it and try something else.

Haset openly vents to her colleagues the disruptions brought by her chronic illness. This freedom challenges the Ethiopian cultural notion of pride and biomedical narratives that have been positioned as the dominant form of health narrative. Haset conveys her vulnerability to her coworkers, a majority of whom are from Southeast Asia. Not only is Haset expanding her social networks across interethnic groups through this discourse, but she and her colleagues are also confronting their native culture's stigmatizing notions of chronic illnesses (Uba 1992; Lim 2015; Muecke 1983). When they disclose their experiences with hypothyroidism, Haset and her coworkers find support and learn from each other's stories. These individuals reveal their frustrations with their treatments and how they grapple with different cultural explanations of their illnesses. In essence, Haset and her colleagues create their personal illness narratives from a hybrid of discourses, ranging in cultural knowledge and health expectations. Haset circumnavigates the cultural stigma attached to discussing chronic illnesses through this social interaction, and she counteracts allopathic explanations of her health condition. Haset's physician imposed a biomedical narrative, which restricted Haset from freely revealing her physical and emotional feelings. However, Haset's conversations with her coworkers affirm her illness experiences and perceptions. She inhabits multiple worlds as an immigrant, a woman, and a healthcare worker. Through this mix of discourses, Haset refines her identity in the midst of uncertainty. Her stories are "no longer...secondary.... They have their own primary importance" (Frank 1995, 7). These accounts make her life more orderly by

realigning her body, self, and her "life's map" (Frank 1995, 7).

### **Faith: "God will free me from this illness one day not medicine"**

When Almaz was diagnosed with type 2 diabetes, she was outraged. "How could it be me? I don't eat unhealthy foods?!" exclaimed Almaz before taking a sip from her teacup. Almaz and I were sitting at her dining table and eating breakfast—qinche (bulgur wheat with Ethiopian butter) with moringa tea. At the start of our conversation, Almaz exuded her animated personality. Admittedly, I had some trouble keeping up with Almaz's zeal and fast-paced Amharic. But when we began discussing her illness experience, Almaz's behavior changed. She became shy, fiddling with her teacup's handle and staring at the dining table. It was as if Almaz had morphed into a different person.

Almaz was born in Dessie, Wollo, in northeastern Ethiopia in 1962. Her family moved to Addis Ababa soon afterward, but at six-years old, Almaz was sent to live with Emamaya, a neighborhood mother-figure. As an energetic child, Almaz often got in trouble. Almaz laughingly reminisced, "I just remember getting disciplined a lot! I loved playing, but Emamaya likes peace and quiet." Almaz lived with Emamaya until she graduated from high school. Then, Almaz became an assistant secretary at a military base, which closed when the Tigrayan-led Ethiopian People's Revolutionary Democratic Front overthrew the Derg in 1991. But as an outspoken critic of both groups, Almaz had to escape to Sudan. "I had the chance to go elsewhere [i.e. Europe or the U.S.] from Sudan, but I didn't want to wait another six months or undertake a dangerous journey," explained Almaz. She returned to Ethiopia, where she continued to openly express her political views. Almaz soon became a political target. So with the support of her friends, she left for Cairo, Egypt, in March of 1995.

Almaz persevered despite these circumstances. In Cairo, she worked as a nanny for a wealthy family. Similar to Genet, Almaz fondly reminisced about her time in Egypt, raising two boys. "We would go on vacations

together.... We relaxed and played [together].... It was a good time," recounted Almaz with a big smile. The children's parents had a friend who worked at the Egyptian Embassy in Washington, D.C. When they overheard Almaz express her desire to immigrate to the U.S., the parents helped her fulfill her desire with the embassy's support. Almaz arrived in D.C. in March 1998, where she reconnected with childhood friends and lived with them in a small apartment while working various service jobs. She got married in 2003 but decided to not have kids for personal reasons. Two years later, Almaz enrolled in CNA courses, and she was employed at a senior living facility, where she still works today. Almaz's work makes her aware of critical health issues, but she did not expect them to personally affect her.

Almaz was appalled when she was diagnosed with type 2 diabetes. Her biological mother had diabetes although Almaz does not know which type. Almaz felt targeted by her diagnosis, and she even refused to take her medication at first: "The doctor gave me fifteen days [to start taking medication on my own], and then she made me start taking it." Almaz did not think her unusually high water intake indicated that she had diabetes, but her abnormally high blood glucose levels confirmed that she had the disease. Almaz's denial was further reinforced by her husband's reaction. "He denied all diagnosis!" exclaimed Almaz with a nervous laugh. It has been almost ten years since Almaz's diagnosis. But to this day, she still does not accept her health status, and she has altered her lifestyle minimally in response to her illness. Almaz admitted, "I exercise a little bit, but really my mind hasn't fully accepted that I have diabetes." Why does Almaz react this way?

First, Almaz does not feel physical pain or symptoms from her illness. She claimed, "I don't feel anything. Sometimes, I eat white bread and cake.... People have to remind me that I have to monitor what I eat." In fact, Almaz's untroubled approach is reinforced by her refusal to take recommended prescriptions. Almaz is given medication for high cholesterol in addition to insulin, but she stopped taking the former because she did not deem it necessary. Almaz stands by her own actions, asserting that

"medicine extends your life, but it does not end your illness." Thus, Almaz trusts that prayer is more effective in dealing with her chronic health conditions. Almaz's goal is not to live a functional life with diabetes but to enjoy one without it. She believes that sickness is a spiritual warfare: "The devil wants you to take medicine, which hurts another organ. And then, the medication makes you sick, so you have to take another prescription." Almaz must trust God to win this war.

Additionally, Almaz believes her illness is a temporary fight. As a devout Ethiopian Orthodox, she trusts that God will bless her with "good health" as a result of her faith: "I view good health as a blessing from God. Bad health and sickness are from the devil.... I believe that God will free me from this illness one day not medicine." For Almaz, "good health" is ultimately being healed from type 2 diabetes, but until then, small health improvements are signs that God is working in her favor. Almaz admitted that there have been times when she did not take proper care of her diet, but God blessed her with good health results—an indication that Almaz was not meant to get diabetes. Almaz shared that she is so strongly rooted in this belief that "I don't take the [diabetes] medicine regularly.... Sometimes, I skip for three or four days. I forget other times, or during [Orthodox] fasts, I don't take it at all. It's God who has helped me so far." By focusing on Almaz's committed faith in God, I am not suggesting that Almaz is irresponsible toward her health. I observed her taking her medication on several occasions along with tsebel (holy water). Until she is healed, Almaz prioritizes giving gratitude to God to ensure the arrival of this victorious day. Faith is believing things that cannot be seen, and it empowers Almaz over biomedical illness narratives.

Similar to Haset, Almaz views her diagnosis as an unanticipated event. She was taking care of her physical health by eating nutritious foods and of her spiritual well-being through continuous fasting and prayer. However, Almaz was unexpectedly diagnosed with type 2 diabetes and high cholesterol. This lack of a clear origin in Almaz's illness story contributes to a sense of a disorderly future. To create stability, Almaz believes she should not rely on biomedical interventions. Rather, God will heal

her of her health issues in response to her devotion to Him. Almaz's reaction to her diagnosis also echoes the tensions between biomedical and lay narratives. Almaz's resistance toward taking her prescriptions demonstrates her refusal to accept the medical interpretation of her body and health. She does not believe the numbers that showed she has high blood glucose levels. Instead, she trusts her physical senses. This defiance illustrates Almaz's struggle to stress the primacy of her perspective. While crafting and sharing her story, Almaz takes command over this unexpected change in her life. Her narrative is a meta-control over the challenges she has endured (Frank 1995). In this process of narration, Almaz is making sense of her experiences, arranging them in a way that is true to herself. Storytelling allows Almaz to generate order and to exert power in her life.

Unlike Haset, Almaz expresses optimism for her future health. Almaz's trust in God motivates her to believe that one day she will no longer live with type 2 diabetes. But until she is healed, Almaz must continue to demonstrate her faithfulness to God to overcome this illness. As a devout Orthodox Christian, Almaz follows the characteristics of individuals blessed by God in the Bible because of their commitment to Him. Such attributes are as simple as Almaz giving praise to God. During her interview, Almaz would interrupt our conversation when she discussed God's grace in her life, pointing her palms to the ceiling with her arms bent and saying Amharic blessings to God. This act of devotion is a way for Almaz to attain control in the midst of this life event. Although Almaz cannot immediately end the suffering brought by diabetes, she immerses herself in her spiritual beliefs. The end result may not come quickly, but this hope is what pushes Almaz to continue enduring the interruptions caused by her chronic illness. It is a relief, which stimulates determination and not defeat. This determination and optimism points to how illness does not deter her. Almaz's diagnosis reinforces her faith in God, motivating her to develop a stronger relationship with Him. Ultimately, Almaz emphasizes the significance of faith and hope, two beliefs that can help sick people endure the physiological, emotional, and psychological challenges of illness.

## Conclusion: "A good conversation is better than a good bed"

"A good conversation is better than a good bed" (መልካም ንግግር ከመልካም አልጋ ይበልጣል።) is an Amharic proverb that expresses how a pleasant discussion provides better comfort than adequate physical rest. Throughout my fieldwork, I noticed this sense of ease among my interlocutors as they shared their migration and illness narratives. I was in fact a bit surprised to observe my interviewees' openness in telling their stories, but this experience showed me the liberating and constraining elements of storytelling and how they can provide clarity on complicated issues yet not resolve problems from the past.

The goal of this article is to convey these complex features of narratives and to show how chronically ill Ethiopian immigrant women are active agents in shaping their stories. Genet, Haset, and Almaz find their own ways to assert control over their bodies and lives despite facing the pressures of the Ethiopian cultural notion of pride. For Genet, this declaration means confronting the cultural stigma of diabetes and personally disclosing her health status to her family. In response to her frustrating diagnosis, Haset turns to her coworkers, who help her deal with hypothyroidism by openly sharing their interpretations and experiences with this disease. Almaz casts her fears aside and places her faith in God, believing that He will heal her of diabetes. Each of these accounts make visible the multiple worlds that chronically ill Ethiopian immigrant women inhabit and that foster new meanings on their illness experiences.

I engage with illness narratives through a prism of personal, cultural, and religious ideas throughout this article because this approach conveys an intimate glimpse into my interlocutors' everyday lived realities. These perspectives humanize my interviewees' stories by recognizing these individuals' manifold experiences, multiple identities, and continually developing selves. As German literature scholar Jack Zipes (2012, 126) writes, "[s]tories are effective and we cannot do without them because they shape the way we live.... [W]e have an ethical responsibility to seek out those

stories that benefit societies and provide a means for understanding the truths in our lives.” The narratives I have collected represent a few of the plethora of stories that highlight the often-overlooked daily realities of immigrant women around the world. As a budding anthropologist and a daughter of immigrants, I aspire to continue capturing these narratives to better understand the complex challenges that immigrant women experience as they rebuild their lives and assert control over their bodies in unfamiliar countries.

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# Applications of Biopower to NGO-Donor Partnerships for HIV Prevention in Jordan

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## ABSTRACT

NGOs serving marginalized groups in the developing world often lie under heavy donor influence, so they must toe the line between compliance with and resistance against their funders to best promote the well-being of their beneficiaries. Jordanian health NGOs have grappled with these power dynamics since the 1990s when donor countries began pouring money into Jordan's private sector as part of structural adjustment. I use ethnographic data from a Jordanian HIV prevention NGO to analyze how Foucault's (1978) theory of biopower applies to international NGO-donor relationships. I argue that the international aid chain transforms NGO staff and the populations they serve into biological subjects expected to adhere to norms set by American and European donors. Biopower manifests differently depending on donor approaches to project implementation, monitoring, and evaluation.

