

THESIS

SURGICALLY ENFORCING NORMALCY: A CRITICAL ANALYSIS OF
INTERNATIONAL CRANIOFACIAL NGOS

Submitted by

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ABSTRACT

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The purpose of this study is to deconstruct dehumanizing representations of children with facial differences in the Third World and catalyze a critical understanding of the work of international craniofacial NGOs, organizations that provide free reconstructive surgery to children with facial differences around the world. This study focuses on four of those organizations – Smile Train, Operation Smile, Little Baby Face Foundation, and Operation of Hope. Considering the social, political, and economic positions of the children treated by the organizations, their messaging has powerful consequences.

The research questions follow: (1) What role does ideology play in international craniofacial NGO's representations of children with facial differences in the Third World?, and (2) To what extent and in what ways do international craniofacial NGOs address the systemic barriers faced by children with facial differences in the Third World, as portrayed by their social media materials? This study uses a multimodal critical discourse analysis (MCDA) of social media sites to explore the research questions.

Findings reveal that the NGOs contribute to the problems that they aim to address. Their messaging promotes neocolonialism, ableism, heterosexism, classism, and eugenics. Ironically, these same systems of power create the lack of access to medical care, stigmatization of norm-challenging bodies, and abuse that the organizations aim to address. Rather than arguing for the elimination of international craniofacial NGOs, this study calls for new ways to address the challenges faced by children with facial differences.

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DEDICATION

This thesis is dedicated to my niece, Emma Pfeif, who inspires me to make this world a better place for the next generation. I hope that my thesis can be a contribution to that change.

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CHAPTER 1: INTRODUCTION

It has been a wonderful and heart felt experience seeing classmates, all the families of past patients, and all of my many 'dear little buddies' who have now become accepted as part of the human community.

–Dr. Kenneth Salyer, *Facebook*

Salyer, a renowned plastic surgeon and founder of the World Craniofacial Foundation (WCF), posted this reflection on his public Facebook page following a tour of his book release for *A Life That Matters* (2013). Salyer refers to children with facial differences as his “dear little buddies.” According to Salyer, his “dear little buddies” were not “accepted as part of the human community” until they received reconstructive surgery that offered them a “normal” facial appearance and function. This statement implies that children with un-operated facial differences are subhuman and ostracized from human connection. Considering that the process of dehumanization catalyzes cruelty and genocide (Livingstone Smith, 2011), the idea that a prominent craniofacial surgeon and figurehead of international craniofacial NGOs perceives children with facial differences as subhuman has incredible consequences for the children and their families.

The WCF provides free reconstructive surgery to children with facial differences around the world, primarily in the Third World, who otherwise would not have access to medical care (World Craniofacial Foundation, n.d.). Western society marks the children treated by the WCF as Other by their disability status, race, ethnicity, class, and nationality. Thus, Salyer’s term “dear little buddies” disguises the hierarchical relationship between the American surgeon and his patients under a cloak of egalitarian friendship. Reading Salyer’s quote with the knowledge of these power dynamics highlights the oppressive ideology that informs his messaging.

I felt a sense of outrage and horror on several levels when I read this Facebook post as both an insider and outsider to the work of the WCF. First, I have undergone the transform that Salyer claims makes children with facial differences become “part of the human community.” I was born with a unilateral cleft lip, cleft palate, and nasal deformity. I underwent several surgeries and various medical interventions throughout childhood to correct my cleft. The medical treatment ensured that I could not only eat, breath, hear, and speak normally, but also look like my typical peers. Imagining that my norm-challenging facial appearance and function placed me outside of the “human community” prior to my operations is incredibly upsetting, to say the least. Second, this post sheds light on Salyer’s motives for treating children’s facial differences, myself included. Salyer headed my cleft team as a child in Dallas, TX. I now wonder to what extent Salyer’s personal ideas about who can be “accepted as part of the human community” directed the type of care that I received. Finally, the post horrifies me as a social justice activist. Implying that children with facial differences treated by international craniofacial NGOs, many of whom are marked by their disability status, race, ethnicity, socioeconomic status, and nationality, are subhuman has immense consequences. It invokes a history of colonization, eugenics, genocide, and imperialism. My visceral reaction to this post told me that something more must rest behind the work of the WCF.

Sadly, this post was only one of many upsetting interactions I had with Salyer and the WCF. I met a few of the children treated by the WCF during my childhood surgeries, which took place at the International Craniofacial Institute in Dallas, TX, the headquarters of the WCF. I remember visiting with a young girl, orphaned by her parents, my same age during our hospital stays. She was born in China and lost her nose to a pig attack as an infant. I overheard the nurses, doctors, and media talk about her during my hospital stays. They used words that invoked

sympathy and sensationalized her visit to the U.S. Even at a young age, I understood that these adults believed that children treated by the WCF and American patients with health insurance constituted two distinct groups. I recently reconnected with Salyer through my work with a local non-profit organization serving children with facial differences and their families. While he clearly cares very much for his patients, I also noticed the same problematic language that he used in his Facebook post throughout our personal conversations. In an email to me explaining his book, he stated that “it is about the lives of these children [treated by my practice and the WCF] and providing them a normal life like you are now experiencing” (personal communication, August 16, 2014). I am grateful for receiving high quality medical care, and I acknowledge the immense privileges that having a “normal” face offers me. Still, Salyer’s focus on normalcy as the outcome of surgery strikes a deep chord. This quote invokes the violence committed throughout history in pursuit of achieving a “normal” ability status, race, ethnicity, class, gender, sexuality, and nationality. While craniofacial surgery helped me and countless others gain access to systems of privilege, I question the costs of this access.

My personal experience of being born with a facial difference and interacting with the founder of an international craniofacial NGO offers me a tiny glimpse into the lives of the children treated by the WCF and other similar organizations. Although I share the experience having a facial difference, I remain an outsider in this research. I am a white, educated, American woman conducting research on children in the Third World who lack access to basic medical care. I have educational and class privileges that position me economically and socially to be able to conduct this research. I also lack the personal experience of growing up with an un-operated facial difference, because I had access to high quality medical care from birth. Recognizing that my geographical, economic, social, and political positions pervade all aspects

of my research, I aim to continuously interrogate my position and systems of power throughout the research process.

I share my personal story to describe the origins of this topic and to self-locate in the research. Understanding my relationship to the children at the heart of this study is essential, because “it is the refusal to acknowledge the importance of the differences in our identities that has led to distrust, miscommunication, and thus disunity. [...] When I refuse to listen to how you are different from me, I am refusing to know who you are” (Alcoff, 2006, p. 6). Refusing to acknowledge difference in positionality denies histories and cultures, while a deep and honest understanding of difference forms the basis of radical social change. On this note, I hope that my research project contributes to a foundation of solidarity across lines of difference on which social change for children with facial differences can be built.

Study Overview

The purpose of this study is to deconstruct dehumanizing representations of children with facial differences in the Third World and catalyze a critical understanding of the work of international craniofacial non-governmental organizations. International craniofacial NGOs, organizations typically based in the U.S. that provide free reconstructive surgery to children born with facial differences around the world, aim to transform the lives of children with facial differences. This study focuses on four of those organizations – Smile Train, Operation Smile, Little Baby Face Foundation, and Operation of Hope. The research questions follow: (1) What role does ideology play in international craniofacial NGO’s representations of children with craniofacial differences in the Third World?, and (2) To what extent and in what ways do international craniofacial NGOs address the systemic barriers faced by children with craniofacial differences in the Third World, as portrayed by their social media materials?

Contextualizing these questions requires a theoretical framework that can deconstruct the intertwined systems of power that inform the work of the NGOs. Due to gaps in existing intersectional frameworks, I propose a new theoretical framework that brings together insights from Ethnic Studies, Disability Studies, and Feminist Studies. To develop the framework, I thread together four concepts – intersectionality, disability justice, postcolonial disability theory, and transnational feminism. In order to push back against Ethnic Studies’ and Feminist Studies’ exclusion of ableism and disability justice’s ignorance of neocolonialism, this framework explicitly centers disability and nation as critical axes of analysis. I call this new framework transnational disability justice, a paradigm for analysis and praxis that aims to simultaneously resist systems of ableism, colonialism, capitalism, racism, and heteropatriarchy.

Transnational disability justice guides literature review by encouraging a critical, intersectional lens for analyzing previous research. This approach significantly contrasts the goals of most previous research on facial differences and the work of international craniofacial NGOs, which stems from a medical based positivist framework. The literature review begins by introducing international craniofacial NGOs in general and highlighting the four organizations included in this study. Then, I investigate the problems that the NGOs aim to address, the main solution offered by the organizations, and one outcome of their work, representations of children with facial differences in the Third World. The literature review illustrates the urgency of conducting critical, intersectional research on the work of international craniofacial NGOs.

The methodology for this study is informed by the theoretical framework and literature review, which demonstrate the need for an analysis of representations of children with facial differences in the Third World that focuses on deconstructing systems of power. This study uses multimodal critical discourse analysis (MCDA) built on a framework of social semiotics that

connects critical discourse analysis and multimodal studies. Social media posts from the four NGOs' Facebook and Twitter accounts constitute the data. Data is selected through theoretical sampling based on conceptual significance and relevance to the research questions. Discursive narrative analysis, which is primarily used to analyze visual narrative presentation from photographs with supplemental written materials, guides the implementation of MCDA. This process includes three steps – visual description, interpretation, and explanation of macro systems. The data analysis uncovers the role of ideology in the creation of the social media posts.

Findings from this study and previous critical research contrasts the majority of research on facial differences in the Third World that stems from a hegemonic positivist paradigm. Unlike the dominant focus on the pathology of children with facial differences (Strauss & Broder, 1991), this research deconstructs the ideology that portrays the children as pathological and in need of fixing. I identified the following six themes in the analysis: (1) non-disabled white people save Third World children, (2) Western culture presumed as the norm, (3) objectifying norm-challenging bodies, (4) the necessity of capitalism for improving access to medical care, (5) defining successful womanhood and girlhood, and (6) normalization through surgery. The themes tell a hierarchical story about the lives of children in the Third World with facial differences and their relationship with international craniofacial NGOs.

This study reveals that the NGOs exacerbate and potentially even create the problems that they aim to address. The social media posts promote neocolonialism, ableism, heterosexism, classism, and eugenics. Ironically, these same systems of power create the lack of access to medical care, stigmatization of norm-challenging bodies, and economic disadvantages that the organizations seek to tackle. Considering the positive outcomes of increased survival rates for the children and greater awareness transnationally, these findings have complex implications.

Rather than arguing for the elimination of international craniofacial NGOs, this study calls for new ways to address the challenges faced by children with facial differences that center systemic social change and working in solidarity with affected communities.

Defining Terms

I chose to define key terms in this project for three reasons. First, this project introduces craniofacial literature to Ethnic Studies and Ethnic Studies literature to craniofacial scholars and advocates. As such, the two communities may be unfamiliar with the terminology of the other. Second, I aim to illustrate the intentionality of each term. I chose terms that stem from a critical and intersectional framework to support the goals of this project. Third, I seek to reduce ambiguity regarding the multiple uses of the key terms. The key terms defined in this section follow: craniofacial difference, disability, third world, and systems of power.

While the NGOs often use the terms “craniofacial deformity” or “facial deformity,” I chose the term facial difference. Based on my experience as part of the community, facial difference is the term used most frequently by patients with craniofacial conditions and their families. A craniofacial condition affects the growth of the head and skull and may lead to trouble with speech, eating, hearing, breathing, vision, and development. The impacts of a craniofacial condition vary significantly from a minor aesthetic difference to a life threatening complication. Approximately 1 in 500 babies are born with a craniofacial condition, and more develop conditions from disease, trauma, and tumors. Depending on access to medical care, the children often undergo reconstructive surgery and receive a variety of other treatments (World Craniofacial Foundation, n.d.). The term facial difference marks a departure from dominant ideology that identifies a craniofacial condition as an error in need of correction.

Disability is an ambiguous, contextual, and controversial term with various uses. In line with the purpose of this project, I chose a definition that centers an understanding of power. Garland-Thomson (1997) and Davis (1995) both argue that disability constitutes a bodily defiance of ableist norms. Garland-Thomson explains “disability, then, is [...] not so much a property of bodies as a product of cultural rules about what bodies should be or do” (p. 6). Davis elaborates on this idea, specifying two categories of cultural rules. He states “disability presents itself to ‘normal’ people through two main modalities—function and appearance” (p. 11). Considering the visibility and heterogeneity of facial differences, this definition will be critical to identifying the relationship between craniofacial conditions and ableism.

I use the term Third World to refer to the communities that receive treatment from the NGOs. While many of the NGOs provide services in the US and around the world, their marketing materials focus almost exclusively on the Third World. I struggled with selecting a term to talk about the communities for several reasons, including the inconsistent language between and within the organizations, the political significance of the terms used by the organizations, and the heterogeneity of the communities referenced by the terms. I draw from transnational feminists’ definition of the term Third World, which refers to a particular relationship between communities and power. Mohanty (1991) uses the term as “an analytical and political category [...] that links] the histories and struggles of third world [people] against racism, sexism, colonialism, imperialism, and monopoly capital” (p. 4). Additionally, the term refers to the “colonized, neocolonized, and decolonized countries whose economic and political structures have been deformed within the colonial process, [as well as] to black, Asian, Latino, and indigenous people in North America, Europe and Australia” (p. 4). Unlike the use of the term Third World by the NGOs, I use it to align my work with decolonizing literature.

CHAPTER 2: THEORETICAL FRAMEWORK

[T]he omission of disability as a critical category in discussions of intersectionality has disastrous and sometimes deadly consequences for disabled people of color caught at the violent interstices of multiple differences (p. 355).

– Erevelles & Minear (2013)

While Ethnic Studies and Feminist Studies recognize the importance of an intersectional framework, they often exclude or marginalize disability as a category of analysis (Erevelles & Minear, 2013; Erevelles, 2011; Garland-Thomson, 2013). Erevelles & Minear (2013) explain that Ethnic Studies and Feminist Studies researchers who critique dominant scholarship that erases the experience of communities marked as “Other” by multiple systems of power unconsciously erase the experiences of disabled people. The researchers treat intersectionality as a “race, class, gender triad” that excludes disability (Davis, 1995). Conversely, Garland-Thomson (2013) argues that “feminist theory’s omission of disability differs from disability studies’ [sic] ignorance of feminist theory” (p. 334). For instance, Bell (2006) terms Disability Studies “White Disability Studies” for its single-issue politics and ignorance of developments from other progressive disciplines (p. 374). The lack of solidarity between Ethnic Studies, Feminist Studies, and Disability Studies means that the scholars’ use of an intersectional framework fails to place individuals and communities on the margins of society at the center of analysis.