**Keywords:** biopower; Jordan; HIV/AIDS; NGOs

understood through biopower, defined by Michel Foucault (1978) as a technology of power in which the governed population becomes a biological product that governing actors use to reap desired outcomes. Because funding becomes the principal instrument of power over public health NGOs, donor policies shape the programming these NGOs can provide and the populations they can serve. The specific dynamics of power exertion vary by donor, and Majhul has learned to navigate this terrain while also promoting the long-term well-being of its beneficiaries.

In this context, the term “beneficiaries” describes the population served by Majhul. While terms like “client” and “partner” could be substituted, the staff of both Majhul and its donors exclusively used the term “beneficiary” during my research period. “Client” and “partner” would connote that the populations served have a dialectic relationship with Majhul in which they hold sway over the services they receive. “Beneficiary” loses this connotation and suggests only that Majhul benefits these populations.

In this article, I draw on my fieldwork at Majhul to reveal how donor-NGO relations in the field of HIV prevention provide a window into the everyday workings of biopower. I elucidate how Majhul’s barriers to successful project implementation are interwoven with the at times overbearing norms set by donors, which Majhul navigates by pairing compliance with advocacy. I then highlight case studies from Majhul’s relationships with two of its most important international funders. I contrast these relationships, using each case study as an example of how biopower underlies important aspects of NGO-donor partnerships.

## Methodology

I first visited Majhul in the summer of 2018, when I met its manager while exploring Jordan’s HIV prevention movement. I returned in the summer of 2019 to conduct ten weeks of ethnographic fieldwork. Prior research has relied on quantitative data to describe HIV in Jordan (Al-Khasawneh et al. 2012; Al-Khasawneh et al. 2014; Alkaiyat et al. 2014; Marnicio 2016; Nawafleh, Francis, and Chapman 2005). Ethnographic research provides a window into

While conducting ethnographic fieldwork at a Jordanian HIV prevention NGO, which I will call Majhul, I listened in on a video call between the NGO’s staff and a representative from a British donor organization. The donor representative spoke entirely in English, so Majhul’s one English-speaking employee was responsible for communicating with him. Majhul’s manager, who was on the call but did not speak English, followed along as best as he could. The donor representative expressed that his organization wanted to give Majhul a grant. He then asked for various English-language documents, and he explained that representatives from his organization would travel to Jordan soon to visit Majhul and talk with its staff. He emphasized that his organization would aim to work with Majhul on improving its services over a prolonged period, so he would visit Majhul many times in the future to assess their long-term progress.

Towards the end of the call, Majhul’s English-speaking employee told the representative that they would email him all of the documents he requested and send him their goals for improvement by the end of September. The representative responded that this would be okay, but it would cause a time crunch, as he must visit Majhul before the end of the calendar year. Majhul’s manager wrapped up the call by saying in broken English that he did not want the grantor to come to Jordan and tell Majhul how to do its job. Rather, he hopes that Majhul’s staff will be able to tell the donor what Majhul needs. The donor representative agreed with Majhul’s manager, then the call ended.

This vignette and many others from Majhul’s relationships with its donors reveal how many of the funding challenges facing public health NGOs in the developing world can be

the everyday practices that define donor-NGO relationships, the power structures NGO staff and beneficiaries must navigate, and how these structures exemplify biopower as a theoretical explanation for international aid.

The research presented here draws on over 360 hours of participant observation at Majhul, as well as analysis of Majhul's printed and online media about the needs of its beneficiaries. I collected data from nearly all of the settings Majhul's staff work in, including its health center, its administrative floor, and other conference centers and NGO sites across Jordan. I also conducted semi-structured interviews with Majhul's employees. I sought to interview a wide range of part-time and full-time staff, so I asked nearly every staff member I met. Ultimately, I was able to interview six of the approximately fourteen full-time and part-time staff members. All interviewees read through an informed consent script and orally expressed consent prior to their interview.

I triangulated the participant observation, staff interviews, and media I collected to explore Majhul's relationship with foreign donors, tracing how power flowed from donors through Majhul to its staff and beneficiaries in often multifaceted and unexpected ways. I found that donor use of earmarked funding and upward accountability compelled Majhul to follow donor norms when providing health services to its beneficiaries; this exemplifies the presence of biopower in NGO-donor relationships.

Some of the limitations of my study include the limited availability of some of Majhul's staff, the reluctance of some staff members to agree to be interviewed, and temporal constraints on my participant observation period. I had limited opportunities to engage with some staff members because many staff work part time, staff often work from outside of Majhul's main offices, and some staff left Majhul during my research period. Additionally, Jordan has a history of limiting freedom of expression, so staff were likely cautious about making public remarks that could be viewed as critical of the government even though my research was not of an overtly political nature (Wiktorowicz 2002). As an American researcher, I was advantaged in that I could position myself as separate from

the Jordanian government. However, I am similar to many of Majhul's donors in that I'm American and English-speaking, so Majhul's management may have viewed my research as a way to recruit donors. I emphasized that participation in my study was not linked to financial compensation, but Majhul's staff may have nevertheless regulated their behavior and comments around me to portray Majhul in a positive light.

## **Global Health Funding in the Late 20th and Early 21st Centuries**

The current relationships between Arab NGOs and their international donors were shaped by the World Bank's structural adjustment programs of the 1980s and 1990s. Structural adjustment exacerbated inequality throughout the Arab world, simultaneously increasing the need for NGOs and sparking popular distrust of intergovernmental aid. Although Arab countries were widely touted by the World Bank as "success stories," many of these countries were forced to cut their social safety nets, pushing much of their populations into abject poverty (El-Said and Harrigan 2014). Healthcare increasingly came to be seen as a commodity rather than a right. It was privatized and user fees were introduced, as in many other countries across the developing world (Basilico et al. 2013; Packard 2016).

The World Bank sought to reform Jordan's health system through privatization (Quinn et al. 2001). It removed government responsibility for public health and shifted power over the health sectors towards private actors, chief among them foreign donors. This led to Jordan's private healthcare sector ballooning; the number of private hospital beds in the country rose by 28% between 1988 and 1994 (Kumaranayake 1998). At the same time, it reversed many of the Jordanian government's successes in public health from the 1980s, hitting Jordan's marginalized and vulnerable populations the hardest (Baylouny 2008; DeJong 1995). It therefore set the stage for the creation of NGOs like Majhul, which are devoted to Jordan's vulnerable populations.

The World Bank was the largest distributor of global health funding worldwide by the early 2000s (Packard 2016). At this time, it began to

push for additional monitoring of and grassroots accountability for the initiatives it funded, encouraging a vision of “health investments” worldwide. Health investment became one of the dominant paradigms of global health and development (Packard 2016, 287).

The early 2000s also saw a massive, unprecedented surge in global support for HIV/AIDS prevention. This support culminated in the launch of the Global Fund, a key donor for Jordan’s HIV prevention NGOs. Many of the Global Fund’s core values align with those of the World Bank. For instance, as Packard (2016) explains, the Global Fund usually mandates that local NGOs and other private actors be stakeholders in its grants, and it has distinguished itself through its use of extensive monitoring and evaluation to demand accountability from its grantees. Packard (2016) argues that the Global Fund’s neglect of the existing health systems in countries it served and its distrust of local governments furthered some of the consequences of structural adjustment: governments continued to lose power over healthcare to the private sector, and health became increasingly medicalized and commodified.

The Global Fund’s emphasis on HIV funding has also faced criticism for propagating “HIV exceptionalism”: the notion that HIV is an exceptional health crisis requiring a funding stream separate from the rest of global aid. This has tended to create “silos” of funding, divorcing HIV from related social and medical services. HIV exceptionalism has had at best a mixed and controversial effect on health systems across Africa (Benton 2015; Grépin 2012; Nguyen 2010). I found through my research at Majhul that HIV exceptionalism has also challenged Jordanian NGOs by creating silos of HIV prevention funds separate from funding for related issues like human rights and poverty prevention in Jordan.

HIV exceptionalism was one of many recent controversies in the provision of international AIDS funding. For instance, UNAIDS declared in 2015 that international funding could “end HIV by 2030.” Das and Horton (2018) argue that this declaration set the stage for global complacency around the HIV pandemic, as it led

governments and NGOs to erroneously believe that the current international HIV/AIDS prevention efforts are enough to stop HIV’s spread. Consequently, global HIV funding decreased even as the global population living with HIV grew. According to Majhul’s director, the “end HIV by 2030” declaration decreased both foreign and domestic donors’ willingness to prioritize HIV prevention in Jordan. UNAIDS also promoted a problematic “post-AIDS” discourse, with catchphrases like “zero new HIV infections, zero discrimination, and zero AIDS-related deaths” and the “90-90-90” campaign (90% diagnosed; 90% on treatment; 90% virally suppressed). This discourse oversimplifies the ongoing challenges in global HIV prevention and treatment, as it neglects the diversity of lived experiences that people living with HIV face. Therefore, it fails to acknowledge that HIV-related discrimination and access to HIV diagnosis and treatment vary greatly by region and demographic group, so a “post-AIDS” world remains far out of reach for many (Walker 2017).

## **Donor Policies as they Relate to HIV Prevention**

American and European donors often set norms around global development that NGOs in developing countries must follow in order to receive funds, with funding conditional on NGO behavior (Bornstein 2006; Ebrahim 2002; Mueller-Hirth 2012; Reith 2010; Wallace, Bornstein, and Chapman 2007). One of the most important of these norms is the rational management approach, a “business model” for development described by Tina Wallace, Lisa Bornstein, and Jennifer Chapman (2007). They explain that according to rational management theory, development progress is marked by the completion of specific steps that lead to the achievement of larger goals when followed linearly. Progress is therefore controlled, predictable, and trackable by monitoring success indicators through a “logical framework,” a document that outlines the project’s goals, timetables, and indicators of success. This framework is drawn up before the project’s inception, and then closely followed throughout the project. Wallace, Bornstein, and Chapman (2007) suggest that rational management is attractive to donors because it

enables them to easily track the effectiveness of their donations via monitoring and evaluation. Through the monitoring of success indicators, donors align with the World Bank's vision of "health investments"; donations are perceived not as charity but as investments in foreign "implementing partner" NGOs. Return on these "investments" is assessed through fulfillment of success indicators.

Wallace, Bornstein, and Chapman (2007) are highly critical of the donor focus on upward reporting and accountability that comes alongside rational management. They argue that reporting within the logical framework is onerous and time-intensive, as reports must often be written in English, reporting structures are not standardized among donors, and donor management styles and reporting demands are ever-changing. Hummelbrunner (2010) echoes many of their arguments, attacking logical frameworks' tendency to oversimplify objectives, decrease project flexibility, and result in a form of "tunnel vision" where the sole focus of donors and implementing partners alike is to achieve predetermined results in order to deliver a "return" on the "investments" donors make. Wallace, Bornstein, and Chapman's (2007) and Hummelbrunner's (2010) findings are reflected in various ethnographic studies of African NGOs (see Bornstein 2006; Mueller-Hirth 2012; Porter 2003; Nguyen 2010; Reith 2010).