Two fields in particular have attempted to address the ignorance of Feminist Studies and Ethnic Studies within Disability Studies. First, Critical Disability Studies emerged as a direct critique of the single-issue approach to Disability Studies. Goodley (2012) defines Critical Disability Studies as a space to deconstruct multiple systems of power that marginalize disabled

people. Devlin and Pothier (2006) explain that Critical Disability Studies stresses systemic understandings of power. In contrast to Disability Studies, Critical Disability Studies centers the ways in which ableism is constructed by and maintains heteropatriarchy, capitalism, and racism. Second, self-identified disability justice advocates similarly center a critical intersectional approach to activism. Proponents of disability justice critique the assimilationist civil rights discourse of mainstream disability activists who fail to consider how theory and praxis differently affect various disabled communities. Although both Critical Disability Studies and disability justice center an intersectional approach, they continue to marginalize neocolonialism as a critical axis of analysis (Erevelles, 2011). As a result, existing theoretical frameworks in Ethnic Studies, Feminist Studies, and Disability Studies cannot fully deconstruct the interdependent relationships between ableism, neocolonialism, capitalism, racism, and heteropatriarchy.

This study uses two main steps to develop a new framework that aims to simultaneously resist ableism, colonialism, capitalism, racism, and heteropatriarchy. First, I thread together four concepts to develop what I call a transnational disability justice framework – intersectionality, disability justice, postcolonial disability theory, and transnational feminism. In order to push back against Ethnic Studies’ and Feminist Studies’ exclusion of ableism and disability justice’s ignorance of neocolonialism, this framework explicitly centers disability and nation as critical axes of analysis. Second, I apply transnational disability justice as a case example to demonstrate the uses of this new framework. I selected the work of international craniofacial NGOs, because the children treated by the organizations are marked as “Other” in multiple ways by the systems of ableism, neocolonialism, capitalism, racism, and heteropatriarchy. I hope that this framework

calls attention to the significance of disability and nation in intersectional analyses and provides tools for research conducted *with* communities on the “borderlands” (Anzaldúa, 1987).

Coining Transnational Disability Justice

A transnational disability justice framework builds upon the vital works of women of color, queer people with disabilities, and Third World women. This framework is only possible because of the vision, passion, praxis, and scholarship of the brave individuals who have come before me. I aim to bring these scholars and activists into conversation with one another in order to illuminate the radical potential of solidarity across lines of disability/ability, race, class, gender, sexuality, and nation. In this section, I outline four key concepts in transnational disability justice and conclude with identifying several applications of this framework.

The first concept in this discussion, intersectionality, was coined by Kimberle Crenshaw (1989) as a critique of the single-axis analysis used by many scholars and activists. Crenshaw resists the single-axis approach to analysis that dominates antidiscrimination law, feminist theory, and anti-racist politics by calling for an intersectional framework. She argues that dominant theorizing has a "tendency to treat race and gender as mutually exclusive categories of experience and analysis" (p.23), and that scholars need to adopt an intersectional analysis "because the intersectional experience is greater than the sum of racism and sexism" (p.24). In other words, Collins (1998) explains that “[a]s opposed to examining gender, race, class, and nation as separate systems of oppression, intersectionality explores how these systems mutually construct one another” (p. 63). While implicit intersectional theorizing has a long history (see Anzaldúa, 1987; Kollontai, 1908; Lorde, 1982; Truth, 1863), the introduction of the term in the late 1980s has resulted in several theoretical and practical advances.

Although Ethnic Studies, Feminist Studies, and Disability Studies scholars agree on the importance of intersectionality for deconstructing systems of power, a number of divisions amongst intersectional scholars remain. For one, three types of intersectional scholarship have emerged. Erevelles & Minear (2013) define the three types of intersectional frameworks as follows:

(1) anticategorical frameworks that insist on race, class, and gender as social constructs/fictions; (2) intracategorical frameworks that critique merely additive approaches to differences as layered stigmas; and (3) constitutive frameworks that describe the structural conditions within which social categories in the above models are constructed by (and intermesh) with each other in specific historical contexts (p. 354).

Crenshaw (1996) critiques the anticategorical framework for erasing the significance of lived experience. She explains that social categories and their associated identities, which are minimized by postmodernism, are critical to how women of color experience power relations. Still, Erevelles & Minear (2013) assert that the dominant intracategorical framework used by feminists of color falls short of being able to fully conceptualize disability as a critical axis of analysis. Although the intracategorical approach rejects “additive approaches to differences,” it does not offer the strategies necessary for approaching disability from an intersectional lens. Erevelles & Minear pose Yuval-Davis’s (2006) intercategorical or constitutive framework as a possible solution to the limitations of the intracategorical approach.

Disability justice demonstrates the applications of a constitutive intersectional framework. Mia Mingus (2013), a central figure in the disability justice arena, explains it as a movement and theoretical framework that understands disability as a multi-issue politic and centers the intersections of disability, class, race, gender, citizenship, colonization, and

militarization. She continues to explain “disabled people aren’t just disabled people” (EquitableEducation.ca, 2013). Rather, “we are disabled people who are people of color; women, genderqueer and transgender; poor and working class; youth; immigrants; lesbian, gay, bisexual and queer; and more” (Mingus, 2011, para. 12). When considering the race, class, sexuality, gender, and immigration status of disabled people, we can no longer be understood as a monolithic group. As such, disability justice recognizes the limitations of intersectional frameworks that treat identities as stable and monolithic categories. Instead, disability justice centers a systemic analysis of power that deconstructs how ableism, racism, classism, capitalism, heteropatriarchy, and neocolonialism constitutively other communities that defy dominant conceptions of how bodies and minds should look and function.

Disability *justice* marks a significant departure from the hegemonic disability *rights* movement. The distinction between justice and rights means a difference in theory, action, and vision between the two movements. Regarding theory, Mingus explains the departure of disability justice from disability rights as “talking about what justice and liberation would look like, not just equality, which is very different” (EquitableEducation, 2013, 16:20). While equality pushes for the assimilation of a select few disabled people into current systems of power, justice proposes changing the systems to benefit all communities. This theoretical framework carries over into the praxis of disability justice. Mingus argues that disability rights focuses on “access just for the sake of access,” (9:40), while disability justice fights for “access for the sake of justice and liberation; access for the sake of deeper connection” (EquitableEducation, 2013, 8:20). “Access for the sake of justice and liberation” recognizes that ableism is inextricable from other systems of power. Disability justice imagines a world where community and

interdependency is valued, where people on the margins can be their whole selves in all spaces, and where difference is valued for the knowledge and experience it yields.

While disability justice marks significant progress towards a constitutive intersectional framework, it continues to marginalize Third and Fourth World people. Disability justice developed with a Western context, and the literature does not explicitly include a transnational perspective. For instance, although Mia Mingus (n.d.) identifies as a “disabled Korean woman transracial and transnational adoptee, born in Korea, raised in the Caribbean, nurtured in the U.S. South, and now living in Northern California,” she rarely explicitly includes the category of nation or considers the specificity of location in her analyses. Additionally, Erevelles (2011) argues that “while there have been a few books that have examined disability outside the United States, their discussions are restricted primarily to disability issues in the advanced industrialized countries” (p. 19). Disabled people in the Third World continue to be marginalized by disability advocates. A disability justice approach that lacks an understanding of colonialism and neocolonialism can have deadly consequences.

Erevelles (2011) explains the significance of the intersection of disability and nation as follows: “With the Third World already designated as a space of terror, disabled people who are confined to these spaces run the risk of almost complete erasure, and, subsequently, face the most extreme dehumanization on account of this non-human recognition” (p. 122). Disability justice advocates, already committed to liberation that transforms erasure of otherness into a celebration of difference, must also deconstruct the dependent relationship between ableism and colonialism. Following Crenshaw’s (1989) logic that “when [communities on the margins] enter, we all enter,” placing disabled people in the Third and Fourth Worlds at the center of analysis advances the goals of constitutive intersectionality (p. 51).

Postcolonial disability theory begins to address the significance of nation, location, and colonialism in resisting ableism. Ashcroft, Griffiths, and Tiffin (2007) use the term postcolonial to refer to “all the culture affected by the imperial process from the moment of colonization to the present day” (p. 2, cited in Sherry, 2007). Barker & Murray (2013) and Sherry (2007) identify similar problems that arise from the separation of Disability Studies and Postcolonial Studies, pointing to the misuse of disability as a metaphor for colonization, simplistic comparisons between disability and race, and overlooking the methodological and theoretical gains that can stem from an integrated approach. Additionally, Sherry (2007) explains that the division contributes to an exclusively identity based understanding of disability and colonization, “as if they were of concern only to those people who identify both as disabled and members of a colonized group” (p. 16). As a result, disability and postcolonial scholars advance a misunderstanding of systemic power relationships.

Postcolonial Disability Studies scholars have proposed several strategies for addressing the misunderstanding of power that stems from the gap between Disability Studies and Postcolonial Studies. Barker & Murray (2013) argue that Disability Studies must be decolonized by “interrogat[ing] the universal approach to disability naturalized within the social model of disability in particular” (p. 67). Similarly, Sherry (2007) states that Postcolonial Disability Studies scholars must use a “culturally-specific examination of disability and impairment” (p. 17). Decolonizing Disability Studies requires developing and using models of disability based within particular communities and experiences, rather than imposing the hegemonic Western understanding of disability that stems from the social model. Both Barker & Murray and Sherry argue that new approaches must center a critical understanding of power dynamics that critiques

the additive approach to intersectionality and instead employs a constitutive understanding of the relationships between ableism and colonialism.

Transnational feminism provides additional strategies for decolonizing Western knowledge, particularly in terms of fostering coalitions across national and geographic borders to resist systems of power. Similarly to postcolonial disability theory's critique of the colonial tendencies in Disability Studies, transnational feminism developed in response to the hegemony of Western feminism. In an auto-ethnographic analysis of a visit to Egypt, Angela Davis (2011) rejects dominant Western feminist understandings of non-Western women. She critiques their understanding of "saving" Third World women, explaining that this approach disregards the agency and dignity of the women and their communities. Furthermore, Western feminists rarely have the necessary knowledge about the communities they claim to "help." The hegemonic ideology of Western feminism results in a problematic understanding of Third World women "as an embodiment of lack, and mirror ableist representations of disabled women" (Erevelles, 2011, p. 130).

Mohanty (1988) identified central tenants of transnational feminism in response to critiques like those of Davis. The key approaches and values include placing feminist scholarship within a global framework, conducting particularized analyses that connect to global frameworks, the examination of the "political implications of our analytic strategies and principles," and a vision of solidarity across borders (p. 64). Salem (2014) also stresses the importance of self-reflexivity and grassroots activism in transnational feminism. A transnational perspective provides a framework for resisting the colonial tendencies of Western academics and activism.

Weaving together the concepts of intersectionality, disability justice, postcolonial disability theory, and transnational feminism offers a nuanced understanding of systems of power. I call this transnational disability justice, a paradigm for analysis and praxis that aims to simultaneously resist systems of ableism, colonialism, capitalism, racism, and heteropatriarchy. The name explicitly recognizes disability, which has been marginalized as an axis of analysis within Ethnic Studies and Feminist Studies, and nation, which has been sidelined within disability justice. Transnational disability justice identifies ways in which the concept of intersectionality has unintentionally been used to advance the social, economic, and political location of particular communities at the expense of others. Transnational disability justice has similar implications as Erevles' (2011) concept of the "transnational feminist disability studies perspective." She explains this framework as one "that engages gender and disability and their intersections with race, class, and sexuality within the material context of the post/neocolonial state" (p. 141). Both perspectives deconstruct the origins and effects of normalcy that works to justify the seemingly "natural" inferiority of communities marked as Other. Marginalized communities must work in solidarity with one another across physical and social borders, deconstructing the ways in which their own relationships to privilege and oppression affect one another. Working in solidarity changes the focus of progressive movements from advocating for civil rights for a particular group, which requires integration into the existing systems of power, to envisioning liberation for all from systems of power.

Theorizing Facial Differences in the Third World

In order to identify the applications and significance of transnational disability justice, I use the paradigm to analyze a case study. Although transnational disability justice has wide applications for a constitutive intersectional analysis, I focus here on one particularly illustrative

case, children with craniofacial differences in the Third World. Systems of ableism, neocolonialism, capitalism, racism, and heteropatriarchy directly shape the social, political, and economic positions of the children and their families. The children's visible physical differences, ethnicity, language, geographic location, nationality, sexuality, and economic status all challenge hegemonic Western norms of bodies. The ways in which the children defy these norms becomes particularly evident in their interactions with international craniofacial NGOs. By demonstrating the applications of transnational disability justice, this case analysis also begins to challenge hierarchical power dynamics that impact the children and their communities. A transnational disability justice analysis of the social position of children with craniofacial differences in the Third World raises several insights about systems of power and categories of difference.

First, the framework points towards the challenges of defining disability within a critical intersectional context. Davis (1995) argues that contrary to dominant belief, the category of disability is unstable, ambiguous, and politically defined. The political influence in definitions of disability is particularly evident in the tension between the individual and social models of disability. The individual model defines disability as a problem stemming from the physiology of individual bodies and locates the solution to disability as medical intervention. Disability activists critique this model for reducing the challenges faced by disabled people to impairment and disregarding the effects of systems of power (Oliver, 1996; Shakespeare 2013). In contrast, the social model adopts a structural approach to understanding disability that "claim[s] that disabled people are an oppressed group" (Shakespeare, 2013, p. 215). Several critiques of the social model have emerged. For instance, the model minimizes the impact of impairment on disabled people's lives and suggests a strict division between disability and impairment. Furthermore, the social model reflects the values, knowledge, and goals of an exclusive group of

disabled people. Shakespeare (2013) explains that the dominant authoring organization of the social model the Union of Physically Impaired Against Segregation (UPIAS), were a “hard-line, male-dominated, and determined” group from Britain. (p. 215). Although the social model makes significant progress towards resisting ableism, it continues to marginalize disabled people by advancing a hegemonic Western and heteropatriarchal notion of disability.

Critical approaches to defining disability center a constitutive intersectional framework that untangles the ways in which the category of disability has been constructed in relationship to race, class, gender, nationality, and sexuality. Baynton (2001) explains how the category of disability has been used to justify the marginalization of several communities marked as Other. For example, proponents of American slavery justified the oppressive system by claiming that black people lacked the intelligence necessary to fully contribute to society. Additionally, the government has policed American citizenship through defining deserving and undeserving immigrants on the basis of disability. Erevelles (1996) proposes a similar argument, but focuses on how the constitutive construction of disability operates on a broader systemic level. She states that

the ‘ideology’ of disability is essential to the capitalist enterprise because it is able to regulate and control the unequal distribution of surplus through invoking biological difference as the ‘natural’ cause of all inequality, thereby successfully justifying the social and economic inequality that maintains social hierarchies (p. 526).