## **HIV Prevention in Jordan**

Intense stigma and decades of neglect have limited the body of research on HIV in Jordan. Only eight social and behavioral studies had been published on HIV in Jordan as of 2012, and these studies were, for the most part, confined to specific, ungeneralizable datasets (Al-Khasawneh et al. 2012). Since then, only three more academic articles and one working paper have been released. These studies predominantly use ethnography to explore perceptions of HIV in various subsets of the Jordanian public. For instance, Al-Khasawneh et al. published two studies about Jordanians' knowledge of and attitudes towards HIV. The first (2013) study focuses on Jordanian youth ages 14-25, while the second (2014) focuses on students and staff at two Jordanian universities. These studies are complemented by an article

on HIV perceptions among Jordanian men who have sex with men (MSM) (Alkaiyat et al. 2014) and a working paper about HIV education for Jordan's youth (Marnicio 2016). No scholarly ethnographies of HIV prevention NGOs in Jordan have ever been published.

HIV data collected by the Jordanian government and by Jordanian NGOs, who usually work with or under the surveillance of the government, is often marred by bias. This bias is apparent in Jordan's Global AIDS Response Progress Reports, which synthesize various government-sponsored studies on HIV. The most recent progress report cites data with small or skewed sample sizes and selectively presents findings to portray the government in a favorable light (Global AIDS Response Progress Reporting: Country Progress Report 2014).

Larger-scale reviews of HIV across the Middle East and North Africa (MENA) region produce conflicting results. While major discrepancies exist in studies regarding HIV prevalence and risk behaviors in different populations, cities, and countries in MENA, most scholars and institutions worldwide agree that MENA is one of the only world regions where rates of HIV transmission and death from AIDS continue to increase (Abu-Raddad et al. 2010; Mumtaz, Riedner, and Abu-Raddad 2014).

My research complements the existing literature by using ethnography to highlight the everyday practices of an NGO at the forefront of HIV prevention and the work its staff must do to navigate the sometimes-conflicting norms established by international donors. I use case studies from Majhul's relationships with two of its donors to reveal how Foucauldian biopower plays a role in the imposition of donor norms.

## **Majhul's Structure, Mission, Values, and Programming**

Majhul was founded with the mission to support the health of Jordan's marginalized and vulnerable at both the individual and the population level. It provides a web of support services focused upon HIV prevention, catering its services to "key populations" (KPs) that are determined by Majhul and its donors to be at high risk for HIV transmission. The staff of Majhul and its donors use the term "KPs" to

define demographic groups that they expect their beneficiaries to fit into. Biopower manifests in the use of this term, as individuals only join "KPs" when they meet socio-biological criteria such as gender (female), sexuality (MSM), or disease (HIV-positive). Through the lens of biopower, the bodies of individuals with these traits are subject to surveillance and management. Majhul's KPs include refugee women, gay men, sex workers, injecting drug users, and people living with HIV.

Majhul's ideology centers on the belief that structural violence (Farmer 2003) in the form of unemployment, stigma, and poverty undergirds KPs' struggles to achieve health equity. Majhul's management thus believe that a focus on the social context of HIV transmission better enables them to serve KPs. This focus also protects Majhul from stigmatization as a gay men's health center, thus helping it survive in an unforgiving cultural environment. Most of the health workers I interviewed cited stigma towards KPs as a major challenge for Majhul.

Like all Jordanian NGOs, Majhul must contend with the Jordanian government, which uses various laws and policies to constrain the agency of Jordanian civil society (Wiktorowicz 2002). Majhul positions itself as a resource for the Jordanian Ministry of Health's National Program to Combat AIDS, where members of its leadership used to work. Therefore, it partially acquiesces to government power, sacrificing some of its autonomy. Yet, it also gains power by capitalizing on the government's resources and legitimacy, as both donors and government bureaucrats are more likely to support NGOs that have established ties with the government.

Majhul emphasizes the links between HIV prevention and the rights of KPs, aligning itself with a growing body of social theory on the linkages between health, development, and human rights (Mann et al. 1994; Uvin 2004). Majhul uses its autonomy as a government-affiliated NGO to set itself apart from the predominant cultural discourse that ignores or disavows the rights of KPs. Many of Majhul's services are meant to help KPs access their social and economic rights, and Majhul works closely with partner NGOs to provide beneficiaries with comprehensive support.

## Biopower and Majhul's Relationships with Donors

Foucault (1978) describes biopower as the process by which governing bodies exert power over individuals and populations by defining and promoting traits that constitute a "model" body while seeking to "correct" any deviation from these traits. Through this lens, funding becomes the principal instrument of power over Majhul. International donors selectively allocate, monitor, and manage funds, while the Jordanian government either allows or restricts the transfer of funds between donors and NGOs. International donors and the Jordanian government set norms that Majhul must follow to maintain funding. They therefore create certain types of biological "subjects": bodies subject to their scrutiny and under pressure to conform with their demands. For instance, they establish norms for a "model health worker" or "model beneficiary" and seek to correct deviation from these norms.

International donors and the Jordanian government each compel Majhul to follow their own norms, which often conflict with one another. International donors often base their norms in British and American corporate culture, enshrining the English language, European ethical codes, and the rational management approach to development, while the Jordanian government tends to base its norms in traditional Arab culture, emphasizing chastity, heteronormativity, family life, and abstinence from drug use.

Majhul struggles to fit the norms mandated by international donors and at times finds itself forced to change or selectively prioritize its KPs in order to align with donor definitions of a "target population" and thus sustain funding. Likewise, Majhul often alters its programming in order to fit donor norms regarding the traits that should be promoted in KPs. For instance, Majhul diverted resources from its existing HIV prevention campaigns to host violence-prevention workshops for refugee women because Majhul had received a foreign grant focused on the ties between HIV, displacement, and gender-based violence. By treating Majhul's staff and beneficiaries as biological subjects who must conform to Anglo-American norms,

international donors sometimes bar Majhul from meeting the biosocial needs of the populations it serves. Therefore, excess enforcement of donor norms is at times violent in that it limits vulnerable populations' access to health services and the resultant health outcomes for these populations.

Power and resistance are closely related. According to Foucault (1978), power and resistance are mutually constitutive; points of resistance inevitably arise throughout a social system in response to the exertion of power. Lila Abu-Lughod (1990) defines power in terms of resistance, suggesting that resistance occurs at the intersection of overlapping spheres of power. Along these lines, Majhul resists the power exerted upon it by the Jordanian government and international funders by simultaneously maintaining healthy relationships with each of these groups, using its management's personal ties to government ministries and donor organizations as a source of power. Another way Majhul resists is through advocacy campaigns aimed at reducing stigma and communicating its core beliefs. These campaigns include the production and distribution of media about KPs, training on HIV transmission and prevention for donors, bureaucrats, and other community members, and meetings with Jordanian cultural, political, and religious leaders. Through these campaigns, Majhul resists government and donor discourse that promotes a siloed, medicalized approach to HIV prevention by instead highlighting the links between HIV, structural violence, health, and human rights.

The dynamics of these relationships between funding, power, and advocacy are illustrated well by two projects Majhul was implementing, at times simultaneously, during my fieldwork period. One of these projects was funded by a European nonprofit, which I will call HELISOC, while the other was funded by a Global Fund affiliate. In the rest of this paper, I use case studies from each of these projects to illuminate and compare manifestations of biopower in NGO-donor partnerships.

### **Case Study I: The HELISOC Grant**

HELISOC has a branch in Jordan that provides aid to Syrian refugees and other vulnerable

populations. As part of its gender-based violence (GBV) prevention campaign, the HELISOC Jordan office offered Majhul funding to help pay the salaries of its employees and hire new staff. In return, HELISOC required Majhul to host GBV education workshops and support groups. Majhul served as a valuable implementing partner for HELISOC because it had connections within the communities HELISOC was trying to reach, as many of Majhul's KPs disproportionately face GBV.

HELISOC set primarily quantitative targets for each KP it wanted Majhul to reach, and then Majhul hosted GBV workshops for the targeted populations. Many KP members sought out additional services from Majhul after attending the workshops. Majhul then referred some of these attendees back to HELISOC, thus helping HELISOC Jordan reach the numerical targets set by its European donors. In this sense, HELISOC Jordan paid Majhul as a subcontractor to bring in the KPs HELISOC needed. Majhul's funding was contingent on the adoption of HELISOC's qualifiers of success and the referral of desired KP members to HELISOC Jordan. HELISOC and Majhul called the referred members "beneficiaries," presuming that they could benefit from the provided services. Yet, in addition to being presumed beneficiaries of HELISOC and Majhul, the referred populations became products that Majhul provided to HELISOC in exchange for funding.

The Majhul-HELISOC partnership required Majhul's staff to work within the HELISOC case management framework. "Case management" was a term used by HELISOC to describe the collection of beneficiary information via interviews and the subsequent linkage of beneficiaries to social support services. I sat in on a case management training session that HELISOC hosted at Majhul. A social worker who plays a role at Majhul analogous to case management attended the training and was asked to participate in a mock case management interview. The Majhul employee was criticized by HELISOC's staff for asking interview questions not directly related to GBV.

This vignette elucidates how biopower manifested in HELISOC's relationship with Majhul. While the HELISOC training was not mandatory for Majhul staff, the structural

power (Closser 2010) that HELISOC held as a source of funding put pressure on Majhul's social worker to attend. During the training, HELISOC portrayed the "model beneficiary" as a case where GBV can be assessed and managed separately from the beneficiary's other characteristics and challenges. In doing this, HELISOC imposed a norm that workers should only ask about the aspects of a beneficiary's life that directly relate to GBV. This norm parallels HIV exceptionalism in that it views GBV in a silo separate from other health issues and socioeconomic contexts.

After the training, the Majhul employee told her coworker about her mock interview and the HELISOC workers' critique of it. They both seemed upset by HELISOC's ignorance of how various aspects of beneficiaries' lives interrelate and are therefore important to GBV prevention. They were frustrated with the HELISOC case managers' product-oriented approach to social work, in which the product was defined as a beneficiary who had been "corrected" of their struggles with GBV via the HELISOC case management framework. Beneficiaries who had been helped in other ways were not valued as products. This strict definition of the "model beneficiary" clashed with Majhul's emphasis on the links between human rights, development, and health.

HELISOC's management sought to generate "model beneficiaries" by subjecting KPs at Majhul to the case management framework. They offered financial incentives to beneficiaries who Majhul referred directly to HELISOC, and then they assigned each of these beneficiaries a HELISOC case manager who displaced the role of Majhul's social work staff. Foucauldian biopower manifested in HELISOC's product-oriented approach to social work, as HELISOC worked through Majhul to define and promote ideal traits in biological subjects (beneficiaries) with the intent to create biological products (model beneficiaries) that fit a specific, predetermined norm ("corrected" of GBV through the HELISOC case management framework). HELISOC management also sought to transform Majhul's social workers into "model case managers." They posted flyers depicting the "proper" way to counsel a beneficiary according to the case management

framework on the walls of Majhul's social work offices. Furthermore, they imposed an English-language referral system on Majhul, even though, for the most part, neither Majhul's nor HELISOC's staff were proficient in English. Therefore, inputting beneficiary information into the English-language HELISOC referral forms proved to be a cumbersome task for everyone involved.

Majhul's staff resisted HELISOC's power by quietly asserting that their focus on structural violence, human rights, and the social determinants of health served beneficiaries better than the HELISOC case management framework. For instance, the Majhul employee in the prior vignette resisted by suggesting that various aspects of beneficiaries' lives interrelate, thus drawing criticism from HELISOC's staff. Rather than backing down under this criticism, she asserted that she had been right in asking a wide variety of questions. Majhul leadership also gently pushed back against HELISOC through advocacy campaigns. These tensions over the terms of engagement were recurrent throughout Majhul's relationships with many of its other donors.