Thus, multiple systems of power thrive on a hegemonic definition of disability that frame the category as an inferiority.

Perhaps then a positive understanding of disability can challenge the justification of inferiority on the basis of bodily difference. Both Price (2013) and Samuels (2013) beautifully

describe reasons for embracing disability that challenges systems of power. Price (2013) states “while I respect the concerns of those who reject the label disabled, I have chosen to use a term that includes disability explicitly. In my own experience, claiming disability has been a journey of community, power, and love” (p. 203). Similarly, Samuels (2013) recounts the story of one of her students, Samantha, whose parents criticized her decision to identify as disabled. She “conclude[s] that, for Samantha, ‘being disabled’ means not being a victim, not a special case, but a member of a proud and fierce community” (p. 324). Both depictions contrast the justification for inferiority by associating resistance, agency, and power with disability. This understanding of disability is based in the actual experiences and perspectives of disabled people, rather than the systems that benefit from social hierarchies.

A transnational disability justice understanding of disability must be rooted in the experiences of disabled people and adopt an approach of specificity rather than universality. Elizabeth Cantalamessa (2015) offers a model of disability that does exactly this. She coined the narrative model of disability, an approach that seeks to explain the phenomenological and existential aspects of disability through auto-ethnographic narratives of living with a disability. The narrative model does not attempt to make global claims about the definition or cause of disability. Rather, the model seeks to attribute recognition and validity to the stories of disabled people and their families as valuable knowledge. This model reflects the ideals of transnational feminism by fostering particularized understandings of difference.

While I have the privilege of being able to essentially forget about my cleft due to my positions of privilege that enabled me to access quality medical care from infancy, children in the Third World have a variety of different narratives due to their specific positionalities. Restricted access to medical care, cultural understandings of facial differences, and interactions with

medical NGOs contribute to distinct experiences mediated by systems of power. Following the insights from postcolonial disability theory and transnational feminism, I aim to resist hegemonic understandings of facial differences and disabilities. Thus, my goal here is not to develop a universal model of the relationship between facial differences and disabilities. Rather, I intend to uncover the ways in which insights from the experiences and knowledge of disabled people can inform an analysis of facial differences. Davis (1995) explains that the *language* of disability can be strategically used despite the ambiguity in the *category* of disability. The language of disability allows us to talk about the ways that children with facial differences are impacted by ableism due to their norm challenging facial appearance and/or function. This helps align the analysis with existing literature on the interaction between norm challenging bodies and systems of power, which results in a systemic understanding of the connection between craniofacial differences and ableism, colonialism, racism, capitalism, and heterosexism. Thus, transnational disability justice illustrates the ways in which disability consciousness can inform a variety of analyses regarding norm challenging bodies in ways that resist imposing a hegemonic model of disability.

Second, a transnational disability justice framework fosters coalitional politics across borders of ability/disability, nationality, race, ethnicity, class, gender, and sexual orientation. The paradigm promotes solidarity precisely because it resists hegemonic notions of identity and categorization, as illustrated by the discussion on defining disability. Gloria Anzaldúa's (1987) concept of the "borderlands" provides critical insights regarding solidarity. She developed the concept of the borderlands to describe

a vague and undetermined place created by the emotional residue of an unnatural boundary [...in which...] the prohibited and forbidden are its inhabitants. Los

atravesados live here: the squint-eyed, the perverse, the queer, the troublesome, the mongrel, the mulatto, the half-breed, the half dead; in short, those who cross over and pass over, or go through the confines of the 'normal.' (p. 25)

The borderlands are a place of “ambivalence and unrest,” but also of resistance and strength (p. 25). The idea of the borderlands encourages activists to rethink dominant understandings of identity, the relationship between the Third World and Western powers, and forms of resistance. Furthermore, the borderlands can make sense of the relationship between “los atravados,” despite differences in experiences and positionality, due to their shared inhabitation of this “vague and undetermined place.” Watts (2004) calls Anzaldúa a transnational feminist for the ways in which she challenges traditional Chicano nationalist tendencies through embracing the relationships queers, women, and disabled people *as* Chicano/as.

The concept of the borderlands helps us to conceptualize the theoretical, imagined, and lived space in which children with craniofacial differences in the Third World exist. I argue that the children occupy the “borderlands” due to the ways in which they “go through the confines of the ‘normal’” as constructed by dominant Western ideology. A craniofacial condition varies significantly from a minor aesthetic difference to a life threatening medical problem. Due to the aesthetic and functional aspects of facial differences, the children defy ableist norms that purport that children must speak, hear, see, look, and act a particular way. The children’s defiance of ableist norms works in conjunction with capitalism, illuminating the connection that Erevelles (1996) makes regarding the constitutive functions of disability in the maintenance of a “capitalist enterprise” (p. 526). The children defy ableist norms because they lack access to the economic resources that could reduce their atypical facial appearance and function. Their limited access to medical care is mediated by Western medical NGOs that impose a particular interpretation of the

children's conditions. Theorizing about the political, economic, and social locations of children with facial differences in the Third World within the context of the borderlands illustrates the ways in which normalcy functions to maintain intersecting systems of power. Baynton (2001) explains the role that normalcy plays in "establishing social hierarchies that justify the denial of legitimacy and certain rights to individuals or groups" (p. 3). He argues that the concept of normalcy developed in conjunction with Western beliefs about "evolutionary progress" and eugenics ideology. Los atravesados can unite in a collective mission of challenging concepts of normalcy that have been used to justify their place in the borderlands.

Conclusion

By weaving together the concepts of intersectionality, disability justice, postcolonial disability theory, and transnational feminism, I have built upon existing theories to develop a new paradigm for resisting systems of power. Transnational disability justice offers both broad and specific insights regarding intersectional approaches to epistemology and praxis. Regarding broader applications, transnational disability justice demonstrates the importance of a constitutive intersectional analysis in Ethnic Studies, Feminist Studies, and Disability Studies. Unlike the dominant attempts within these fields, transnational disability justice provides the paradigm necessary for truly placing people on the margins at the center of analysis by centering the valuable perspectives people of color, disabled people, Third World communities, working class people, women, and queer and transgender individuals. Regarding specific applications, this analysis illustrates one way in which transnational disability justice can provide a theoretical framework to research children with facial differences in the Third World. In contrast to most previous research on this topic, a transnational disability justice framework allows this research to be conducted within a critical decolonial context. This framework can make sense of the

significance of international craniofacial NGOs. As Redfield (2007) explains, “a humanitarian response to human suffering, after all, cannot escape either the historical context of conditions to which it responds or its own categorical rejection of any justification for the sacrifice of human lives” (p. 329).

CHAPTER 3: LITERATURE REVIEW

The rise of modern medicine and surgery raised the possibility that deformed or handicapped persons might be offered treatment to improve their situations. The desire to provide treatment and remediation, also known as medical activism, is characteristic of how Western society responds to children with birth defects.

– Strauss & Broder, 1991, p. 154

As Strauss & Broder (1991) describe, a particular social, cultural, and economic context has shaped how “Western society responds to children with birth defects,” particularly children with congenital craniofacial conditions. Social attitudes that deem atypical faces unacceptable, medical advances that offer viable corrections to birth “defects,” unjust distribution of economic resources and associated medical care, and Western notions of charity gave rise to international craniofacial NGOs. Supporters of the organizations pursue “medical activism” through offering surgical solutions to the complex challenges experienced by children with facial differences in low- and middle-income countries. Despite the significant influence of the historical and societal forces that affect Western responses to facial differences, only a handful of researchers consider these forces.

Previous research on facial differences, with only a few known exceptions, stems from a positivist paradigm that perpetuates dominant Western ideology. Most researchers focus on demographics of people with facial differences, medical approaches to correcting facial differences, and the psychological well-being of children with facial differences and their families. Psychological research has positively shifted from historically using a medical model, based on identifying “natural” functional differences of people with facial differences, to recently centering a social model that instead focuses on the environmental influences on well-

being and cultural beliefs about facial differences (Strauss & Broder, 1991). Despite a shift in pockets of research from nature to nurture models, the shift is not a final solution and significant research gaps remain. Little research exists on the systemic influences and effects of how “medical activism” approaches facial differences, particularly in the Third World.

I begin this literature review with introducing international craniofacial NGOs and highlighting the four organizations that will be included in the study – Operation Smile, Smile Train, Little Baby Face Foundation, and Operation of Hope. Then, I investigate three areas of international craniofacial NGOs – the problems that the NGOs aim to address, a main intervention offered by the NGOs, and one key outcome of the work of the NGOs. The conclusion discusses areas of need for future research and identifies how this project fits with current and future research. I hope that this literature review will shed light on the existing critical, systemic literature on international craniofacial NGOs.

Introducing International Craniofacial NGOs

I define international craniofacial NGOs as Western-based medical organizations that offer reconstructive surgery to individuals, primarily children, with facial differences in the Third World. A combination of Western staff and volunteers, local medical professionals, and charitable contributions fuel the organizations. In addition to performing surgeries, many of the organizations also train local medical providers in craniofacial surgical techniques. Despite their similar missions of “improv[ing] the well-being of children affected by facial deformities,” differences in size, scope, and condition focus distinguish the organizations (Weatherley-White, Eiserman, Beddoe, Vanderberg, 2005, p. 560). The growth of international craniofacial organizations coincides with the development of modern craniofacial surgery.

The present day Western medical approach to treating cleft lip and palate developed from religious, cultural, political origins dating back to ancient times. Bhattacharya, Khanna, & Kohli (2009) named the earliest documented history of clefts “the age of denial and ignorance” (para. 2). The Spartans and Romans understood congenital anomalies as the manifestation of evil spirits, and thus they killed or abandoned infants born with facial differences. Greek medical records lack reference to clefts, although a statuette from 700-300 BC depicts a clown with a cleft lip. Chinese surgeons performed the first documented case of cleft surgery on an 18-year-old future soldier in 390 BC. By the 16th century, Fabricius ab Aquapendente suggested that clefts arise from embryological complications, which marked a departure from the earlier superstitious explanations. Knowledge of the etiology and medical treatment of clefts continued to develop from the Renaissance through the 19th century. Current surgical approaches to clefts were refined in the 1950s with the “cut as you go” technique (Bhattacharya, Khanna, & Kohli, 2009). Surgical approaches continue to rapidly improve and expand today.

While the treatment options and medical resources for children with facial differences vary among cultures and regions, a common trend has emerged in the last few decades. Strauss (1992) explains that the survival rate for infants with craniofacial anomalies has greatly increased with the rise of craniofacial surgery, neonatal intensive care, prenatal diagnosis, and outlawing of infanticide in particular regions. With the growth of international craniofacial NGOs in the late 20th century, craniofacial surgery has become a feasible option for children who otherwise would not have the access to medical care

This project focuses on four of those organizations – Operation Smile, Smile Train, Operation of Hope, and the Little Baby Face Foundation. These NGOs share a similar mission of providing surgical care to children with facial differences with limited financial means around

the world, but vary by size, reach, and strategies. This section reviews the history, services, and stories of the four organizations.

Operation Smile (2014a), one of the largest international craniofacial NGOs, has a vision “of a world where no child suffers from lack of access to safe surgery” (p. 2). They aim to deconstruct the financial, geographic, and cultural barriers to medical care for children with cleft lip and palate. Their approaches to improving access to care include sponsoring medical missions, developing local care centers, spearheading research on preventing and treating clefts, training local medical providers on the specificities of clefts, and advocacy. Since Dr. William and Kathleen Magee founded Operation Smile in 1982, the organization has provided over 220,000 surgeries to children in more than 60 countries (Operation Smile, n.d.). In 2014 alone, Operation Smile performed 19,415 surgeries on 16,626 patients and shipped \$6 million worth of medical supplies to various countries. The organization applauds itself for its strong partnerships with local communities, citing that 71 percent of medical volunteers come from low- and middle-income countries (Operation Smile, 2014b). Although the Operation Smile now has successful strategies for increasing sustainability, critiques point out that Operation Smile’s earlier reliance on medical missions disempowered local communities and increased costs (Porter Brown, 2009).

Smile Train developed in part as a response to critiques of Operation Smile. Brian Mullaney initially worked with Operation Smile in 1994, but then split in 1997 to start Smile Train with Charles Wang. Mullaney disapproved of how leaders at Operation Smile initially used a “colonial model” of charity in which “foreign doctors get off the plane and act like Jesus Christ [saying] – ‘Give me your crippled and I’ll health them” (Porter Brown, 2009, para. 7). Medical volunteers would sideline local doctors and offered no sustainable solution to the lack of medical

care. Unlike Operation Smile, Smile Train does not conduct medical missions. Rather, they provide training, funding, and equipment to local partners to ensure they have the resource to provide free surgery to children with clefts. Smile Train uses a business model built on local partnerships to increase its productivity and sustainability. The organization had performed over 880,000 surgeries in 85 countries by 2013 (Schafer, 2014).

Although Smile Train marks a departure from the blatantly imperialistic approach of Operation Smile, dominant Western ideology still underlines the organization's foundation. For instance, during an interview with *Harvard Magazine*, Mullaney uses problematic language to describe his inspiration for working with children with clefts. He explained that during subway rides to work "on advertising accounts for Park Avenue cosmetic surgeons," he would encounter "these kids, mostly immigrant and poor children, with giant port-wine stains or a hairy nevus across their face, kids with six fingers, or missing an ear, or a scar that was wide open, or horrible teeth, and I know my surgeons could fix those" (Porter Brown, 2009, para. 9). His quote clearly reflects his upper-class, able bodied, and American privilege.

Hierarchical power relationships also fill the work of the Little Baby Face Foundation. Dr. Thomas Romo, II and Lauralouise Duffy-Blatt founded the nonprofit to provide free surgeries to children with congenital facial differences in the U.S. and around the world whose families could not afford the procedures. They provide surgery, medical care, family support, physician education, and research. To provide services, the Little Baby Face Foundation flies the children from their home countries to New York City and covers the related costs. The organization has performed over 500 surgeries since its founding in 2002 (Little Baby Face Foundation, n.d.). The Little Baby Face Foundation gained national media attention in 2012 for an operation it performed on a Nadia Ilse, a 14-year-old girl from Georgia born with bilateral

lop-eared deformities. After her mom wrote to the organization because Ilse's classmates bullied her, the organization performed significant plastic surgery on her ears, nose, and chin. Although the story gained attention for the effects of plastic surgery on reducing bullying, Romo insists "she wasn't picked to have her surgery because she was bullied. She was picked for her surgery because of her deformities and we could correct that surgically" ("Nadia Ilse," 2012, para. 7). Ilse's story sparked public conversations about the use of plastic surgery on children to reduce bullying and the definition of facial "deformity."

Unlike The Little Baby Face Foundation, Operation of Hope Worldwide primarily conducts medical missions by sending American doctors to Third World countries, similarly to Operation Smile's early approach. The organization provides "surgical care, healthcare, & medical training programs in under-served areas of the world," focusing on children with facial differences in the Third World (Operation of Hope Worldwide, n.d., para. 1). They are based in San Diego, CA, but provide services through medical missions primarily in Zimbabwe. Their focus on Zimbabwe stems from the prevalence of birth anomalies in the area and the severe stigmatization of children with clefts. Many of the parents who seek treatment for their children report stories of "being told by a n'anga, the traditional village healer, that children with cleft defects should have been drowned at birth" (Lee Ball, 2008, p. 1). Since Dr. Joseph Clawson founded the organization in 1988, they have served over 3,000 children. Although these four organizations have varying reach, histories, and approaches, they are united in their common missions of providing surgical care to children with facial differences who otherwise would not be able to access care due to financial and geographic restraints.

Needs of Third World Children with Facial Differences

The prominence and social significance of the face distinguish the perceived challenges experienced by children with facial differences. Faces are the medium through which sensory input, learning, bodily functions, and interactions occur. Garland-Thomson (2009) expands upon the role of the face in social interactions, stating “our faces, for example, are the first territory our eyes inhabit when we encounter one another” (p. 95). As a result of the prominence of the face in interactions with the world, it is a critical instrument for judging an individual’s character, physical health, and ethnic and family heritage. As Garland-Thomson (2009) puts it, “faces, then, are texts we engage or resist, opportunities for revelation or refusal” (p. 101). A face that defies norms of visual appearance and/or physical or sensory function disrupts these expected interactions. International craniofacial NGOs seek to address the complex physical, emotional, mental, spiritual, and social needs of children with facial differences in the Third World that arise from this distinct context. In this section, I will explore three main needs that the NGOs aim to remedy through their interventions.

First, the organizations recognize that children with facial differences in the Third World lack access to basic medical care. A child’s relationship to power and privilege significantly impact his/her medical care access. Rozendall et al. (2012) explain that the availability of cleft treatment varies by gender, ethnicity, class, and geographic region. For instance, the percentage of children with clefts who receive cleft palate operations differs greatly based on the wealth of the child’s country, ranging from 22 percent in low-income countries to 70 percent in developed countries. A lack of access to medical care can have deadly consequences for the children. Due to undiagnosed cleft palates and associated feeding challenges, babies with clefts who lack access to medical care often experience malnourishment. This results in higher incidents of infection, including malaria and respiratory tract infections. Accurate diagnostic information,

appropriate feeding strategies, and early surgical care can greatly improve the health and well-being of children born with cleft lip and/or palate (Cubitt et al., 2014).

Negative attitudes towards disability and indigenous medicine underline the existing research about the need to provide medical care to children with facial differences. For instance, Salyer (2013) argues that the need for remedying unequal access to care lies in the prevention of disability. He states that “normal speech, vision, and hearing are essential for children’s early years, to become the foundations of productive lives, and many permanent disabilities can be prevented with proper early diagnosis and treatment” (p. 302). This quote suggests that only an able-bodied adult can achieve a “productive life” and that the emphasis in care should be minimizing future disability. Hegemonic values also pervade the research of Cubitt et al. (2014), who point towards a reliance on indigenous medicine rather than Western medicine as a cause of the medical challenges of children with clefts. This analysis suggests that intentions of minimizing disability and expanding Western medicine underline the goals of improving access to medical care for children with facial differences in the Third World.

Second, scarce resources also contribute to the abuse and eugenic infanticide of children born with facial differences. From an anthropological perspective, Scheper-Hughes (1990) cites the economic, cultural, and demographic influences on the mistreatment of the children. In some communities, parents must decide whether or not to raise a child based on the child’s future economic value. They inspect the child’s physical attractiveness and health to predict his or her adult economic contributions and marriageability. She explains “sickly, weak, or physical different neonates may be sacrificed in order to protect scarce resources (including maternal love and attentive nurturing) for older, healthier siblings or the lives of those yet to be born” (p. 302). Babies who fail this initial inspection will not be granted “human status” and will be sentenced to

infanticide or categorized as “untouchables.” Considering that the visibility of the head and face plays a primary role in the decision, children with facial differences are frequently subjected to death or abuse. While the practice of infanticide has diminished during the 21st century in many areas, including amongst the rural Irish of West Kerry and the Baribas in the People’s Republic of Benin, the maltreatment of children with facial differences continues to be acceptable in both Third World and industrialized nations (Scheper-Hughes, 1990). International craniofacial NGOs recognize that children with facial differences disproportionately bear the weight of scarce resources in a community.

While Scheper-Hughes (1990) identifies a critical need of children with facial differences in the Third World, her research lacks a critique of the ways that the positionality of the researcher affects the research. Tuhiwai Smith (2012) critiques dominant Western research, particularly anthropology, for dismissing the history, knowledge, and voices of indigenous communities and imposing Western values. Western researchers have justified the colonization of indigenous communities through claiming objectivity in the research process. In the case of Scheper-Hughe’s research on the eugenic infanticide of babies with congenital facial differences, I approach the conclusions with caution due to the lack of investigation of the ways that her location as a Western anthropologist affects her understanding of the situation. The communities under investigation may give significantly different explanations for their treatment of children with facial differences than those offered by outside Western researchers. Considering the implications of concluding wide-spread infanticide of infants with facial differences, I suggest the need for more critical research that centers the knowledge of the communities.

Third, the infanticide and abuse of children with facial differences goes hand-in-hand with the stigmatization of facial differences (Scheper-Hughes, 1990). Goffman (1963), who

spearheaded research on stigma, defines a stigma as “an attribute that is deeply discrediting” and reduces the person with the stigma “from a whole and unusual person to a tainted, discounted one” (p. 3). Stigma functions to confirm the normalcy of people without stigmatized attributes. Coleman Brown (2013) expands upon Goffman’s understanding of stigma and asserts that stigma acts as a tool of social control to maintain social hierarchies. She explains that “in part, stigmas reflect the value judgments of a dominant group,” because those in positions of power determine which human attributes to deem “undesirable” (p. 146). Thus, stigma not only discredits individuals with undesirable qualities, but also justifies their marginalization.

Western culture especially stigmatizes facial differences due to their visibility and role in social interactions. This conclusion follows from Coleman Brown’s (2013) argument that physical anomalies “may be the most severely stigmatized differences” (p. 148). Viewers assume visible physical anomalies to be representative of bodily deficiency. This is especially true of facial differences, considering the history of physiognomy. Goffman (1963) asserts that “for years the scar, harelip or mishappen nose” have been stigmatized and explains that the face’s “importance in the social and emotional adjustment is unconsciously all embracing” (p. 10). Despite the lack of systemic, critical investigation of facial differences, researchers have consistently identified a clear link between facial differences, stereotypes, and social expectations (Strauss & Broder, 1991). Operation Smile (2014b) points directly to stigma, in addition to medical needs and speech challenges, as a reason for providing surgery to children with clefts. Although researchers and international craniofacial NGOs identify the stigmatization of facial differences as a central challenge faced by the children, they fail to make the connection between stigma and power that Coleman Brown (2013) asserts is essential to understanding the function and effects of stigma.

This section focused on three particular challenges experienced by children with facial differences in the Third World - the lack of access to medical care, infanticide and child abuse, and stigmatization of facial differences. These three areas only represent a portion of the needs that international craniofacial NGOs aim to address. Other perceived needs include the lack of educational opportunities, marriageability, shame, and isolation experienced by children with facial differences in certain communities (Scheper-Hughes, 1990; Strauss & Broder, 19991; Weatherley-White, 2005). Despite the partiality of this exploration, a common theme emerged throughout this analysis. The challenges faced by children with facial differences in the Third World stem from their location within intersecting systems of power. Scarce economic resources, colonization, and stigmatization disproportionately affect children with facial differences in the Third World based on their gender, ethnicity, socioeconomic status, geographic location, national origin, and disability status.

Appearance Normalizing Surgery

The international craniofacial NGOs in this study all use reconstructive surgery as the primary approach for addressing the challenges experienced by children with facial differences in the Third World. As Mullaney purports, “we know what the cure is [for cleft lip and palate]: it’s a simple, 45-minute procedure that costs donors as little as \$250” (Porter Brown, 2009, para. 5). The NGOs claim to address the lack of access to medical care, infanticide, abuse, and stigma experienced by the children by literally altering their faces. The motto of a “45-minute” “cure” to the marginalization and sometimes death of children with facial differences in the Third World has incredible appeal to supporters, donors, and volunteers.

While the NGOs tout surgery as the universal solution to these needs, critical scholars warn against unquestioned surgical intervention on children with congenital differences. In 1995,

professionals in a variety of fields sparked future research with a series of six papers on “Experiencing Clinical Ethical Dilemmas” at the annual meeting of the American Cleft Palate-Craniofacial Association. Following the conference, Erik Parens launched the Hastings Center’s Surgically Shaping Children project in 2001 to explore ethical considerations of appearance-normalizing surgery on children. Out of the project emerged a collection of essays and short personal stories in *Surgically Shaping Children: Technology, Ethics and the Pursuit of Normality*. The book draws parallels between ethical dilemmas in decision-making for surgery on children with craniofacial anomalies, dwarfism, and ambiguous/incomplete genitalia (Parens, 2006). Their research has resulted in major insights regarding the surgical shaping of children with facial differences.

Surgically shaping children raises incredible “conceptual, ethnical, and social issues” (Parens, 2006). Marsh (2006) argues that appearance-normalizing surgery performed on children stems from the dominant perception that “we should use surgery to normalize individuals” (p. 113). The normalizing function of pediatric plastic surgery is especially apparent with craniofacial operations, considering that most congenital facial differences do not pose life-threatening complications when the child receives adequate care and nutrition. For instance, Aspinall (2006), an adult born with a cleft and mother of a son with a cleft, poses the question, “Should I go through surgery to help improve your impression of me, when my sense of self-acceptance is not the issue, but your treatment of me is?” (p. 18). Surgically normalizing children is a seemingly easier way to address the stigma experienced by children with congenital differences than changing the norms that mark the children’s bodies as deviant.

This understanding of the normalizing functions of reconstructive surgery brings up questions of when doctors should perform surgery on children. Marsh (2006) identifies four

conditions in which doctors should perform pediatric surgery: “(1) to postpone death; (2) to prevent irrevocable consequences; (3) to alleviate pain and suffering; and (4) to improve the quality of life” (p.117). Although Marsh clearly defines the conditions, deciding what constitutes “irrevocable consequences,” “suffering,” and “quality of life” poses immense challenges. For instance, Marsh argues that speech delays from cleft palate constitute “irrevocable consequences.” From a disability justice perspective, assuming that speech difficulties or lack of speech should automatically be corrected whenever possible has problematic implications. While medical ethicists and surgeons have made strides in identifying new concerns with the growth of craniofacial surgery, their research is limited by the lack of self-reflexivity on how their upper-class, able-bodied, Western positions influence their conclusions.

Outside of the Surgically Shaping Children project, sociologists, anthropologists, Feminist Studies, and Disability Studies scholars critique the ways that reconstructive surgery eliminates physical difference. Garland-Thomson (2013) argues that reconstructive surgery, which operates as discourses in both medicine and appearance, functions to regulate deviant bodies. She asserts that both cosmetic and reconstructive surgery “expunge the kinds of corporeal human variation that contradicts the ideologies the dominant order depends upon to anchor truths it insists are unequivocally encoded in bodies” (p. 341). As such, plastic surgery’s eradication of norm-challenging bodies supports the continuation of systems of power. Craniofacial surgery in particular illustrates the social control function of plastic surgery. Strauss (1980) argues that facial plastic surgery decreases the range of acceptable facial appearance (cited in Scheper-Hughes, 1990). The universalization of surgical correction for clefts has had several negative consequences, including increasing the stigma of untreated clefts and creating a new understanding of clefts as “a tragic disease or medical disability” (Scheper-Hughes, 1990, p.

306). Scheper-Hughes points to particular cities in Brazil where class determines access to plastic surgery for facial differences, explaining that “one sees these facial anomalies in the poor and working classes only, and the physical difference serves as a further source of stigma separating the rich and the beautiful from the poor and ugly” (p. 306). People in positions of power define the “normal” faces and stigmatize appearances that fall outside of the normalcy range.

International craniofacial NGOs claim to reduce the stigma faced by the children by offering surgery to give them a normal face. However, the very procedures that normalize facial differences stigmatize children who do not have access to the surgeries, primarily children in the Third World and from low-income families in the Global North. The NGOs also seek to correct a lack of access to medical care, but their surgical interventions fail to even consider the causes of medical complications in children with facial differences. Scheper-Hughes (1990) points to a story of a baby with a cleft lip and palate in the Sierra Madre mountains of Mexico who received care from a nurse outside of the community:

The nurse had rescued the baby from near starvation and had arranged for corrective surgery, but neither the lip nor palate could be closed completely. After the baby was sufficiently thriving the nurse summoned the parents and patiently taught them her feeding method. Nonetheless, the baby died less than a month following discharge (p. 303).

The medical care that the baby received did nothing to change the family’s access to basic food and resources or the cultural taboo of raising a child with a facial difference. International craniofacial NGOs’ uses of surgery to address infanticide of babies with congenital facial differences also fails to address systemic causes. Amongst the Bariba people in northern

Nigeria, surgical correction of facial differences only changes the visible indicators of a child's stigma, not "the source of the child's stigma" (Scheper-Hughes, 1990, p. 304). Rather than ending the ostracism experienced by children with facial difference, plastic surgery has contributed to the move from tolerating infanticide to abuse against children with congenital differences among the Bariba. Though limited, current research recognizes that international craniofacial NGOs' surgical approach only addresses manifestations of the systemic causes of the marginalization of children with facial differences in the Third World and has unforeseen negative consequences.

Representations of Children with Facial Differences in the Third World

One significant negative outcome of the work of international craniofacial NGOs is the dehumanizing representations that they produce of children with facial differences in the Third World. In order to raise money and awareness for the organizations, the staff of the NGOs use photographs and stories of the children in their marketing. While very little research has been published about the representations of children with facial differences in the Third World, Disability Studies scholars have laid the foundation for critical research on representations of norm-challenging bodies in general and in charity advertising in particular.

Representations of disabled people play a critical role in mainstream media, charity fundraising, policymaking, the medical industrial complex, and models of disability. Couser (2013) explains that "disabled people have been hyper-represented in mainstream culture" by non-disabled producers who benefit from the objectifying images of disabled people (p. 456). Representations of disability have economic and cultural capital through emphasizing the normal and abnormal divide. Hevey (2013) asserts that representations of disabled people, particularly in charity advertising, serve as "the anchor of the weird, that is, the fear within" (p. 444).