The HELISOC grant ended in late June, causing a dramatic reduction in Majhul's funding. As a result, Majhul's staff morale and capability to host programming for beneficiaries were severely hurt. Four of Majhul's seven full-time employees either quit, finished their contracts, or were laid off, and Majhul ended all of its GBV-related programming. Majhul's turbulent relationship with HELISOC is indicative of how its partnerships are constantly shifting as funders' priorities change. Majhul's management seemed cognizant of their vulnerability to the decisions of HELISOC and other foreign donors. In the words of Majhul's executive officer, "As you know, my project is maybe finished at month six, the HELISOC project. We don't decide whether the project is renewed or not."

I shared a particularly heart-wrenching moment with Majhul's manager in mid-July, a few weeks after the HELISOC funding had been cut. While we were talking, he told me out of the blue, "we're trying to keep Majhul open despite the challenges and difficulties." While HELISOC's short-term, heavily earmarked grant

had allowed Majhul to expand its programming and delve into GBV prevention for a brief period, its abrupt termination resulted in Majhul losing staff and beneficiaries losing access to services almost overnight. By subjecting Majhul's staff and beneficiaries to strict norms that defined a "model" product of the GBV grant, HELISOC had enforced a brittle, heavily siloed care system at Majhul. This system collapsed as soon as the flow of funding from HELISOC earmarked for GBV prevention dried up.

The Majhul-HELISOC partnership and its abrupt end illustrates biopower's presence in NGO-donor relationships. Through its GBV prevention grant, HELISOC established a system in which Majhul's beneficiaries became a biological product provided to HELISOC in exchange for funding. HELISOC enforced a rigid norm of the "model beneficiary" product that Majhul should provide by seeking specifically to correct beneficiary challenges with GBV via a heavily siloed case management framework. Biopower deconstructs the process by which HELISOC defined its biological subjects as "target populations," the traits it sought to promote in those subjects as GBV-prevention strategies, and the biological products it sought to create as "model beneficiaries." Although Majhul's staff resisted these norms, HELISOC's power came to define Majhul's operations to the point that Majhul's programming all but collapsed when HELISOC left.

## **Case Study II: The Global Fund Grant**

A different genre of international donors seeks to check the negative impacts of power imbalances in NGO-donor partnerships by empowering local populations to self-advocate. In doing this, they make NGO workers into a new type of biological subject by defining their return on investments not only in terms of "beneficiaries" reached but also in terms of grassroots research and advocacy.

One of these donors is currently working through the Global Fund to provide Majhul with a grant for advocacy for and research on populations at risk of HIV transmission. Instead of being earmarked for providing specific services to KPs, this grant has the overarching

mandate to help Majhul advocate for the programming necessary to stop HIV's spread, thus increasing the sustainability of Majhul's full range of services. The Global Fund grant more closely aligns with Majhul's mission than the HELISOC grant, as it trades in the siloed approaches of HELISOC and the World Bank for a holistic approach that directly addresses the rights of KPs; its mission statement includes the reduction of "human rights-related barriers" to AIDS prevention. The grant funds two lines of work: advocacy for the rights of KPs and research on the barriers KPs face to accessing health services. It therefore measures success in terms of the quality of Majhul's advocacy programs and the body of research Majhul produces on its KPs.

By funding advocacy work, the Global Fund grant empowers and encourages Majhul to resist its other donors. I saw this dynamic in action when I attended a Majhul training session funded by the grant. The training's target audience was management from Majhul's partner organizations, including HELISOC. Its goal was to shed light on the various ways in which HIV ties into social issues important to donors. Majhul's manager centered the training's afternoon workshop on the links between structural violence, human rights abuses, and HIV transmission. He received resistance from some of the more conservative audience members, which he successfully worked through while avoiding confrontation and maintaining his emphasis on the rights of KPs. For instance, a man in the audience suggested that sex with foreigners may be the principal cause of HIV infections among Jordanians. Majhul's manager did not say that the man was wrong, but he instead insinuated that Jordanians must be having lots of sex with foreigners for this to be a principal cause. This discourse indicates that Majhul's manager held a degree of power over donors who attended the training session, as he could push back against the audience's resistance to points that he made. He could therefore engage the donors who attended in a dialogue about Majhul's values and priorities.

Majhul's manager incorporated the importance of health as a human right by asserting that stigma impedes the right to health of sex workers, MSM, and people living

with HIV. He also told the audience that not all gay men have sex with other men, and he explained how structural violence puts women at a greater risk than men of contracting HIV. By making these points, he argued that HIV transmission is more closely linked to structural violence and human rights violations than to individual promiscuity or poor decision-making. In emphasizing the links between marginalization, structural violence, and HIV transmission, Majhul's manager resisted the siloed approach to health and development that organizations like HELISOC and the World Bank have used. The training was at heart an attempt by Majhul's management to increase the propensity of donors focused on gender equity, social welfare, and human rights to fund a center dedicated to HIV prevention.

The Global Fund grant also called for Majhul's staff to conduct original research on their KPs. Many donors, including HELISOC, collected both quantitative and qualitative data on Majhul's KPs, but the Global Fund grant was unique in that it gave Majhul the power and responsibility to conduct research on its own terms. Majhul used the grant to conduct four focus groups in its drop-in center, each one for a different KP. One of Majhul's employees explained to me that Majhul would use the data from the focus groups to write reports for the Global Fund about the barriers KPs and other marginalized populations face to accessing services with the ultimate goal of making Majhul's services more accessible. Majhul recruited a lawyer with a specialty in Jordanian HIV law and a woman who had previously worked with Majhul and the National Program to Combat AIDS to help with the focus groups. Majhul depended on its network of outreach workers to recruit participants for the groups.

The Global Fund shifted the balance of power towards Majhul throughout the research process. For instance, Majhul did not submit its concept note for the focus groups until after it had conducted them. A concept note is an abridged grant proposal summarizing the proposed project, so it's usually one of the first steps of the logical framework. Since Majhul didn't submit the concept note until after it had used Global Fund grant money to host the focus groups, the Global Fund must have

entrusted Majhul with some funding when the research plan was still malleable. This flexibility empowered Majhul's staff to run the focus groups how they thought best instead of strictly adhering to a pre-agreed upon logical framework.

Majhul's staff not only collected data during the focus groups but also framed research questions, developed a methodology, and drew conclusions from their results. There was no Global Fund representative monitoring the groups; I was the one non-Jordanian present. The Global Fund received only the final products of the research Majhul conducted. Majhul's staff were therefore empowered to determine which findings from the focus groups were pertinent to report to the Global Fund. However, Majhul lacked complete autonomy in the reporting process, as the Global Fund required that third party mapping consultants help consolidate the final reports.

While this partial ownership over the knowledge generation process marked a shift in power towards Majhul's staff, it also turned Majhul's staff and beneficiaries into a new type of biological subject. The Global Fund set norms regarding a "model" beneficiary and "model" staff member when it allocated grant money to grassroots research on Majhul's beneficiaries. The "model" beneficiary provided compelling testimony about the barriers they faced to accessing health services, while the "model" staff member actively solicited this testimony with the intention to generate research that could be used for future advocacy and program development. The Global Fund therefore paralleled HELISOC in that it defined and promoted ideal traits in biological subjects (Majhul's beneficiaries and staff) with the intent to create biological products ("model" beneficiaries and staff) that fit a norm (autonomously facilitating the research process) which served the Global Fund's goals. However, the Global Fund differed from HELISOC in that grassroots empowerment and ownership were key criteria of its biological subjectivity, so it allowed Majhul's staff more freedom to choose how they would create or become model biological subjects.

The Global Fund had a strong incentive to make Majhul's staff into partially autonomous

researchers: past ethnographic research indicates that qualitative data quality improves when “insiders” from the local community facilitate social science research. Insiders often can frame questions in a more culturally sensitive manner, and they possess credibility that enables them to elicit more honest or in-depth responses from research subjects (Baker and Hinton 2011). Through the focus groups, Majhul’s beneficiaries were able to freely voice their opinions, ideas, and frustrations without foreign supervision coloring their responses. The Global Fund reaped the benefits of this research, as it received Majhul’s reports on each focus group’s findings, which it could use to better understand how to fund future HIV prevention efforts in Jordan.

### **Implications of Biopower’s Manifestation in Majhul’s Partnerships with Donors**

As the HELISOC and Global Fund case studies show, donors in the fields of global health and development create biological subjects out of the populations they serve. For NGOs in the MENA region, access to funding is often contingent on the production of a biological product that fulfills donor norms. Donors view their donations as investments and assess return on their investments in terms of their grants’ abilities to generate a “model” biological product. The raw materials for this biological product are donor-determined target populations, which necessarily become synonymous with the “KPs” that their implementing partners serve. For instance, Majhul’s KPs were largely determined by Majhul’s donors; Syrian refugee women became a KP for Majhul because HELISOC listed Syrian refugee women as a target population for their GBV prevention grant. Donors use terms like “implementing partner” and “beneficiary” to describe the type of biological product they expect to receive. They work through partners like Majhul by providing funds with certain conditions attached to implement programs that will transform KPs into beneficiaries—populations who benefit from the imposition of donor norms.

Key international donors have responded to critiques of the strict upward accountability that comes alongside rational management by turning to broader project implementation frameworks, such as the Theory of Change framework, which cites the logical framework as just one of the tools to be used for monitoring project success (Rogers 2014). However, biopower manifests in even the most flexible of NGO-donor partnerships, as all grant-funded global health projects with a pre-agreed upon framework create biological subjects such as “implementing partners,” “target populations,” “key populations,” or “beneficiaries.” These biological subjects must achieve predetermined norms for the NGO-donor partnership to be considered a successful investment.

The HELISOC grant reflected many of Majhul’s other grants in that it imposed a siloed approach to development onto Majhul through its case management framework. HELISOC worked through Majhul to provide a specific service, GBV prevention, to specific KPs until predetermined targets were met. In this system, beneficiaries became a product whose value was determined by their ability to fulfill the rigid biological norms set by HELISOC’s siloed approach. Therefore, HELISOC’s beneficiary referral system with Majhul reveals how NGO partnerships can warp into client-like relationships where KPs become a currency to be exchanged between grantor and grantee. The “beneficiaries” become the product, and their ability to exhibit (or not exhibit) certain traits marks their value. HELISOC had tremendous power to determine the “model” biological subject, whereas Majhul held barely any power. This produced an unsustainable, product-based system that collapsed as soon as HELISOC’s funding ended.

Biopower necessarily manifests in NGO-donor partnerships, but it only becomes violent when donors set strict and unrealistic norms in defining their “model” biological product. The Global Fund grant stands out as an example of a nonviolent manifestation of biopower in a project intended to empower grassroots NGOs and promote innovation. The grant defines its “model” biological product as KP representatives and allies who are empowered to self-advocate and design their own programming. Accordingly, it replaces

traditional rational management theory with a more flexible evaluation process, allowing Majhul's staff leeway to conduct advocacy and research as they see fit. The Global Fund grant does this because its originators view empowered KP representatives and allies as the building blocks of sustainable programming.

Biopower manifested in both the HELISOC grant and the Global Fund grant, but HELISOC differed from the Global Fund in that it enforced its norms more strictly, permitting little deviation from the at times unrealistic biological products it expected Majhul to provide. HELISOC's strict adherence to the rational management approach impeded Majhul's ability to sustainably serve its KPs, especially because it was paired with a siloed approach to GBV prevention in which only a small portion of the potential beneficiary population was valued. HELISOC's inflexibility therefore contributed to structural violence against KPs because it barred certain KPs from accessing resources they needed to stay healthy. This is a recurrent issue with siloed grants that demand specific biological products; strict enforcement of donor norms prevents NGOs from sustainably serving both donor-defined KPs and other potential beneficiaries (Hummelbrunner 2010; Nguyen 2010; Wallace, Bornstein, and Chapman 2007).

Notably, the presence of biopower in Majhul-donor partnerships parallels the power dynamics between NGOs like Majhul and their beneficiaries. Majhul is itself a powerful actor in the space of HIV/AIDS that designates its own KPs and thus creates its own biological subjects. Therefore, biopower manifests in Majhul's relationship with its beneficiaries. Along these lines, Majhul attaches various stipulations to the services it provides; many of these stipulations trickle down from Majhul's donors. For instance, beneficiaries could only receive cash transfers from Majhul if they participated in multiple trainings and interviews with both Majhul and HELISOC. Given the powerful position Majhul holds vis-à-vis its beneficiaries, one would assume that its politics and practices must be met with resistance at times. Due to the limitation of my own research and my decision to focus on Majhul's staff instead of its beneficiaries, I cannot fully explore the

implications of these power dynamics here. The nuance and complexity of beneficiaries' relationships with Majhul warrant future research, including explorations of how beneficiaries navigate Majhul's stipulations regarding service provision and how they resist Majhul's exertion of power.

## Conclusion

In accordance with Foucault's theory of biopower, donors create biological subjects out of NGO staff and beneficiaries by setting norms that NGOs must follow to maintain funding. At times, they bar NGOs from meeting the biosocial needs of potential beneficiaries by strictly defining the "model" biological product they expect NGOs to provide. Therefore, the rigid enforcement of donor norms sometimes becomes violent in that it impedes vulnerable populations' access to health services and the resultant health outcomes for these populations. This was the case for the HELISOC grant, which forced an unsustainable beneficiary care system onto Majhul by mandating a strict, siloed case management framework. The Global Fund defined its model biological product as a KP representative or ally who could innovate and self-advocate. It therefore imbued its grant with more flexibility than the HELISOC grant and avoided much of the violence that results from rigid norm enforcement. Yet, it nevertheless held power as the funding source in its relationship with Majhul; benevolent power is still power.

Exploring the nuances of these NGO-donor relationships allows us to situate each of Majhul's successes and challenges within theories of power. Many NGOs supporting marginalized groups in the developing world rely on foreign donors because they face a lack of local financial support. Therefore, they find themselves compelled to follow global development funding norms set by Europeans and Americans. One of the most pervasive of these norms is the rational management approach, which measures return on donor investments according to success indicators assessed through monitoring and evaluation. Oftentimes, NGOs struggle to meet stringent demands of donors lacking understanding of local customs, needs, and priorities.

Importantly, Majhul exemplifies the thousands of developing world NGOs that rely on international funding. These NGOs are caught between two worlds, that of their donors and that of their beneficiaries. Herein lies the crux of my argument: these NGOs are never fully autonomous. Their services are constrained by national and global structures that give governments and foreign actors a disproportionate amount of power over civil society in developing countries.

There are substantial gaps in current knowledge of development practices in the MENA region. Additional ethnography on NGOs serving marginalized groups in MENA, especially HIV prevention NGOs, would help to contextualize Majhul's challenges and develop new theoretical frameworks for understanding HIV prevention in the Arab world.

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# Living with Food Allergies: The Recalibratory Body

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## ABSTRACT

As a growing global public health concern, an increasing proportion of the UK's population must live with and manage the chronic disease of food allergies. Through a multi-method approach of autoethnography, cognitive mapping, and interviewing, this research investigates what matters to the bodily experience of people living with food allergies. I work with the concepts of embodiment and affect to delineate a theorisation of the allergic body as recalibratory and argue that the adrenaline auto-injector (AAI)—the lifesaving medication prescribed to individuals with severe food allergies—is integral to the allergic recalibratory body. I demonstrate the multiple, dynamic ways in which those living with food allergies “affectively relate” to the AAI and what contributes to this. An account of the body as recalibratory is advanced to account for the dynamicism of the body's affective relations. The recalibratory body becomes a valuable tool for understanding the ways that macro-issues of AAI production shortages and the tragic occurrence of allergy fatalities as well as micro-level everyday experiences matter to those living with food allergies. The essay concludes by exploring how the concept of recalibration can expand beyond allergic bodies to understand what the body—*any* body—can be, do, and mean.

**Keywords:** embodiment; affect; body; chronic disease; food allergy

The rising global prevalence of food allergies presents a growing public health issue (Loh and Tang 2018). In the UK, an estimated two million people are affected by this chronic disease (Wearne 2017), a figure that is rising by five percent every year as more and more children are diagnosed (NARF 2019). Those living with food allergies must manage their condition throughout their daily lives by avoiding exposure to the allergens (specific foods) that would cause the body to react (AAFA 2015; NHS 2019b).

This research investigates the bodily experience of living with food allergies, questioning how the body becomes important to the everyday experience of managing food allergies. I work towards a delineation of the “allergic body,” previously un-theorised within the social sciences, to demonstrate what matters to the everyday experience of those living with food allergies. I argue that adrenaline auto-injectors (AAIs) are integral to the maintenance and everyday life of the allergic body. In the UK, AAIs are prescribed to those with severe food allergies to be administered in the event of an allergic reaction (NHS 2019b). Individuals are advised to carry their AAI with them at all times (NHS 2019a), which becomes a biomedically normative practice through which they are expected to manage their chronic disease.

As my research progressed, it became clear that how individuals related to the AAI varied. Two findings emerged: (1) there are multiple ways in which individuals with food allergies relate to the AAI, and (2) how individuals relate to AAI is not fixed; rather, they shift dynamically as bodies pass through and encounter different spaces and circumstances. These shifting relations between the allergic body and the AAI are termed dynamic bodily relations to reflect

the way they change. I therefore propose the concept of “the recalibratory body” in order to account for the way that the body re-calibrates in response to its dynamic bodily relations.

In this research, an understanding of the body as recalibratory becomes valuable to account for how the allergic body affects and is affected at the micro- and macro-level. Micro-level factors include the everyday experiences of individuals and their immediate social and material relations. Macro-level issues describe those that occur in the public eye and affect allergic bodies both materially and affectively. These include allergic fatalities and AAI shortages. For example, fifteen-year-old Natasha Ednan-Laperouse died tragically on July 17th, 2016 after suffering an allergic reaction to the sesame contained in a baguette from Pret-a-Manger (Anaphylaxis Campaign 2018), prompting key changes in UK food allergen labelling regulations (FSA 2019). The recalibratory body becomes valuable for understanding how hearing of the circumstances around allergy fatalities can matter to individuals’ everyday allergic experiences. Second, issues surrounding the supply of AAIs have arose in recent years, making it difficult for those with allergies to obtain this life-saving medication (Kent 2020). A prescription validation process was implemented in the UK in 2018, which limited individuals to two AAIs per prescription (Kent 2020). Rather than critiquing the production issues of the bioindustry, this research reflects upon the implications of such policy changes upon people’s allergic experience (following Mol 2002) through a theorisation of the body as recalibratory.

Whilst born from and concerned with the specificity of the allergic body in this research, an understanding of the body as recalibratory has further value to account for what the body, *any* body, can be, do, or mean. This research provides an important theoretical contribution to the long-standing history of geographical scholarship on the body. It draws upon and works with the concepts of embodiment and affect to develop a theorisation of the body as recalibratory, which foregrounds the dynamicism of the body’s relations.

## Approach to Research

As someone living with a peanut allergy, which was diagnosed at a young age, my own experiences have informed this research. Two personal assumptions informed my research questions: (1) individuals with food allergies experience a heightened awareness of their body and surroundings, and (2) the EpiPen (a brand name for the generic AAI) in particular comes to matter to allergic experience. I conducted autoethnography, interviewing, and cognitive mapping to investigate:

1. What does a study of the experience of those with food allergies tell us about the body?
2. In what ways do the body's relations come to matter to the everyday experience of those living with food allergies?
3. How does the AAI come to matter to the everyday experience of those living with food allergies?

This multi-method approach enabled me to investigate both my own and others' allergic experience. My position as an "insider" to the allergic community facilitated both access to participants for this research through my social network and the building of rapport with interviewees. Rather than view my allergic identity as a potential obstacle to research, it is leveraged as a methodological tool for understanding allergic experiences (Longhurst, Ho, and Johnston 2008).

Autoethnography enabled both the scrutiny of my own embodied experience and normative assumptions about allergy management throughout the research process (Butz 2010) and a rigorous account of the implications of my positionality as an "insider" to the allergic community (Butz and Besio 2009). I sustained this immersive method over a period of five months, writing diary entries on the occasions that my allergy came up. Whilst intended as a complementary method, autoethnography proved instrumental to the theorisation of the recalibratory body. It provided intimate insight into my allergic experience, allowing me to identify the instances in which the AAI came to matter as well as when the ways that I relate to the AAI alter.

I avoided the presumption that by way of my allergic identity I could attend to all allergic experiences, remaining open to the potential for others' allergic experience to differ (as Latour 2004 recommends). Semi-structured interviews and cognitive mapping allowed different normative assumptions about allergy management and the multiple ways in which allergic individuals may relate to the AAI to come to the fore. I conducted an interview with one professional in the field, Kate Latchford from the Anaphylaxis Campaign—a non-profit organisation that advocates on behalf of those living with food allergies in the UK—to ascertain the key issues it addresses regarding the everyday experiences of those living with allergies. Latchford brought to my attention that the EpiPen was a brand of adrenalin-auto-injector (AAI), exposing my assumption that individuals in the UK were prescribed an EpiPen. As a result, this article uses the generic term AAI to refer to any of the three brands on the global market: Jext, Emerade, and EpiPen (Medicines and Healthcare products Regulatory Agency 2019). However, brand names feature where participants use the term.

To access a diversity of allergic experiences, I conducted seventeen semi-structured interviews with individuals of a mix of ages and genders with a variety of food allergies (table 1). I recruited fourteen participants via convenience sampling from an extended social network, and I used snowball sampling to connect with subsequent participants (Bradford and Stratford 2005). The majority of participants I interviewed were white women under 30 years of age. Given the lack of wider representation of the allergic population, I turned to the online allergic community and found a further three participants from an online support group. Although the sample was largely homogenous in terms of gender, age, and racial identities, it included a diversity of allergic experiences: individuals' stages of diagnosis varied (some had lived with the condition for many years whilst others were diagnosed very recently), some allergies were late-onset or exercise-induced, and many also had other non-related food allergies.

Alongside the interviews, I asked the nine participants whom I met face-to-face to draw a map of their awareness of their allergy.

**Table 1: Research Participant Demographics and AAI Use**

		Total	Female	Male	< 30yrs	> 30yrs
<b>Number of Participants</b>		17	13 (76%)	4	12 (70.6%)	5
<b>Food Allergy</b>	Tree Nuts	8	6	2	6	2
	Peanuts	4	2	2	3	1
	Shellfish	2	1	1	1	1
	Multiple	3	3	-	2	1
<b>AAI Prescribed</b>	Yes	16	13	3	11	5
	No	1	-	1	1	-
<b>AAI Carried</b>	Yes	13	13	1	11	4
	No	2	-	2	1	1

Cognitive mapping was useful to better understand embodied experiences within and between particular spaces (Gieseeking 2013). Through the combination of drawing and talking in this method, I drew out the immersive aspects of participants' allergic embodiment (Hayes-Conroy 2010), asking, for instance, "how do you feel in that particular space?"