Nonprofits play on the fear that non-disabled viewers feel when observing the “enfreakement” of disabled people. This is especially evident in the use of poster children by disability organizations, including the Muscular Dystrophy Association, Easter Seals, and March for Dimes. The National Society for Crippled Children and Adults, which set the standard for poster child fundraising in the 1930s, emphasized children’s visible health conditions and pled for the children to have “normal” lives. Children with disabilities became “objects of charity” through the poster child model of fundraising (Longmore, 2013, p. 35)

The precedent of critical research on poster children helps demonstrate the significance of international craniofacial NGO’s use of children with facial differences in the Third World as fundraising tools. Charles Minister (2012) points towards advertisements from international craniofacial NGOs as an example of representing disabled people as “charity-cases in need of salvation” (p. 154). He describes how Smile Train uses stylistically medical photographs that center close-up, expressionless images of the children with clefts who are visually cropped from their surroundings. Dittmer DeRidder (2013) seconds Charles Minister’s description, explaining that Smile Train’s ads focus exclusively on the children’s visible differences and thus “evok[e] a diagnostic categorization used by the scientific community” (p. 99). Smile Train’s depiction of the children reinforces “an aesthetic of ability by aesthetically ‘invalidating’ the child with a cleft palate from full human being [sic]” (Charles Minister, 2012, p. 155). Smile Train pulls from the discourse of disability that labels norm-challenging bodies as charity cases and therefore sub-human. One of the few articles about craniofacial representations published in a craniofacial journal comes from Saman, Gross, Ovchinsky, & Wood-Smith (2012) who argue that media plays a critical role in the stigma of orofacial clefts. They conclude that many of the challenges

currently faced by individuals with facial differences stems from media and artistic representations of craniofacial conditions.

Attempts at encouraging international craniofacial NGOs to reconsider their marketing strategies have proven unsuccessful. In 2011, I attended a fundraising event for Operation Smile where the organization's representative told the story of a boy with a "horribly deformed face," in other words a cleft lip and palate. According to the representative, the boy had a meaningless life before he received surgery. When I contacted Operation Smile to express my concerns, I received a reply justifying the story and claiming the derogatory language as simple truth (personal communication, May, 2011). Murphy (2010) had a similar experience with Smile Train. He criticized the organization for using a demeaning image of a child with an un-operated cleft. Smile Train responded with a justification based on marketing research showing higher donation response for that type of photograph. Murphy raised crucial questions from his interaction: "Do NGOs have the opportunity to operate both ethically and successfully?" and, "Should short term awareness and financial support take precedence over long term harm to education of poverty?" (para. 6). These questions will play an important role in the data analysis and discussion.

Conclusion

This literature review illustrates the urgency of critical, intersectional research on the work of international craniofacial NGOs. Current research on the need for these organizations stems from the same dominant discourses that contribute to the challenges faced by the children in the first place. For example, American doctors write about the need for improving access to care without acknowledging the ways that the medical industrial complex has been built to benefit middle- and upper-class Westerners at the expense of others. Research also shows an incredible need for addressing the marginalization of children with facial differences in the Third

World in ways that do not only rely upon surgically normalizing the children, but has yet to consider alternatives. I hope that my project can address these critical literature gaps, propose parameters for alternatives to a singular reliance appearance-normalizing surgery, and counter Smile Train's and Operation Smile's justification of dehumanizing representations of children with facial differences in the Third World.

CHAPTER 4: METHODOLOGY

This study analyzes the messaging materials produced by U.S. based international craniofacial non-governmental organizations that provide free reconstructive surgery to children with facial differences in the Third World, including Smile Train, Operation Smile, Operation Hope, and Little Baby Face Foundation. In an effort to fundraise for the children's procedures and raise awareness of their work, the NGOs use a variety of communications platforms ranging from traditional mail solicitations to innovative social media sites. Messaging includes photos of the children, stories of the children's medical journeys, inspirational quotes, and accounts of the medical missions from the organization's providers. These messages depend upon representation to "stand in" for the experiences of the children, their families, and communities (Borgerson & Schroeder, 2002, p. 571).

Representation created by the NGOs of the people they serve has significant consequences. Borgerson & Schroeder (2002) explain that representations of global communities typically use "simplified, even subordinating" depictions that minimize the humanity of those being represented (p. 571). These representations contribute to the viewer's distorted understanding of the community's experiences and lives. Messaging materials by international craniofacial NGOs are especially relevant for understanding the creation and implications of global representations. The organizations' leadership, staff, volunteers, and donors predominantly occupy positions of privilege as Westerners with the time and financial resources to advance the organizations' missions. The children treated by the organizations occupy positions of Otherness, as defined by Western values, due to their relationships to the categories of race, ethnicity, disability, class, nation, and sexuality. Considering the hierarchical relationship between the NGOs and those being represented, significant potential for exploitative misrepresentation exists in the NGOs' messaging.

Social media platforms used to publish representations of the children demonstrates an urgent area of study for several reasons. First, social media fills a unique role of fostering dialogue between organizations and stakeholders (Lovejoy & Saxton, 2012). Unlike websites or mailings, social media easily allows for a two-way conversation between publisher and viewer. As a result, organizations have immediate feedback from their stakeholders on their messaging. Second, the social media pages of the NGOs have a wide reach. Consider that Operation Smile has over 89,000 likes on Facebook and 52,000 followers on Twitter (Operation Smile, 2015a; Operation Smile, 2015b). Investigating Operation Smile's page reveals that they reach individuals, business, and organizations around the world. In part because of this extensive reach, the NGOs have the potential to create and/or contribute to dominant understandings of the lives of the children they serve. Third, nonprofits use social media to communicate calls to action, such as requests for donations and volunteers to assist with medical missions (Lovejoy & Saxton, 2012). Responses to these asks can influence the ways that the organizations operate and serve the children. The combination of two-way dialogue, wide reach, and calls to action demonstrate how social media plays a significant role in the NGOs daily operations. Thus, I selected social media platforms of international craniofacial NGOs as the site of analysis for representations of children with facial differences in the Third World.

The purpose of analyzing the representations produced by the NGOs is two-fold. First, I aim to challenge dehumanizing representations of children with craniofacial differences in the Third World, often depicted by the NGOs as emotionally distraught, impoverished, and isolated. Deconstructing these representations requires understanding the ways that the NGOs use representations to stand in for the lives of the children and identifying the ideology that informs the construction of their representations. Second, I hope that this study will catalyze a critical

understanding of the work of international craniofacial NGOs. By applying a transnational disability justice framework to the interpretation of the organizations, I aim to propose an alternative narrative about the organizations that centers values of social justice.

The study purpose informed the choice of research questions. The research questions follow: (1) What role do systems of power play in international craniofacial NGO's representations of children with facial differences in the Third World? This question addresses the ways in which ableism, racism, neocolonialism, and capitalism inform the NGOs' visual and verbal choices when constructing social media posts. (2) To what extent and in what ways do international craniofacial NGOs address the systemic barriers faced by children with facial differences in the Third World, as portrayed by their social media materials? I aim to uncover how the NGOs understand their role in the communities they serve and whether their interventions align with the needs of the communities.

This section reviews the methodology and methods used to address the research questions. A transformative paradigm, which holds social and economic justice as central values in research, forms the foundation for this study. A qualitative research approach is used due to the nature of the research questions and the social justice values of this project. Multimodal critical discourse analysis (MCDA), which merges the tools used in multimodal studies with the goals of critical discourse analysis, guides the research design and data analysis. Data is selected through theoretical sampling based on conceptual significance and relevance to the research questions. Discursive narrative analysis, which is primarily used to analyze visual narrative presentation from photographs with supplemental written materials, directs the implementation of MCDA. The goal of the data analysis is to uncover the role of ideology in the creation of the social media posts.

Methodology

This section explores the theoretical underpinnings for the research approach. The methodological choices stem from a transnational disability justice framework, which centers values of liberation, justice, and community for people who inhabit the “borderlands.” Thus, I selected methodological components that challenge hegemonic Western ideology, center the knowledge of *los atravesados*, and deconstruct the role of the researcher. This methodology discusses a research paradigm and the associated epistemology, the theoretical tradition from which the methods stem, and the reasoning for selecting a qualitative research approach.

A transformative research paradigm creates the foundation for this methodology. Mertens (2007) describes the transformative research paradigm as a “framework for addressing inequality and injustice in society” (p. 212). A transformative paradigm recognizes that research has political goals and implications. As such, researchers must prioritize the ways in which an investigation can influence those directly involved with the research, including participants and the researchers, as well as communities and institutions connected to the research topic and environment in which the research is conducted (Creswell, 2003). Unlike a positivist paradigm, a transformative paradigm recognizes that the social, economic, and political context cannot be separated from the research itself. Tuhiwai Smith (2012) critiques positivism for originating from the European academy, claiming objectivity, and its use for defending acts of colonization. The transformative paradigm arose in the 1980s and 1990s directly as a critique of dominant paradigms that “had been developed from the white, able-bodied male perspective” (Mertens, 2005, p. 17).

A central tenant of a transformative paradigm is “that power is an issue that must be addressed at each stage of the research process” (Mertens, 2007, p. 213). In contrast to positivist

researchers who claim neutrality, I recognize that my relationship to systems of power and control plays a significant role in every aspect of this project. Thus, I chose to self-locate in the research to both acknowledge and deconstruct the ways in which my social, political, and economic positions impact this research. I occupy a position as both an insider and outsider in this research. Like the children who receive treatment from the craniofacial NGOs, I share the experience of being born with a facial difference and undergoing a series of operations. My medical treatment consisted of interactions with doctors and staff from an international craniofacial NGO, because my surgeon was the founder of the World Craniofacial Foundation (WCF). I recall meeting children treated by the WCF and witnessing the media coverage of their procedures at the WCF medical headquarters in Dallas, TX. My understanding of a Western medical system is further informed by my experience of navigating it as a queer woman with a physical disability. I have experienced incredible skepticism from providers and even denial of medical care for not conforming to the medical system's understanding of values, consciousness, and bodies. My personal experiences and worldview position me to be critical of international craniofacial NGOs that physically and psychologically impose dominant norms on the children they treat.

Still, my class, race, and Western privileges locate me as an outsider. As a child, my family's class privilege afforded me the health insurance and travel funds to be able to receive top medical care out-of-state. The only traces of my cleft lip/palate and nasal deformity are small scars on my body. Despite the visibility of a facial difference, I can often pass as having a typical face because of the quality medical care that I received. In contrast, the craniofacial NGOs provide treatment to certain children precisely because they lack access to medical care and may grow up without receiving reconstructive surgery. Furthermore, as a white, middle-class

American I almost always share the same language and culture as my providers. This means I have access to streamlined communication, a certain level of trust and respect from the doctors, and cultural knowledge of how to navigate an American medical system. I personally benefit from this system that privileges white, middle-class Americans, and I easily have the potential to reproduce the same systems that I aim to deconstruct in this project. Following the tradition of a transformative research paradigm, I will center an analysis of power throughout the project and recognize the limitations of my positionality in conducting this research.

The theoretical underpinnings of this project, dedicated to unpacking the power invested in visual and verbal representation, align with a transformative paradigm. Developed by Barthes (1957), semiology is a “mode of perception” that challenges dominant ideology (cited in Sandoval, 2000, p. 91). Barthes (1972) defined semiology as “a science of forms, since it studies significations apart from their content” (p.111). Semioticians study signs, the basic unit of communication, as rich data for understanding representations of ideology. Barthes argues that signs are composed of the signifier, the image or sound attached to a sign, and the signified, the object represented in the sign. Colonizing knowledge perceives the connection between the signifier and the signified as “history” or “truth.” In contrast, semiology understands the relationship between signified and signifier as arbitrary, and thus recognizes that questioning the components of signs has social and political significance. Semiotics provides the framework for deconstructing the ways that systems of power inform the production of social media materials created by international craniofacial NGOs.

Semiotics further aligns with a transformative research paradigm because of its progressive political goals. Sandoval (2000) identifies semiology as one of the first “methodologies of the oppressed.” She explains the “methodology of the oppressed” as “a methodology of renewal, of

social recognition, of emancipation – or perhaps better – a methodology of love in the postmodern world” (p. 10). Unlike a positivist approach, semiotics emphasizes culturally constructed meaning. Dominant visual and linguistic analysis focuses on aesthetics at face value, while semiotics considers the systems that guide the meaning making process (Parsa, 2004). As a “methodology of the oppressed,” semiotics supports an intersectional topic and deconstructing the social, political, and economic circumstances in which this research is conducted.

Wang (2014) built upon social semiotics to develop a research approach that merges critical discourse analysis (CDA) and multimodality. Critical discourse analysis (CDA) is a “‘mode’ or ‘perspective of theorizing, analyzing, and application’ that rejects the existence of objective research (Van Dijk, T.A., 2001, p. 353). Discourse refers to communication through language, which can include speech, written text, music, information, media, pictures, manual languages, and other forms. Although scholars disagree on the specific meaning of discourse analysis, they agree that it “involve[s] studying language and its effects” (Johnston, 2002, p. 2). Discourse analysis can reveal the meaning of language that is “not immediately apparent” (Johnston, 2002, p. 7). Unlike descriptive discourse analysis, CDA focuses on the ways in which power informs the creation and effects of discourse. As a result, “critical discourse analysts [...] want to understand, expose, and ultimately resist social inequality” (Van Dijk, 2001, p. 352). An approach to data analysis that holds social justice as a core value is critical to exploring the research question.

Although CDA aligns with the research purpose, it cannot fully address the research question. Wang (2014) argues that dominant research trends in CDA ignore or minimize visual images as a form of discourse. Considering that both the visuals and written text associated with social media posts are critical to the meaning of the posts, CDA cannot effectively be applied to

the data. A second research approach, multimodal studies, analyzes discourses with multiple modes of semiosis, such as visual, auditory, and tactile (Wang, 2014). Van Leeuwen (2012) explains that although scholars recognize the importance of merging CDA and multimodal studies, such a merger has not yet been successful (cited in Wang, 2014). Wang performs this merger through conducting a CDA of visual semiosis, using picture news as the data, and then developing a theoretical framework for multimodal critical discourse analysis (MCDA). Wang identifies three components to this theoretical framework – (1) a theoretical foundation of social semiotics, (2) a theoretical paradigm that merges CDA and multimodality, and (3) the implementation level. MCDA maintains the social justice potential of CDA while providing strategies for researching multimodal material.