### Theorising the Allergic Experience

As food allergies have gained prevalence, so too has academic interest. The psychosocial impact of food allergies on individuals is well recognised within sociology, anthropology, public health, and geography. Findings of a recent review of the impact of food allergies on mental health highlight the negative impact that food allergies can have on the quality of life of children, adolescents, and their families, and explains that food allergies are associated with higher risks of depression, anxiety, and PTSD/S (Feng and Kim 2018). Other work explores the way food allergies are socially constructed via public discourses and the media (see Harrington et al. 2013; Abo, Slater, and Jain 2017).

Qualitative research on the everyday, lived experiences of those with food allergies has also increased. However, studies of allergic experience have disproportionately focused upon (1) key populations: children, teenagers, and parents (see Stjerna 2015; Otarnyk and Elliot 2016; Johnson and Woodgate 2017) and

(2) key spaces: schools and restaurants (see Kwon, Lee, and Wen 2020; Fenton, Elliott, and Clarke 2013). This focus is understandable: the burden of allergic disease in children is growing, heightened responsibilities for allergy management are borne by parents and teenagers, and allergy management often becomes more difficult within public versus private spaces. However, adult-onset allergies are increasingly common (Warren et al. 2018), and a focus upon particular spaces or phases of the life-course forecloses the potential for understanding the dynamicism of allergic experience.

Fenton, Elliott, and Clarke's (2013) study of the experiences of children with food allergies in schools is a valuable starting point from which this research builds. The authors offer a sense of the dynamicism of allergic experience as the school is framed as an "interrupted" space where changing characteristics such as a new teacher alter children's experiences. The scholars highlight the micro-level relations that come to matter to allergic experience, such as children's social relations to other bodies, like teachers. However, they also dichotomise the "interrupted," dynamic space of the school with the regulated, static space of the home, which possibly oversimplifies allergic experiences. Furthermore, limited existing research examines the interactions between the everyday, lived experiences of those with food allergies at the micro-level and the macro-level social, political, and economic factors that

shape understandings and experiences of food allergies within society. Through a novel focus on bodily experiences in and through space, my research aims to bridge this gap and explore how allergic experience is mediated through relations both at the micro- and macro-level. A focus upon the allergic body as it passes through and encounters different spaces and circumstances exposes the dynamicism of allergic experience.

## Theorising the Body

Over the past three decades, the body has become an important site of social science inquiry. Scholars have asked questions of what the body is (Longhurst 1997), what the body does (Deleuze 1992), what else becomes important for/to the body (Butler 2014), and what brings the body into being (Latour 2004). Gillian Rose's (1993) seminal critique of geography's treatment of the body as universal has fuelled a proliferation of efforts to delineate the specificities of the "X" body (see Probyn 2016; Colls 2007). However, the question of the allergic body has yet to be taken up. To work towards a theorisation of the allergic body as recalibratory, I draw upon the interdisciplinary contributions of feminist theories of embodiment, actor-network theory, affect theory, and work around the biopolitics of health.

## Embodiment and Bodily Relations

The feminist concept of embodiment is foundational to understanding everyday allergic experience. Emerging from Merleau-Ponty's (1962) phenomenology, the concept emphasizes that what it means to have a body is to experience life corporeally—through the body (Grosz 1994). For those with allergies, this bodily experience of life is more pronounced as individuals may experience a heightened awareness of both their bodies and their body's relations. This idea of the body's relations refers to other bodies or materials that may be typically considered "external" to the body yet can come to shape an individual's bodily experience. Bodily relations include and go beyond "social" relations. For instance, in Fenton, Elliott, and Clarke's (2013) study, the presence of a new teacher who is unaware of a child's allergy impacts a child's feeling of

security within the school—this other body becomes important to a child's allergic experience on account of the body's relations.

The allergic body's relationship with that which may be considered external to it is therefore important. Early feminist literature has critiqued understandings of the body as a bounded, discrete unit. For instance, Longhurst (2001) describes how the body interacts openly with space and material external to it. Considering the body and its inter-relations with space becomes valuable when considering the potential for the allergic body to react through an exposure to allergens (NHS 2019). However, my research demonstrates that the allergic body's relations encompass far more than its allergens alone; rather, various social and material arrangements can be considered integral to what the body is (see Butler 2014). Where we consider embodiment, the questions of which bodily relations come to matter to allergic experience and how they shape it become important (Evans, Colls, and Hörschelmann 2011).

I draw on the work of Nikolas Rose and Paul Rabinow to understand why both (1) a heightened bodily awareness and (2) the body's relations become particularly important to the experience of allergic individuals. Like all individuals, those with food allergies have a responsibility to manage their own health via their bodies (Rose 2001). However, their chronic condition provides an expectation to manage their allergies by avoiding exposure to allergens (NHS 2019a). A level of bodily awareness of both the body and its relations becomes important to the allergic body as an allergy management practice.

Key normative assumptions as to how individuals "should" manage allergies stem from biomedicine. The UK's NHS advises all those with life-threatening allergies to carry prescribed AAIs at all times (NHS 2019) in proximity to the body. However, as this research demonstrates, not all individuals with allergies perform this "responsibility" when managing their allergies. Through personal experience, individuals develop their own normative assumptions regarding how their allergy should be managed and may come to feel like the "expert" at managing their own

health and body. The concept of “somatic expertise” can be extended to reflect this idea. Whilst Rose (2007) uses the concept to refer to qualified individuals (e.g., geneticists, therapists, allergists) with specialist knowledge, the term is also useful for reflecting the sense of bodily expertise an individual develops via their personal experience of managing a condition.

However, responsibilities for health management extend beyond the individual (Rose 2007). Members of an individual's social network or particular organisations can assume responsibility for the health of others and similarly have normative assumptions around how conditions should be managed. These people and groups too may gain “somatic expertise” of allergy management. In this research, I find that others’ normative assumptions surrounding allergy management can impact an individual’s allergic experience. Rabinow (1996) proposes the term biosociality to refer to a collective that is brought together around a shared biomedical knowledge or condition. Biosocialities that are brought together around the allergic body may include individuals with allergies, parents/caretakers, friends, teachers, physicians, patient organisations such as the Anaphylaxis Campaign, and their associated support groups. This concept is useful to exemplify the types of social bodily relations that have the potential to influence the allergic body and shape individuals’ allergic experience.

### The Body as Affected

The concept of affect (see Anderson 2016) is useful to account for why the body’s relations can be considered integral to what the (allergic) body is. The verb “affect” refers to something that has an effect on or makes a difference to something (Oxford Dictionaries 2021). It is useful to recognise the potential for the body’s relations to do something, to *affect* the body as well as the body’s capacity to be affected by them (Latour 2004). I use the term “affective relation” to recognise this potential for the allergic body’s relations to do something to it. Should allergic bodies be viewed through the lens of binary states (healthy versus in reaction to an allergen) without consideration of affect, we would be unable to account for the multiple ways in which the “healthy” allergic body is

affected by its relations on an everyday basis as it passes through and encounters different spaces and circumstances.

As aforementioned, the allergic body’s relations encompass social relations not only with other bodies but also with materials. For those with food allergies, the body’s affective relation to the biomedically prescribed AAI is particularly important, yet individuals affectively relate to the AAI in multiple ways. The AAI performs a mediatory role in the relationship between the allergic body and space, shaping an individual’s awareness of the body and its relations. Considering the work of Bruno Latour, Michael Serres, and Judith Butler is valuable for understanding the paradoxical ways that the AAI comes to mediate this affective relationship and the different ways in which the AAI may come to matter to the allergic body.

Latour (2005, 207-8) equips us with the language to consider the body’s capacity for affect as conditional. He argues that the body trains to be affected via mediatory materials. Latour draws upon the example of odour kits containing differing fragrances to explain this idea. Specialists in the perfume industry are trained to become sensitive to these differences. However, it is the odour kit that acts as a mediatory tool through which the body gains the capacity to differentiate fragrances. The odour kit facilitates the body’s capacity to be affected by these different smells and therefore distinguish between them. Could the AAI tool behave like the odour kit, heightening the allergic body’s awareness and capacity to be affected?

Similarly, Serres’ (1982) concept of the quasi-object highlights the mediatory role of an object that bring both the subject and the collective into being through its possession by an individual. The quasi-object plays a mediatory role as it exposes the individual who possesses it to other individuals, therefore increasing the individuals’ capacity to be affected by others.

Throughout my analysis, we find that it is the AAI that brings the allergic body into being, increasing its capacity to be affected by others’ normative judgements about how to manage one’s allergy. For those living with allergies, it is therefore not simply their biological identity

that results in this sense of responsibility (Rose 2001), but the biomedical prescription of the AAI as a tool through which to manage food allergies: the AAI has the capacity to bring biosocialities of allergic and non-allergic bodies together around the health management of individuals with food allergies (Rabinow 1996).

Finally, Judith Butler's (2016) concept of corporeal vulnerability is useful to consider the AAI alternatively as an infrastructural support for the allergic body. For Butler, the body is inherently vulnerable—its supports are integral to what the body is. However, this corporeal vulnerability only becomes visible once its infrastructural relations are removed. This research finds that for some individuals, the AAI becomes a supportive tool for the allergic body. Its supportive, mediatory role is exposed when the tool is forgotten, resulting in a heightened awareness of the body's relations.

### **Towards the Body as Recalibratory**

As I work towards a theorisation of the recalibratory body, it is useful to turn to its etymology. Recalibration stems from the verb "calibrate," which refers to the gauging of an instrument (for instance) against a standard (Oxford Dictionaries 2020b). For those with allergies, this standard is the normative biomedical expectation to always carry the AAI. As my research demonstrates, all those with allergies affectively relate to the AAI, yet they do so in multiple ways. Allergic bodies can be said to recalibrate from this biomedically prescribed relation to the AAI.

Actor-network theory becomes useful to account for a second key research finding: how those living with food allergies affectively relate to the AAI is dynamic and changes over time. By considering the allergic body as positioned within Latour's (2005) assemblage of the social—which positions society as constructed by the coming together of many individual parts—we gain an appreciation of the dynamicism of the body's relations as the allergic body may be affected by multiple, re-assembling relations that are constantly in flux. I consider how the body's relations may be shaped by other material and social arrangements in this broader assemblage, which is the key insight into the dynamicism of the body's affective relations and becomes

instrumental to working towards a theorisation of the body as recalibratory.

My analysis proceeds as a series of vignettes that intertwine autoethnographic, cognitive mapping, and interview data to demonstrate what comes to matter to myself and others' allergic experience. More specifically, I consider what contributes to individuals' affective relations to the AAI and their normative assumptions around allergy management.