A qualitative research approach aligns with MCDA for two main reasons. First, qualitative research supports a transformative research paradigm. Charmaz (2006) critiques quantitative research in the social sciences for its association with positivism, stating that:

[social scientists'] beliefs in scientific logic, a unitary method, objectivity, and truth legitimized reducing qualities of human experience to quantifiable variables. Thus, positivist methods assumed an unbiased and passive observer who collected facts but did not participate in creating them, the separation of facts from values, the existence of an external world separate from scientific observers and their methods, and the accumulation of generalizable knowledge about this world (pp. 5-6).

Thus, a quantitative research approach fails to deconstruct power relations in the research process, a central goal of the transformative paradigm. In contrast, qualitative research acknowledges multiple ways of knowing and situates the researcher squarely within the research process.

Second, a qualitative approach can best answer the research questions. The research questions focus on exploring a nearly untouched topic, developing new theories for understanding representations of children with facial differences in the Third World, and offering a critical lens for a non-academic audience for consuming marketing materials created by international craniofacial NGOs. Corbin & Strauss (2008) identify several reasons for conducting qualitative research, many of which correspond with this research project. They explain that qualitative research is used to “determine how meanings are formed through and in culture, and to discover rather than test variables” (p. 12). Furthermore, qualitative research has “relevance for nonacademic audiences” (p. 14). Considering that this project aims to make an impact in the community, a qualitative research approach best aligns with the goals of this study.

Methods

Data Collection

Existing texts and images, those not created for the purpose of this project, form the data for this project. I selected two social media platforms for data collection, Facebook and Twitter. I excluded Google+ due to the limited presence of international craniofacial NGOs on the platform and YouTube due to the complexity of conducting a MCDA on a video. Each platform has a distinct target audiences, primary media type, and purposes. Each social media post constitutes one unit of data. By collecting data from multiple sources, I aim to strengthen the validity of the analysis through data triangulation.

I selected the NGOs for this study based on an initial analysis of several NGO’s websites, social media pages, and informal conversations with local providers and activists. The NGOs selected for the study include Operation Smile, Smile Train, Operation of Hope, and the Little Baby Face Foundation. These four NGOs share a mission of providing surgical care to children

with facial differences in the Third World, have active and prominent social media presence, and use messaging with conceptual significance to the research questions. Social media followings vary significantly across the organizations, ranging from over 89,000 Facebook followers for Operation Smile to 2,600 Facebook followers for Operation of Hope (Operation Smile, 2015a; Operation of Hope, 2015). All organizations post to Facebook and Twitter several times a week. The World Craniofacial Foundation and Facing the World were excluded due to their infrequent social media use in 2014. The variations between the selected NGOs yielded richer data.

Sampling

This study uses theoretical sampling, a strategy developed by Glaser & Strauss (1967) “for generating theory whereby the analyst jointly collects, codes, and analyzes his [sic] data and decides what data to collect next and where to find them, in order to develop his [theory] as it emerges” (p. 45). Unlike other types of nonprobability sampling techniques, theoretical sampling allows researchers to move between data collection and data analysis in an attempt to develop theory. Researchers using theoretical sampling collect “pinpointed” data in order to “saturate” emerging theoretical categories (Charmaz, 2006, p. 110). The number of data sampled is determined by saturation, when each theoretical category has sufficient content. Although Glaser & Strauss (1967) developed theoretical sampling to support grounded theory, critical discourse analysts have adopted it as a common approach for supporting theory development (Wodak & Meyer, 2008).

Within theoretical sampling, the following five criteria specific to this study guided the sampling process:

- (1) Social media posts must be published between July 2014 and December 2014. This timeline captures end-of-year fundraising campaigns.

- (2) Posts are original content published by the organization. They cannot be posts shared from another organization or individual.
- (3) The posts use both photographs and written texts. Additional components of the posts, including external links and reader comments, are excluded.
- (4) Posts must include a photo of a child with a facial difference. The facial difference can be operated or un-operated. Operated facial differences are identified by scars post-surgical equipment visible on the child's face; an implicit reference, or an explicit mention of the child's facial difference in the associated text.
- (5) The text and/or photograph references children in the Third World. This determination follows from Mohanty's (1991) definition of the Third World as the "colonized, neocolonized, and decolonized countries whose economic and political structures have been deformed within the colonial process, [as well as] to black, Asian, Latino, and indigenous people in North America, Europe and Australia" (p. 4).

Data Analysis

Following from theoretical sampling, the purpose of the data analysis is to develop theoretical categories to lead to the creation of theory regarding representations of children with facial differences in the Third World. Data was analyzed using discursive narrative analysis, one of the three implementation types from MCDA. Discursive narrative analysis was selected for two reasons. First, the data type for this study fits with discursive narrative analysis. The sampling criteria requires both visual and written content to be included in each unit of data. Wang (2014) asserts that discursive narrative visual analysis best supports research on discourse "presented primarily through photographs with supplementary written explanations" (p. 281).

Second, discursive narrative analysis can address the research questions. The analysis stems from the concept of three-dimensional discursive analysis developed by Fairclough (1989, 1995) for analysis of political discourse. Wang (2014) summarizes Fairclough's concept as follows: "In linking a micro-analysis of the text to the macro-structure of society, Fairclough's three-dimensional conception of discourse analyses offers a powerful framework for deconstructing the ideology, power and dominance encoded in verbal texts" (p. 268). Connecting micro-analysis with macro-structures will be critical to understanding the influence of systems of power in the NGO's representations of the children and ways that the NGOs address systemic barriers faced by the children and their communities. Discursive narrative analysis aligns with the purpose and approach of this project.

Wang (2014) identified three steps to conducting discursive narrative analysis for MCDA. First, the researcher visually describes the sampled data. This step involves detailed description and categorization of the visual components of a unit of data, including "the description of the representational structure, interactive meanings and compositional system of the visuals" (p. 270). The visual description stage is guided by a chart of subcategories of these three visual components created by Wang (appendix A). Second, the researcher interprets the visual description developed in step one. The purpose of this step is to identify the semiotic gap between the signifier and signified, and thus uncover the ideology that informed the production, distribution, and consumption of the image. Finally, the researcher connects the interpretation to an explanation of macro-level systems. This step makes sense of the ways in which ideology justifies the relationship between the signified and the signifier as truth or common sense, what Wang describes as the "macro-mechanism of legitimation" (p. 269). Through discursive

narrative analysis, I aim to understand the role that power and control play in international craniofacial NGOs' representations of children with facial differences in the Third World.

CHAPTER 5: FINDINGS

This chapter presents findings from the multimodal critical discourse analysis of social media posts published by international craniofacial NGOs. I analyzed 20 posts published by Smile Train, Operation Smile, the Little Baby Face Foundation, and Operation of Hope on Facebook and Twitter (Appendix B). The organizations published these posts between July 2014 and December 2014. This analysis revealed the following six themes (1) non-disabled white people save Third World children, (2) Western culture presumed as the norm, (3) objectifying norm-challenging bodies, (4) the necessity of capitalism for improving access to medical care, (5) defining successful womanhood and girlhood, and (6) normalization through surgery. The themes tell a hierarchical story about the lives of children in the Third World with facial differences and their relationship with international craniofacial NGOs.

These findings build on the limited previous research from a critical perspective on representations of children with facial differences in the Third World. Critical research asserts that international craniofacial NGOs represent the children as “charity-cases in need of salvation” and present facial differences primarily as a medical diagnosis (Charles Minister, 2012, p. 154; Dittmer DeRidder, 2013). Representations of children with facial differences mimic the problematic charity advertising of disabled people that displays individuals with norm-challenging bodies as subhuman. Findings from this study and previous critical research contrast the majority of research on facial differences in the Third World that stems from a hegemonic positivist paradigm. Unlike the dominant focus on the pathology of children with facial differences (Strauss & Broder, 1991), this research deconstructs the ideology that portrays the children as pathological and in need of fixing.

Theme 1: Non-Disabled White People Save Third World Children

The international craniofacial NGOs in this study portray non-disabled white people as the saviors of children with facial differences in the Third World. Their messaging materials suggest that non-disabled white people can eliminate the stigma, medical complications, and mistreatment that children with facial differences in the Third World experience. Many of the posts represent the concept of “healing smiles” by displaying a hierarchical power dynamic between non-disabled white bodies and norm-challenging Third World bodies. The semiotic gap between this signified and signifier holds the Western ideological notion that non-disabled, white, Westerners have more to contribute economically, medically, and intellectually than norm-challenging, Third World communities.

The NGOs use two main strategies to convey the theme of Western child saving. First, in nearly all of the images that include a staff or volunteer from the NGO and a patient, the representative from the NGO enacts the action process while the child passively receives the action or is physically absent from the scene. In Photo 18 (see Appendix B), a white doctor hovers over a boy with a facial difference from Zimbabwe. While the doctor examines the boy’s face, the boy lies almost lifeless on a hospital table. The straight vertical angle on the doctor and the high vertical angle on the child depict the white doctor as an equal to the viewer and the child as a subordinate. Similarly, Photo 2 shows a white doctor examining a Third World baby with an implied facial difference being held by his mother. Formatting of the photo crops the facial expressions from both the child and mother while highlighting a three-quarter view of the doctor’s expressive face, making the doctor the most salient person in the interaction. The semiotic gap between the signified of the joys of giving and signified of a hierarchical relationship between a white doctor and Third World child and his mother presumes this is a

normative relationship between givers and receivers. This theme conveys that white non-disabled Westerners supposedly have something to give to children with facial differences in the Third World and the children have a need that can be met by the Westerners.

Second, the NGOs visually contrast non-disabled white people and children with facial differences in the Third World. Several posts show a non-disabled white person alongside a physical photograph of a Third World child with a facial difference. In Photo 6, a clear visual divide exists between the young white woman and the photograph of a black toddler with a cleft lip. A combination of the woman's smile and business attire and her positioning at a far personal distance depicts her as an image of comfort and familiarity. In contrast, the child only occupies a presence in the scene as an edited photograph. The accompanying text on the child's photo, "every three minutes a child is born into the uncertainty of facing life with a facial deformity," instills a sense of fear, discomfort, and unfamiliarity in the viewer. Cropping the child's photo in close personal distance focuses the image on her cleft lip and black skin. She exists in the photo only as Other, cut off from her body, environment, family, and community. Due to the significantly disproportionate size of her photograph in the image, she becomes the most salient person. Placing a salient photograph of otherness next to a representation of normalcy, according to Western standards, emphasizes the differences between non-disabled white people and children with facial differences in the Third World. This contrast lays the foundation for conveying the savior relationship. The little girl seems to reach out from the photo with her hand to ask for help. Conveniently, the white woman is physically positioned touching the photo of the girl. This positioning suggests that the white woman is the answer to the child's plea.

Similarly, Photo 9 contrasts the familiar non-disabled white body with the otherness of a child from the Third World with a facial difference. The photo shows a white man holding the

photo of a girl with an operated cleft holding a photo of herself prior to surgery. The photo intends to convey a message that fundraising can “heal smiles.” The progressive proximity of the figures, from far social distance of the white man to the intimate distance of the photo of the photo of the girl with an un-operated cleft, provides context to the life of the man and isolates the girl from her family and community. Operation Smile uses the semiotic gap in this image to advocate that non-disabled white supports can “heal” the smiles of Third World children with money, rather than suggesting that the communities affected by facial differences can “health” themselves with their own means. International craniofacial NGOs are able to advance Westerners as the saviors of Third World children based on an underlying assumption that Western cultures and bodies have more value than Third World individuals and communities.

Theme 2: Western Culture Presumed as the Norm

The same assumption of valuing Westerners over Third World communities that underlies the first theme runs through the second theme of presuming Western culture as the norm. Operation of Hope, the Little Baby Face Foundation, Operation Smile, and Smile Train hold aspects of Western culture, such as iconic American figures and Christian holidays, as the unquestioned baseline against which to judge Third World communities. The presumed norm of Western culture builds upon a self/other binary in which the viewers of the social media posts occupy a position of self and the children represented in the posts occupy a position of collective otherness. Social media posts that depict this theme have a similar semiotic gap. The posts intend to convey the benefits of giving and use signifiers of Western icons. Capitalist Western ideology fills the gap with the assumption that Westerners have money, time, and support to give.

A primary strategy for conveying Western culture as the norm is unquestioned references to Western holidays, including New Year’s on the Gregorian calendar and Christmas. Photo 5,

published in December of 2014, shows three children with operated clefts from the Third World holding photos of themselves prior to surgery. Operation Smile positions the children's photographs against a dreamy red background with text about the spirit of giving during the "holiday season." The post conveys a clear assumption about which holidays should be included in this "holiday season," that of the Western viewer. Assuming a hegemonic Western norm of the viewer's holiday preferences reveals a lack of consideration for the religious and cultural backgrounds of the children featured in the image. Photoshopping together three children from distinct communities into a Western context implies that the children's backgrounds do not matter. Similarly, Photo 14 places Third World children with facial differences within a Western holiday presumed as universal. The image features a quote stating that "Everyone smiles in the same language," and the text associated with the post invites supporters to celebrate the New Year. Ironically, Smile Train pairs a quote that has tones of colorblind racism with an assumption of Western, Christian holidays. The hegemony of Western holidays pervades these posts. The assumed normalcy of Western traditions stems from the denial of heterogeneity in religious and cultural celebrations.

Another strategy employed by the NGOs to convey the presumed normalcy of Western culture stems from the strategic use of Western icons. In Photo 1, the Little Baby Face Foundation shows a teenage girl with a facial difference and her mother, wearing a hijab, posing next to a statue of Teddy Roosevelt. Differences in texture, color, size, dress, and posture visually contrast the girl and woman from Roosevelt. The compositional system of the photo symbolically places Western culture, symbolized by Greek columns, in the upper or "ideal" portion of the photo. The American volunteer, conveyed by the associated text, takes the photo from a high vertical angle, reflecting her position of power over the Third World women. These

visual strategies pose Western history and culture as the ideal to which families affected by facial differences in the Third World should aspire. While iconography in itself is not problematic, the exclusive depiction of Western culture and the hierarchical positioning of Western ideals against Third World communities perpetuate oppressive ideology.

Theme 3: Objectifying Norm Challenging Bodies

International Craniofacial NGO's social media posts depict Third World children with facial differences in ways that offer the greatest economic benefit for the organizations. Thus, objectifying the children becomes a key strategy for fundraising. Objectifying photos of children catch the attention of viewers and prompts emotions of unease at the sight, superiority of the viewer over the object, and pity for the children. In this case, objectification goes hand-in-hand with the commodification of children's bodies. Attaching calls for donations to objectified representations of children with facial differences transforms the children into body parts to be used for economic exchange. To do so, the NGOs remove the children from their cultural context, strip them of personal identifiers, crop their bodies from their faces, and portray children with un-operated facial differences only as ghosts of the past.

Several photos from Operation Smile and Smile Train objectify children with facial differences from the Third World using the motif of photos within photos. Photos 5, 6, 8, and 9 display children with operated clefts hold earlier photos of themselves with un-operated clefts. The objectifying outcome of this motif is especially clear in Photo 9. A white man poses with a photo of a Third World girl with an operated cleft holding a photo of herself as an infant prior to surgery. Operation Smile shows the man at a far social distance, the girl with an operated cleft at a far personal distance, and her photo prior to surgery at an intimate distance. According to the post description, the man "raises funds to heal smiles" through his presence at the Operation

Smile photo booth. The man has the most human characteristics due to displaying almost his entire body, the associated text that describes him as doing the action, the fact that he is the only person physically present, and his overall salience in the photo. In contrast, the photo of the girl as an infant prior to surgery has the most traits of an object. The post shows her as twice removed from the scene and her body is entirely cropped from her face, emphasizing her cleft at the center of the photo. Children with un-operated facial differences have a presence in these photos literally only as objects. Through almost universally pairing this motif with donation requests, Operation Smile and Smile Train essentially sell depictions of dismembered heads of children with facial differences to middle- and upper-class Westerners under the guise of charity.

Theme 4: Necessity of Capitalism for Improving Access to Medical Care

An assumption that improving access to medical care for Third World communities requires capitalism lies behind the objectification and commodification of children with facial differences. International craniofacial NGOs present financial support within a neoliberal context as a primary solution to the challenges experienced by children with facial differences in the Third World. According to the social media posts, Westerners simply need to shop, express gratitude to corporations, and send money in order for the children to access the medical care that they need. Such a message has a clear appeal to particular middle- and upper-class American audience that believes in economic freedom, endorses the growth of capitalistic enterprises, and assumes economic inequality as a given.

Photos 8, 9, and 10, all created by Operation Smile, use a variety of visual strategies to designate a clear middle- and upper-class Western audience for donation asks. In Photo 8, a Third World boy with an operated cleft holds a medical photo of himself prior to surgery. Operation Smile photoshops the image onto a “Holiday Giving Catalog” with a call for readers

to “give smiles this season.” The boy makes a demand to viewers through his eye contact and the straight vertical angle. The compositional structure of the catalogue places the boy in the position of the known and real, while the call for donations as the ideal and new. By associating a visual ask for donations with explicit text about holiday giving, Operation Smile identifies their audience as middle- and upper-class Westerners. Photo 9 actually visually displays the ideal donor, an able-bodied white man, who “raises funds to heal smiles.” In Photo 10, Operation Smile verbally credits Westerners with excess money to give with the happiness of a baby girl with a cleft in the Third World by stating “her SMILE begins with YOU.” They visually credit middle- and upper-class Westerners by physically cropping out all but a portion of the caregiver’s arm and focusing the photo on the baby’s frontal stare. These visual cues create an exclusive relationship between the viewer and the child, separate from the support of the baby’s family and community. The children’s support networks are presumed incompetent due to their class status. In all of these photos, “giving smiles” and “heal[ing] smiles” requires the financial resources of middle-and upper-class Westerners. Thus, access to medical care relies on a capitalist enterprise that generates excess money for certain social classes at the expense of others.

Photos 6 and 16 rely on capitalist symbols to represent the origins of the organizations’ support. Photo 6 strategically positions a jewelry stand imprinted with “La Dragon d’Or” at the front and center and describes the post with an expression of gratitude to the company. Meanwhile, a poster of a girl with an un-operated cleft and doomsday-like text paint the backdrop of the image. A symbol of capitalism, expensive jewelry, takes salience over the contrasting depiction of the needs of children with facial differences in the Third World. In photo 16, Smile Train points to one of the most salient symbols of American capitalism, Black Friday.

By pairing an image of a smiling Third World girl with an operated cleft and wrapped presents with text about shopping on Black Friday, Smile Train suggests shopping can provide the children with the resources they need to live happy lives. These two photos portray support for capitalism as an easy solution to the immense challenges experienced by children with facial differences in the Third World.

Theme 5: Defining Successful Womanhood and Girlhood

Patriarchal and colonialist ideology informs the creation of social medial materials published by international craniofacial NGOs. The NGOs convey a clear message regarding their understanding of successful women and girls. According to the photos in this study, Third World women fail as mothers due to their inability to provide for their children. Western women who conform to norms of white femininity can act as surrogate mothers to the children of failed Third World women. Third World girls with facial differences also fail to fulfill their expected roles as daughters and future mothers due to the problems associated with their facial differences. Supposedly, international craniofacial NGOs can address the needs of Third World communities that result from the failed femininity of girls with facial differences and their mothers. By providing surrogate white mothers and normalizing girls with facial differences through surgery, international craniofacial NGOs re-instill the “natural” gender roles and hierarchy.

International Craniofacial NGOs portray Third World mothers of children with facial differences as incompetent and unimportant in the lives of their children. For instance, Photo 2 shows the mother and child as passive recipients of the kindness and generosity of a white male doctor. The doctor is the most salient figure in the photo due to physical space that he occupies, the associated text, and the fact that the photographer shows all of his facial features. In contrast, the positioning hides the mother’s and baby’s faces and shows them as inactive participants. The

oblique horizontal angle and lack of eye contact with the viewer places the viewer in a position as an outsider. Thus, this photo conveys a message that the viewer can objectively judge the generous work of the doctor and the insignificance of the mother's contributions. Photo 10 conveys the failure of Third World mothers by almost entirely cropping out the baby girl's caregiver. Text claiming that "her SMILE begins with YOU" and the girl's direct eye contact with the viewer suggests that the assumed Western viewer, not the cropped caregiver, can provide the child with the resources she needs.

While Photos 2 and 10 depict the failure of Third World mothers through strategic representations of Third World women, Photos 3 and 11 show the failure through the exclusion of Third World women. Photo 11, a two part image of the child before surgery on the left and after surgery with her mother on the right, Smile Train only includes the mother in the after photo. This depiction suggests that Third World mothers can only love their children if they have typical faces. In a hospital scene where a viewer would expect a mother to be holding her sick child, a white woman happily embraces a Third World child in Photo 3. The associated quote regarding "the beauty of a woman" applauds the white woman for her caregiving role. Such a positive representation of the white woman contrasts the complete absence of the child's mother. Where Third World mothers fail, white women from international craniofacial NGOs supposedly can pick up to provide for the children.

International craniofacial NGOs convey particular gendered and racial expectations for girls in the Third World as well. Photo 15 shows a girl with a cleft holding a stuffed animal in a dreamy setting with the associated text "help Camila know what it's like to give a kiss to her loved ones." The text pushes Camila to live up to the gendered norms for girls to kiss and show affection. By suggesting that Camilia can "know what it's like to give a kiss" only through

undergoing surgery, Smile Train implies that a normal facial appearance is necessary to give and receive love. Unlike Photo 15's focus on affection, Photo 17 conveys gender norms through depicting household chores. The visual strategies in Photo 17, a far distance and disengagement with the camera, portray the scene as an intrusive look on the life of a girl with an operated facial difference and her mother. While the mother stands in a background with messy household items, the girl tidies her bed. In conjunction with the positioning of the mother in a context that signals poverty, the associated text of "a new smile gives her confidence at home" implies that the mother could not provide the support her daughter needed. By undergoing surgery offered by Western supporters, the child can now fulfill her girlhood duties. Similarly to the depiction of the mother in Photo 3, Photos 15 and 17 suggest that craniofacial surgery offers an easy "fix" for the ways that Third World girls and women fail to fulfill their expected roles.

Theme 6: Normalization through Surgery

The most salient theme in this analysis is the message that children with facial differences in the Third World can be normalized through reconstructive surgery. International craniofacial NGOs frequently use the signifier of before-and-after photos of the children to signify the assumption that surgery improves the lives of children with facial differences. Colonialist, patriarchal, ableist, and capitalist ideologies fill this semiotic gap by defining quality of life and individual value. The before and after photos imply that surgery allows children an opportunity to live a normal life involving smiling, laughing, kissing, working, and singing. The associated text in Photo 4, a before-and-after photo of a boy with a cleft, perfectly summarizes the shift that the NGOs believe occurs during surgery:

So many children like Mfakazi come to Harare Central hospital in Zimbabwe when the Operation of Hope team arrives. Many of them are scared. Many come from rural areas

and have been excluded from their communities just because of the way they look. Many fathers are ashamed, many mothers are blamed and many children are not only abandoned some are even killed. [...] Even though the numbers are high, for Mfakazi and the other cleft children they feel alone. That is, until they see how many children arrive to meet Operation of Hope. [...] When little Mfakazi woke from his surgery, he looked in a mirror and smiled. His mother was overjoyed and in tears. Just the next day, as the doctors checked on their healing patients, Mfakazi was found in his bed singing and holding his stuffed animals that were given by donors to the Operation of Hope team. He was a changed boy. It seemed his spirits were lifted and a smile was gained.

Operation of Hope portrays surgery as the simple solution to normalizing the boy's childhood, causing an instant shift from an abnormal childhood of isolation to a normal life filled with the simple youthful pleasures. Thus, the NGOs suggest that surgery not only normalizes a child's facial appearance, but also his/her life as a whole, family, and community.

International craniofacial NGOs use two main tactics to convey the message of normalization through surgery in the before and after photo trope. First, the NGOs place objectifying representations of children with un-operated facial differences alongside somewhat humanizing representations of the same child with an operated facial difference. Photos 5, 8, 9, and 14 use this same strategy, showing children with operated facial differences holding their before photos. In Theme 3, I discussed the visual techniques of objectification. These objectifying before photos represent abnormality and undesirability, since children with un-operated facial differences only exist in the posts as objects, not real children. In contrast, the after photos often show smiling, engaged children who were actually present during the taking of the photos. The NGOs typically show the child's body from his/her waist up and include a

background setting in the after photo, suggesting that a child with an operated facial difference is like any other “normal” child. International craniofacial NGOs can construct normality only through depicting representations of abnormality.

Second, the NGOs medicalize children with un-operated facial differences to point to surgery as the solution for the abnormality of the children. Medicalization, a term coined by Zola (1983) describes a “process whereby more and more of everyday life comes under medical dominion, influence, and supervision” (p. 210). Photos 4 and 13 similarly use medical photographs of children to depict clefts as an exclusively medical phenomenon. The photos crop the children from their environments, highlight the children’s clefts by having the children squarely face the camera, and exclude speech and action processes. These visual cues suggest that the NGOs took the photos during clinical visits. Both objectification and medicalization imply that children in the Third World with facial differences can be normal if only they receive reconstructive surgery.

Conclusion

“The meaning of particular signs is always relative to specific kinds of readers, on specific occasions” explain Najafian, & Dadaghi (2012, p. 24). Semiotic analysis has the potential to reveal multiple meanings, and this study is no exception. Although international craniofacial NGO’s social media materials hold an array of meaning, the transformative research paradigm of this study leads to critical interpretation of that meaning. With the goal of aiming to deconstruct systems of power, I identified themes that portray Third World children with un-operated facial differences as subhuman. Although the social media posts have strong appeal to Western donors, the message of subhumanity may have unforeseen consequences.

The themes tell a problematic story about the lives of children in the Third World with facial differences and the relationship that they have with international craniofacial NGOs. According to the social media of international craniofacial NGOs, children with un-operated facial differences lead lives of shame, isolation, depression, and inactivity. Their mothers fail at fulfilling their womanly duties of providing unconditional and quality care to their children. The children and their families live in isolation from their communities and lack basic resources. Yet a simple 45-minute surgery can supposedly alter the course of a child's life. Able-bodied, middle- and upper-class white Westerners kindly and generously make the surgeries possible. After undergoing reconstructive surgery the children become happy, loved, confident, and most significantly of all, "normal."

One out of the twenty posts included in this analysis conveys a slightly different story. Photo 19 shows two babies, one with an operated cleft and one with an un-operated cleft, lying on their backs surrounded by baby blankets and a bottle. The photo displays both children from their torsos to their head and includes objects that invoke love and care, which contrasts the medicalization and objectification of children with un-operated facial differences in the other photos. The associated text states that "we dream of a world where no child suffers from lack of access to safe surgery. That's why we do everything we do." Although Operation Smile still poses surgery as a positive gift from Westerners, the text points towards a somewhat systemic understanding of the challenges faced by the children. Representing a child with un-operated cleft in a humane way and placing the child within a systemic context makes this post stand out from the others. Positive representations must follow the lead of Operation Smile in Photo 19 by showing the humanity of children with un-operated facial differences in the Third World.

Semiotic analysis reveals the ideology that underpins the messaging of international craniofacial NGOs and suggests directions for future improvements. Neocolonialism, ableism, heteropatriarchy, and capitalism inform the construction of social media posts published by Operation of Hope, Little Baby Face Foundation, Smile Train, and Operation Smile. These findings demonstrate the urgent need to deconstruct systems of power in the work of international craniofacial NGOs and use critical, intersectional frameworks to advance justice for children with facial differences in the Third World.

CHAPTER 6: DISCUSSION

For the master's tools will never dismantle the master's house. They may allow us temporarily to beat him at his own game, but they will never enable us to bring about genuine change

- Lorde, 1984, p. 112

Using a transnational disability justice framework, I argue that international craniofacial NGOs use the “master’s tools” to uphold the “master’s house.” International craniofacial NGOs seek to address the lack of access to medical care, abuse, eugenic infanticide, and stigmatization experienced by children in the Third World with facial differences. As demonstrated by the literature review, these challenges result from hierarchical power relationships or the “master’s house.” In an attempt improve the lives of children in the Third World with facial differences, international craniofacial NGOs offer reconstructive surgery as a seemingly easy solution. Although craniofacial surgery has incredible medical benefits, it also functions as a tool for managing the children’s deviance from norms of ability, race, class, gender, and nation. The findings from this study reveal that international craniofacial NGOs create surface change to temporarily help children with facial differences, but the ideological underpinnings of their work prevent them from “bring[ing] about genuine change.”

This discussion will connect the theoretical framework, literature review, methodology, and findings to illustrate the ways that the “master’s tools” used by international craniofacial NGOs uphold the “master’s house.” These tools include neocolonialism, appearance-normalizing surgery, and eugenics. As the discussion will illustrate, in an attempt to address the challenges faced by children with facial differences in the Third World, international craniofacial NGOs exacerbate and potentially even create many of the issues they aim to correct.

Master's Tool #1: Neocolonialism

Through the transcendence of national borders, imposition of Western norms, enforcement of hierarchical power dynamics, and used capitalist ideology, international craniofacial NGOs constitute a neocolonialist enterprise. Nkrumah (1965) defines neocolonialism as the replacement of colonialism as the “main instrument of imperialism” today. Neocolonialism presents as exploitative economic and governmental control by a State over a territory or region. The themes from this study of non-disabled white people saving Third World children and Western culture presumed as the norm speaks directly to the neocolonialist functions of international craniofacial NGOs by demonstrating the hierarchical relationship between Westerners and Third World communities.