### **The AAI is Integral to the Allergic Recalibratory Body**

For the majority of allergic individuals in this study, the AAI emerged as a valuable insurance to be relied upon should any allergen exposure occur. However, the AAI matters beyond this moment of allergen exposure for all of my participants, becoming important more broadly to their bodily experience within space. For instance, university student Phoebe's reliance on the AAI came to the fore during her cognitive mapping activity: she drew the space of her high school prom as a time in which she was particularly aware of her food allergy (see figure 1). Phoebe has been working towards managing her allergy with greater confidence over the past couple of years, and she explained that this time was particularly difficult as she had forgotten her AAI:

The food was covered in like a sauce and that scared me cause I didn't know like what it was \*sniffs\* I didn't have that safety net there... it was a bit dark so you couldn't really see what you were eating...there were two boys on my table and I was like they must think I'm an absolute psychopath cause they'd just gave me a food and I'd like just cry. \*laughs\*

What is striking is the level of detail and specificity that Phoebe provides of her allergic experience. In the absence of "that safety net" of the AAI in proximity to her body, Phoebe is increasingly sensitised to and aware of the material and social arrangements in this space. It is therefore only in its absence that how the AAI matters to the allergic body comes to light: in mediating the body's affective relationship with its relations. As opposed to heightening the body's capacity to be affected by its relations as in Latour's (2004) account, the



accounts for these absences. For instance, whilst AAls remain absent from my own cognitive map (figure 2), an analysis of autoethnographic data reveals their mediatory role and large importance in my preparation for a trip to Nepal.

In an entry written towards the end of my trip, I reflect upon an experience of eating out at a restaurant:

I only realised after I'd gotten back from dinner that night, but I'd taken my EpiPen out of my bag in all the commotion. I'd actually gone for something really different to eat as well, a mutton paneer curry. I would have never ordered on my own but someone else had suggested that we split it. I can remember saying "It doesn't look like it has nuts in" and taking it slow, but I wonder if I'd have acted different, or even not ordered something new should I have realised at the time.

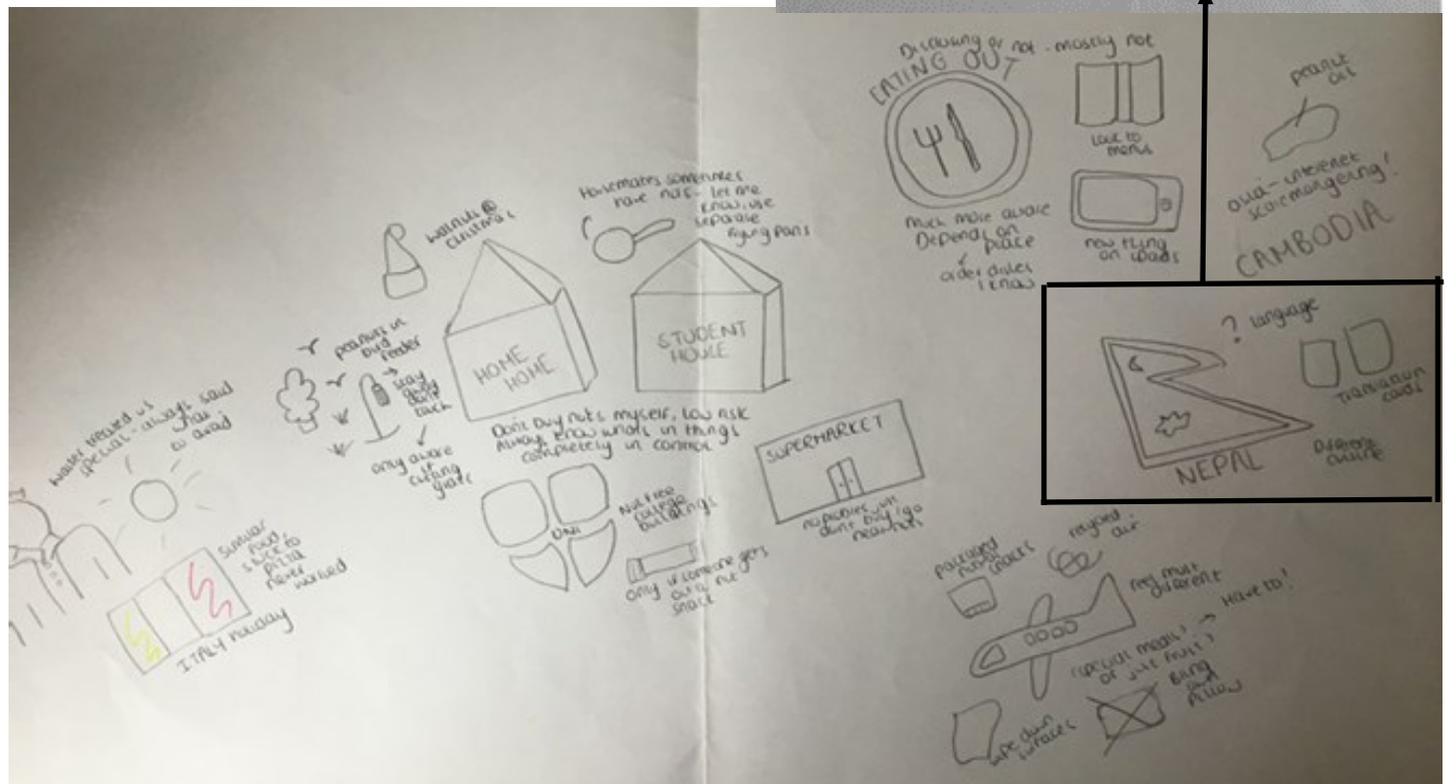
Autoethnography Entry – 17/09/19

Here, I appear to recognise the affect of the AAI upon my allergic body and its mediatory role as I consider the potential that my experience and the decisions I made may have been different had I realised its absence. The AAI was

particularly important to my allergic experience when travelling abroad, and making sure to take plenty of AAls was a typical allergy management practice for me. This was of similar importance to other participants like Michelle, who mentioned that she employs this strategy to manage her shellfish allergy when travelling: "I must admit I take double EpiPen's, my GP gives me a second prescription so in the hotel room I can keep a backup, in case anything goes missing." The mediatory role of the AAI therefore becomes valuable in enabling those living with food allergies to both access and feel comfortable within particular spaces.

As the importance of the AAI to the allergic body becomes clear, we begin to gain a sense of how and why issues like AAI shortages and AAI involvement in the circumstances around allergy deaths may come to matter to the

Figure 2: Showing my cognitive map and a closer excerpt.



allergic experience of those with allergies. However, the centrality of the AAI to the allergic body can be complicated through my research finding that individuals relate differently to it. For instance, both Jake and Dave completely rejected the need to carry the AAI to manage their food allergies.

University student Jake does not feel he needs an AAI to manage his peanut allergy because his past allergic reactions have never required one. He explains, "I've always tried to sort of distance myself from the EpiPen... I don't like having it around as a sort of reminder which I don't feel like I need." In his choice not to carry the AAI, the way in which Jake relates to the tool differs greatly from the way that the AAI comes to matter for Phoebe, Michelle, and myself. Nonetheless, the AAI still does something to Jake, affecting his allergic body. Unlike the quasi-object (Serres 1982), the AAI does not require possessing to bring the allergic body into being. Rather, it is the bioindustrial tool of the AAI and its prescription to individuals to manage their allergy that becomes integral to what the allergic body is.

Similarly, Dave, who has been managing his peanut allergy for over forty years, is confident that he does not need an AAI. However, through close analysis I found that it is his recognition of the mediatory role of the AAI and its effect on the allergic body that contributes to the way he relates to the tool: "What I've heard other people say [is], they're not as careful cause they know they've got the pen." For Dave, this mediatory role of the AAI undermines an individual's ability to manage their allergy. He alludes to the potential that carrying an AAI reduces an allergic individual's awareness of and capacity to be affected by their body and its relations (Latour 2004). In this way, the mediatory role of the AAI appears to make the allergic body vulnerable as opposed to providing infrastructural support (Butler 2014). This finding complicates Butler's (2016) theorisation of corporeal vulnerability, highlighting that there may be multiple ways in which the body can be made vulnerable. What is also striking here is the indication that gender may play an important role in the different ways in which individuals affectively relate to the AAI. How bodily experience is connected to

gender, sexuality, and other aspects of identity is well-established within the literature by scholars such as Ahmed (2006). However, further research with a more representative sample is needed to consider whether a denial of the body's vulnerability or sense of control of the body without the aid of medical devices may be seen as a gendered form of embodiment.

Despite both Dave and Jake's rejection of the need to carry an AAI, we see that it still affects their allergic bodies. On account of its biomedical prescription, my research found that all of my participants living with food allergies affectively relate to the AAI. Following Butler (2014), the allergic body is therefore untheorisable outside of its affective relation to the AAI. However, I also found that there are multiple ways in which individuals affectively relate to the AAI. The AAI can be said to, in fact, bring multiple allergic bodies into being (Mol 2002). In rejecting the need to carry an AAI, both Jake and Dave reject the normativity of this allergy management practice. Their allergic bodies can be said to have recalibrated away from this normative biomedical expectation to always carry the AAI. To return to the etymology of the recalibratory body: as a transitive verb, for something to recalibrate requires an object (Oxford Dictionaries 2020a). For allergic bodies, it is the AAI that becomes important to the body's recalibration and allergic individuals' experience of particular spaces.

## **The Allergic Recalibratory Body as Affected**

To complicate our understanding of the allergic body, Dave's account of his allergic experience can be scrutinised further to more closely consider the role of affect. I found that it is Dave's implicit judgement of the ways that others with food allergies relate to the AAI that contributes to his affective relation to the tool. He is critical of the way that many of the other participants interviewed in this study relate to the AAI and their normative assumptions around allergy management. Dave's allergic body therefore appears to have been affected by others' differing normative assumptions around allergy management. Considering the role of affect enables us to appreciate how

others' normative assumptions around allergic management may come to matter to individuals with the potential to affect the allergic body. It is clear that what matters to the everyday experience of allergic individuals extends far beyond allergen exposure, as may be presumed through a binary lens.

My own experiences offer insight into this potential for allergic bodies to be affected by and recalibrate in response to other allergic bodies due to differing normative assumptions around allergy management. During my flight to Nepal, I recount::

When I got up from my seat to go to the toilet, a member of the cabin crew offered me the cardboard cup that was on the side—naturally, it was a cup of peanuts the staff had been snacking on. He put it right under my face and I felt myself lean away. I found myself eyeing the hands of staff that was making my tea that I'd just asked for, wondering whether she'd had some and had washed her hands since. I was annoyed at myself for not actually knowing whether the trace of peanuts would actually affect me. I took an allergy tablet just in case—this isn't actually something I'd ever done before, more as a preventative measure than anything.

#### Autoethnography Entry – 18/08/19

Close analysis reveals that my adoption of this novel behaviour emerged closely following my interview with Amanda, who spoke of her allergy management practices and strategy to “load...[her] system” with allergy tablets in preparation for a flight. Hearing of the normativity of such practices for Amanda appears to have affected my allergic body, altering what I did to manage my allergy on this occasion. My allergic body can be said to have recalibrated in response. At the time, I was unaware of how my interview with Amanda had affected my allergic body, which highlights the possibility for the body's recalibration to operate below the level of consciousness, as recognised in affect (Anderson 2016). It was only through the complementary analysis of autoethnographic and interview data that this bodily recalibration came to light. The concept of the recalibratory body enables us to

recognise this potential for the allergic body to be affected by and recalibrate in response to an encounter with others' normative assumptions around allergy management. This example shows that not only do multiple kinds of allergic bodies exist on account of their differing affective relations to the AAI (Mol 2002), but also they have the potential to influence each other via affect.

However, I also found that this potential for allergic bodies to be affected and recalibrate is not limited to other allergic bodies. For instance, Jake reveals that, on occasion, he has been unable to distance himself completely from the AAI. On a recent trip to Singapore, his girlfriend's parents wanted him to bring it along: “I didn't want to bring this EpiPen, but I was being forced to...it was stressful not because I was worried about it but because of others, there was an external influence.” In adopting responsibility for Jake's allergy management (Rose 2007) with differing normative assumptions, his girlfriend's parents had the potential to affect his allergic body.

It is therefore the biomedical prescription of the AAI that exposes Jake's allergic body to the normative judgements of his girlfriend's parents. A second, alternative mediatory role of the AAI emerges within these research findings: the AAI exposes allergic bodies, increasing their capacity to be affected by others' differing normative assumptions around allergy management. On account of its biomedical prescription, the AAI brings not only the allergic body into being but also a biosociality of individuals with the capacity to affect it, both resulting in its recalibration (Serres 1982; Rabinow 1986). The AAI plays a paradoxical, mediatory role in shaping the relationship between the allergic body and its relations: both mitigating and increasing its capacity to be affected. When we talk of allergic bodies, we therefore must recognise that we are also talking of the other allergic and non-allergic bodies that come to matter to an individual's allergic experience. These are examples of the bodily relations that may come to matter to the everyday bodily experience of those with allergies in their affect upon the allergic body.

Yet, as we know, Jake's normative assumptions around allergy management and

his affective relation to the AAI does not alter as a result of the views of his girlfriend's parents. A final turn to etymology is useful to remind us that it is the concept of the recalibratory body as opposed to the calibratory body that is advanced through this research. To recalibrate is to *"calibrate again or differently"* (Oxford Dictionaries 2020a). The concept of the body as recalibratory therefore recognises the *ongoing potential* for the body to recalibrate as the body is affected by its relations. The exposure of the allergic body to others' differing normative assumptions about allergic management does not presume its recalibration will lead to a change in its affective relation to the AAI.

What contributes, then, to the emergence of bodily recalibration? My fieldnotes following my interview with Amanda provides some indication of this. Amanda's allergic experience was unusual amongst my participants; with multiple, late-onset food allergies, her proactive approach to allergy management and familiarity with using the AAI surprised me. She reflects that "The hardest thing to do in the world is to stab yourself. Everything in your body says no, don't do that. So, you do it, but it lasts twenty minutes and [the paramedics] take 20 minutes to arrive." This specific insight into how long the adrenalin released from AAIs lasts once administered was shocking and new information for me. In her display of such knowledge, Amanda becomes an individual who I view to have experience and authority in managing her allergy. It is perhaps my own assumptions of her somatic expertise (Rose 2007) that may have contributed to my body's recalibration on this occasion: my allergic body is affected in hearing her speak so confidently about her allergy management. This meant that in my moment of surprise and uncertainty when encountering peanuts on the plane to Nepal, I followed her approach and adopted her normative allergy management strategy. Of course, other aspects of our positionalities beyond our allergic identities, such as our age difference (Moss 2005), may have contributed to why my allergic body was affected by Amanda's normative assumptions around allergy management, resulting in its recalibration. Nonetheless, this demonstrates that the specific dynamics of bodily recalibration depend upon the (allergic) body in

question and the particular relations that come to affect it.

## Complicating the Allergic Body as Recalibratory

Throughout this analysis, a complex theorisation of the allergic body and its potential for recalibration has emerged. Through Michelle's, Jake's, and my autoethnographic account, we gain a sense of the dynamicism of the allergic recalibratory body in its potential to be affected by others' normative judgements around allergic management. A second key finding of this research has emerged: how individuals affectively relate to the AAI is not fixed but dynamic. However, this potential for bodily recalibration can extend beyond an individual's immediate experience and social relations. This final section of analysis begins to explore the broader expanse of bodily relations at the macro-level that may contribute to the allergic body's recalibration.

Like many participants, carrying the AAI was something that always used to reassure university student Zoe: "In my head then I think, I've got the medication and that will work." However, hearing of the death of Natasha Ednan-Laperouse has meant the way Zoe affectively relates to the AAI has altered: "...that was what was so scary about the girl on the plane because she'd had two EpiPen's and they didn't work." Zoe's concerns are remarkably similar to Dave's whose rejection of the need to rely upon the AAI is also informed by its potential to fail. And yet in Zoe's interview, we are able to identify exactly where these concerns stem from: her allergic body was exposed to the potential to be affected through hearing an interview with Natasha's father on the radio. This highlights the potential that circumstances beyond one's immediate experience and bodily relations may contribute to the allergic body's recalibration.

As such a high-profile case, Ednan-Laperouse's tragic death has had a large impact upon many within the allergic community. Kate Latchford of the Anaphylaxis Campaign spoke of the particular spaces that those with food allergies often fear or avoid: "Planes, especially after what happened to

Natasha, people are particularly scared about how allergies are treated on planes.” Latchford recognises the potential for factors beyond an allergic individuals’ immediate experience to affect their everyday experiences. Furthermore, a key aspect of Latchford’s work as Outreach Coordinator involves the overseeing of local support groups, which are “safe, neutral spaces” for those to reach out for support and share personal experiences. Of key priority is the dissemination of information, such as new research, updates on the supply of AAls, and inquest outcomes regarding allergy fatalities. Not only does the Anaphylaxis Campaign recognise the wider expanse of bodily relations that come to matter to allergic experience, but also the organization becomes part of them. The NGO acts to mediate how such news reaches and (potentially) affects allergic individuals, thereby playing a role in the allergic body’s recalibration. The NGO is part of the allergic body’s wider field of re-assembling affective relations and biosociality that may contribute to its recalibration (Latour 2005; Rabinow 1996).

Latchford’s interview highlights the further macro-issue of AAI production that becomes important to the allergic recalibratory body. In this study, AAI supply issues came to matter to the everyday allergic experience of many research participants, including myself. Within my autoethnographic data, this affected my allergic body during my preparation to travel to Nepal:

I did get a prescription for more [AAls] a whole four weeks ago (which is really responsible for me!) but I haven’t been able to get a hold of any. I just kept getting told to try somewhere else. The clocks definitely ticking, but the fact they’ve got such supply issues is frankly ridiculous.

Autoethnography Entry – 10/08/19

As I discussed, obtaining AAls when travelling abroad is a normative allergy management strategy that I had used repeatedly in the past. However, the ease with which I can enact this management strategy falls in light of AAI shortages and the UK’s prescription validation process (Kent 2020). This policy change results in a bodily recalibration of my sense that this is

a normative allergy management practice: the shortages disrupt my long-held practice of obtaining extra AAls when abroad; therefore, it can no longer be a norm within my allergy management. Contextualised within these supply issues, it is interesting to consider that Michelle’s perception of obtaining extra AAls as a non-normative allergy management strategy (and her confessional tone) can be accounted for as she perhaps has greater awareness of the policy change or encountered this new policy before I did.

Whilst experiencing these difficulties, I began to question the adequacy of my own allergy management, throwing doubt upon my estimations of my own somatic expertise (Rose 2007):

I did manage to get a hold of two Jext pens in the end. I’d never heard of these ones and so when I collected them, the pharmacist explained how to use them. I remember feeling really ashamed when I realised I had no idea of the differences between how he said you use the Jext pen than the EpiPen—I’ve been so used to having it there as a safety net and yet if anything actually did happen, I wouldn’t even know how to use it properly. I think this realisation, along with speaking to allergic individuals in my interviews, has made me sort of look back at myself, thinking I’m not actually managing it well enough at all, I’m being too lax about it.

Autoethnography Entry – 17/08/19

Through this passage, it becomes clear that multiple bodily relations come to matter to my allergic experience and combine to undermine my sense of somatic expertise. Not only does the UK’s policy implementation around prescriptions come to affect my allergic body, but also the research process, through exposure to others’ differing normative assumptions around allergy management, prompt its recalibration. The recalibratory body allows us to appreciate the implications of macro-level factors such as key policy changes and incidences of allergy fatalities on the everyday experiences of those living with allergies. Its further value emerges in its insight into the broader field of affective relations and biosocialities that have the potential to interact and affect the allergic body, including a social

encounter, the work of organisations such as the Anaphylaxis Campaign, and the political economy of AAI production.

## Conclusion

Through an investigation of the everyday experiences of those living with food allergies, this research has worked towards a theorisation of the body as recalibratory. Following Butler's (2014) work, this research finds that the body's relations are integral to how individuals with food allergies experience their body, yet these relations come to matter specifically on account of their capacity to affect it. The body as recalibratory foregrounds the dynamicism of the body and the way that it is constituted in relation to shifting material and social arrangements. I found that dynamic bodily relations at both the micro- and macro-level have the potential to affect the allergic body and contribute to its recalibration.

An understanding of the body as recalibratory also foregrounds the vulnerability of the allergic body in its capacity to be affected by its relations. It offers a more complex, dynamic appreciation of corporeal vulnerability (Butler 2016) on account of the multiple ways in which individuals relate to the AAI and its mediatory role: I found that not all allergic bodies are made vulnerable in the same way. In this research, it becomes clear that multiple allergic bodies exist, each with the potential to affect (and be affected by) each other. For allergic bodies, the pluralisation of responsibilities for health management and differing normative judgements around allergy management are important to recalibration.

However, the value of the recalibratory body concept extends beyond its ability to account for the experiences of allergic individuals. The concept does not presuppose any specificities of the body. In fact, it challenges the very idea that the specificities of any one body can be theorised, highlighting the limits of recent feminist endeavours to theorise the specificities of the "X" body (see Probyn 2016). We cannot theorise any singular "X" body in light of the multiple other "X" bodies in existence that come to affect what this "X" body is. Instead, the recalibratory body's value arises in its invitation to question what specifically contributes to the

way other bodies recalibrate and why. It allows us to ask of any and all bodies what materials may become important to their recalibration, performing a mediatory role.

In beginning to think about bodily recalibration, we are confronted with fruitful possibilities for further research. Posthumanists, for instance, may further interrogate the human-non-human, social-material relations that come to matter to the body's recalibration or question the extent to which the recalibratory body has arisen through the advancement of technologies like the AAI. Questions arise as to whether there may be gendered, racial, age, etc. dimensions to the recalibratory body. For instance, it is perhaps telling that the two participants who rejected any need for the AAI were both men, and little sense of doubt at the normativeness of their allergy management was traced amongst an analysis of their interviews (unlike in both Michelle's and my own experiences). Feminists may prioritise a consideration of the intersecting aspects of identity (Crenshaw 1991) that may come to matter to the body's calibration. The experiences of a limited cohort of allergic individuals are highlighted in this study: multiple allergic bodies exist in excess of those engaged with in this research, not least because of its geographic limits within the UK. The mediatory role of the AAI may differ in other settings where access to medications is constrained by a lack of financial resources, and socioeconomic status may play an important role in the allergic body's recalibration. Further research in other contexts is therefore imperative to move beyond the western-centrism that characterises existing literature on food allergies.

The concept of the (allergic) body as recalibratory also offers a new way of thinking through the methodological implications of the research encounter upon both participants and the researcher (England 2015). Whilst autoethnography proved instrumental to the theorisation of the body as recalibratory, the concept also enabled me to appreciate that engaging in this immersive method impacted my allergic body. This raises important ethical considerations surrounding autoethnography's implementation. Nevertheless, as this research makes clear, the ongoing potential for a large

expanse of bodily relations to affect my allergic body and contribute to its recalibration at both the micro- and macro-level means that my allergic experience can and will continue to change throughout the course of my life.

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