International medical NGOs play a pivotal role in the creation, implementation, and effects of hegemonic Western norms. These often well-intentioned organizations stem from a response to medical crises that disproportionately affected disabled people in the Third World. Erevelles (2011) cites a 2006 United Nations report that estimates that “650 million disabled people living in areas where the services needed to assist them in ‘overcoming their limitations’ were not available in some third world countries” (p. 18). In an analysis of Doctors without Borders, Redfield (2005) argues that these organizations arise from a crisis response to political failures. Although Doctors without Borders aims to remedy the medical consequences of political failures in Third World countries, the organization incites the same imperialist and colonialist histories that initially created the medical crises. For instance, Redfield states “to work ‘without’ borders confronts the basic territorial logic of the nation state; however, it also recalls the legacy of imperial expansion” (p. 336). We cannot forget the histories and ideologies

from which the NGOs evolved, nor can we forget the historical, social, political, and economic violence that led to the “need” for Western NGO to provide medical treatment.

International craniofacial NGOs in particular demonstrate the imperialist nature of international responses to health care crises in Third World communities. Scheper-Hughes (1990) outlines the need for international craniofacial NGOs, citing the cultural beliefs and economic strains that contribute to the sometimes life-threatening complications of facial differences. However, she also explains that the organizations contribute to the marginalization of the children by universalizing surgical correction of facial differences, stating that prior to the universalization of surgical correction a “nonlife-threatening cleft palate was an unfortunate condition, but it was not understood as a tragic disease or medical disability” (p. 306).

International craniofacial NGOs impose a problematic Western norm of surgical correction of facial differences.

Master’s Tool #2: Appearance-Normalizing Surgery

A transnational disability justice framework can make sense of the use of plastic surgery to normalize marginalized communities. Garland-Thomson (2013) employs an intersectional framework to explore the meaning of reconstructive surgery, explaining “cosmetic surgery’s twin, reconstructive surgery, eliminates disability and enforces the ideals of what might be thought of as the normalcy system” (p. 340). As a result, “ideologies of normalcy and beauty posit female and disabled bodies [...] as pliable bodies to be shaped infinitely so as to conform to a set of standards called ‘normal’ and ‘beautiful’” (p. 340). Garland-Thomson’s analysis illustrates that ableism and heteropatriarchy both thrive on the enforcement of normalcy through plastic surgery. Miller (2006) entitles this type of procedure “appearance-normalizing surgery.” This term carries significant weight when considering the multiple types of norms that children

with craniofacial differences in the Third World cross. Suissa (2011) argues “plastic surgery functions as a modality of social control and management, not only of the physical body as such, but at the social level as well” (p. 619). Transnational disability justice illuminates how plastic surgery functions to physically alter children with facial differences in the Third World to conform to Western standards of beauty and function.

The data analysis illustrates how international craniofacial NGOs use appearance-normalizing surgery to police deviant Third World bodies. The theme of normalization through surgery directly supports this conclusion, emphasizing how the NGOs blatantly present craniofacial surgery not as a medical necessity but as an easy way to reduce the discomfort of Western viewers through normalization. The theme of defining successful womanhood and girlhood shows how the NGOs present their organizations as the saviors of Third World girls and women who fail to fulfill their expected gendered roles. Not only does plastic surgery normalize a child’s physical appearance and function, but it also normalizes both the child and his/her family’s gender, race, and class. The theme implies that conforming to Western beauty standards allows Third World communities to come closer to meeting hegemonic norms of gender, race, and class. Physically altering communities to conform to hegemonic norms clearly acts as a “master’s tool” by encouraging more people to enter a system that identifies certain bodies as more worthy than others.

Eugenics

As discussed in the literature review, international craniofacial NGOs aim to address the eugenic infanticide and abuse experienced by children with facial differences by providing access to appearance-normalizing surgery and encouraging research on prevention strategies. Their efforts literally rid communities of facial differences. An excerpt from a recent book by

Salyer (2013), founder of the World Craniofacial Foundation, illustrates the eugenics mentality of some international craniofacial NGOs:

New simple, noninvasive blood tests for genetic disorders will undoubtedly decrease the incidence of deformity due to known genetic causes. I've personally observed, for example, how the incidence of simple cleft lip and palate has been markedly reduced in Taiwan by early fetal diagnosis and the subsequent termination of that pregnancy. Yet with the broad development of genetic diagnosis, it will be vital for societies around the world to develop strict guidelines for the use of abortion as a tool for reducing the incidence of diseases and disorders of many kinds, guidelines that will take into consideration religious and ethical issues, as well as the cost to families and societies to care for diseased and deformed children who come to term (p. 334).

This quote demonstrates some of the terrifying outcomes of the craniofacial NGOs. Rather than changing the systems of power that deem certain children unworthy of life, Salyer identifies the solution in ridding communities of children with norm-challenging appearance through selective abortion and genetic control. Erevelles (2011) explains the significance of the continuation of eugenics, stating “it is easy to dismiss eugenics as a relic of a bygone era, except that the continued association of race and disability in debilitating ways necessitates that we examine how eugenic ideologies continue to reconstitute social hierarchies in contemporary contexts” (p. 104). International craniofacial NGOs aim to improve the lives of children in the Third World, but physically altering children with facial differences and trying to prevent the birth of infants with facial differences contributes to the victimization of children under eugenics. The NGO’s promotion of eugenics is truly one of the “master’s tools.”

Conclusion

Transitional disability justice highlights that an analysis of international medical NGOs must employ a systemic understanding of power dynamics, an understanding of the historical and cultural context in which the organizations operate, and center the stories of communities affected by the organizations. New solutions must be developed to address the challenges faced by children with facial differences in the Third World and their communities. Performing craniofacial surgery to impose hegemonic norms through neocolonialist methods is not the solution. Eugenics is an unacceptable consequences of using the “master’s tools.” Alternatives should be developed *by* and *with* the communities, not *for* the communities.

Transnational disability justice illustrates the importance of an intersectional approach that can make sense of the exploitation, objectification, and medicalization of norm-challenging bodies for the purpose of fundraising for surgeries aimed at reducing the discomfort of middle- and upper-class, able bodied, Western viewers. Transnational disability justice pushes advocates to resist the power dynamics involved with helping poor children of color in the Global South with norm-challenging bodies to receive surgery aimed at assisting them to achieve “normal” lives. The act of a U.S. based NGO providing free medical care to a child in the Third World relies upon incredibly unequal power dynamics. We cannot forget the origins of the dehumanizing representations of children of color with clefts nor can we forget the historical, social, political, and economic violence that led to the “need” for an American NGO to provide life-saving medical treatment. Considering the positive outcomes of increased survival rates for the children and greater awareness transnationally, these findings have complex implications.

CHAPTER 7: CONCLUSION

This project gives new meaning to Salyer's statement on his Facebook page, "It has been a wonderful and heart felt experience seeing [...] all of my many 'dear little buddies' who have now become accepted as part of the human community." Findings from this study reveal that international craniofacial NGOs define humanity based on oppressive ideologies of neocolonialism, capitalism, heteropatriarchy, and ableism. Salyer, along with the international craniofacial NGOs featured in this study, implies that the children can join the "human community" through undergoing appearance-normalizing surgery and thus closer adhering to Western norms of facial appearance and function. In an attempt to address the needs of children with facial differences in the Third World, international craniofacial NGOs in turn further marginalize the children and their communities by marking them as subhuman. In the conclusion, I will summarize the findings, identify the implications, discuss the limitations, and pose recommendations for future research and activism.

Summary of Findings

The six themes identified in this study suggest that children in the Third World with facial differences gain access to systems of power through processes of normalization. The themes include: (1) non-disabled white people save Third World children, (2) Western culture presumed as the norm, (3) objectifying norm-challenging bodies, (4) the necessity of capitalism for improving access to medical care, (5) defining successful womanhood and girlhood, and (6) normalization through surgery. Collectively, the themes tell a story of subhuman children who become human by undergoing surgery. Non-disabled, middle- and upper-class, white Americans "save" children in the Third World with norm-challenging bodies with their economic resources. Not only does the surgery normalize the children's facial appearance and function, but it also

allows them and their families to fulfill their expected gender roles, become able-bodied, and adhere to Western beauty norms. By undergoing physical alterations, the children can come closer to meeting hegemonic norms of ability, race, class, gender, and nation.

This story provides insight into the two research questions - (1) What role does ideology play in international craniofacial NGO's representations of children with facial differences in the Third World? and (2) To what extent and in what ways do international craniofacial NGOs address the systemic barriers faced by children with facial differences in the Third World, as portrayed by their social media materials? First, the ideologies of neocolonialism, capitalism, heteropatriarchy, and ableism dominate the work of international craniofacial NGOs. The organizations represent children in the Third World with un-operated facial differences as objectified, medicalized, and in need of saving by non-disabled, Western, middle- and upper-class supporters. Second, international craniofacial NGOs address only the surface causes of the challenges faced by children with facial differences in the Third World. By using the "master's tools" of neocolonialism, eugenics, and appearance-normalizing surgery to "save" the children, the NGOs not only fail to address systemic barriers, but actually perpetuate the systems of power that contribute to the children's marginalization and the need for the organizations in the first place.

Implications

The implications from this study stem primarily from two areas. First, the development of transnational disability justice has implications for both scholars and activists. Transnational disability justice addresses the lack of a constitutive intersectional framework in Ethnic Studies, Disability Studies, and Women's Studies that can simultaneously address ableism, racism, classism, colonialism, and heterosexism. It shows Ethnic Studies and Women's Studies scholars

that the exclusion of disability in intersectional analyses has devastating consequences, and reinforces the importance of Critical Disability Studies that centers an intersectional approach. Furthermore, this study provides an example of one of the many applications of transnational disability justice to research. The framework enabled me to critically investigate an innovative topic nearly untouched by Ethnic Studies, Women's Studies, and Disability Studies while still maintaining the values and knowledge from all three fields. Transnational disability justice also provides directions for activists, showing that addressing the limitations of international craniofacial NGOs can be addressed by centering a systemic understanding of the needs of children with facial differences.

Second, the findings from this study show the importance of research on facial differences within Ethnic Studies, Disability Studies, and Feminist Studies. Previous research on facial differences within medicine, anthropology, and social work stems from a positivist paradigm that perpetuates the marginalization of children with facial differences in the Third World. The values, approaches, and insights from critical fields will be crucial to changing the dominant narrative about children with facial differences. The topic is also a rich area of research due to the ways in which it lies at the intersections of race, class, disability, gender, and nation. Together, transnational disability justice and the findings from this study call for new ways to address the challenges faced by children with facial differences in the Third World.

Limitations

Despite the critical insights from this study, the project has several limitations. First, this project lacks the first-hand narratives and experiences of children with facial differences in the Third World. Transnational disability justice asserts the importance of narratives in academic and activist projects. This limitation points towards a systemic problem in which the voices of Third World communities are often isolated from the Western academy and reinforces the

conclusion from transnational disability justice that solidarity across borders is essential to challenging systems of power. Second, the conclusions are limited by the research methods. The study has limited transferability due to theoretical sampling. While the selected data had relevance to the research questions, the selected data may not necessarily represent all of the marketing materials by the NGOs. Additionally, the study has limited validity due to the small sample size and relatively short time frame of data collection. These limitations stem from the approach of MCDA.

Recommendations

The limitations of this project can be addressed by future research. Future research must work towards coalitional politics and be informed by narratives of communities on the margins. Community-based participatory research and photovoice could be valuable research methods for addressing these goals. Additionally, I hope that this paper can be a launching point for further explorations about the applications of transnational disability justice. Similarly to uses of transnational disability justice for theorizing facial differences in the Third World, I hope that this framework opens up new research areas that previously could not be fully conceptualized due to limitations in existing theoretical frameworks. Transnational disability justice may also provide a new perspective and corresponding conclusions about current research in Ethnic Studies, Feminist Studies, and Disability Studies.

I urge international craniofacial NGOs to create new representations of Third World children with facial differences. Humanizing representations have the potential to continue raising funds for medical treatment while also countering the stigma of facial differences. Garland-Thomson (2009) identifies two examples of depictions of people with facial differences created with social justice goals in mind. First, she calls Mark Gilbert's Saving Faces campaign a "productive

staring exchange” for “calling up and calling off our stares (p. 7). Gilbert paints people with facial differences throughout their medical procedures and during their daily tasks, such as playing with their children. While viewers initially engage with the paintings due to the unexpected sight, but they leave with a story about the lives of people with facial differences to which they can relate. Second, Doug Auld painted portraits of children with burn injuries, many with facial burn injuries. These paintings show audiences that the children are not only worthy of being viewed in public, but are in fact beautiful and to be celebrated. Garland-Thomson perfectly describes the outcome of such humanizing representations as follows: “They keep us looking rather than looking away. They grant us more than permission to stare; they use the clout of high art to transform our staring from a breach of etiquette or an offensive intrusion into an act of appreciation” (p. 83-84). Positive representations of children with facial differences must tell a new story of beauty, resilience, resistance, and worth.

Conclusion

I want to return to the following questions posed by Murphy (2010): “Do NGOs have the opportunity to operate both ethically and successfully?” and, “Should short term awareness and financial support take precedence over long term harm to education of poverty?” (para. 6). Murphy identifies a conflict between ethics and the daily operations of international craniofacial NGOs. In order to provide surgeries to children in the Third World, the NGOs need to raise funds and awareness to support their work. This requires appealing to a wide audience with the financial resources, time, and skills that they can contribute. At present, fostering support for the NGOs’s operations to function successfully seems to take precedence over the long-term impact of their work. This study brings the priorities of international craniofacial NGOs into question.

Regarding the first question, we first need to define “ethically” and “successfully.” The definitions for these terms could differ significantly based on ideological assumptions. From a transnational disability justice perspective, I would define ethics in terms of adherence to the values of transnational disability justice. An ethical approach to international medical activism must be rooted in the knowledge of Third World communities, foster coalitional politics, and consider the historical, cultural, political, and economic contexts in which the work is conducted. While international craniofacial NGOs may measure their success in the number of procedures performed and the number of countries with whom they partner, a transnational disability justice advocate would define success as addressing the systemic causes of the marginalization of children with facial differences in the Third World. With these clarifications, Murphy’s question seems to ask if social justice can be used to address the needs of children with facial differences in the Third World. I argue that not only do NGOs have the opportunity to do so, but that this is the only way to dismantle the “master’s house.”

The answer to the first question provides insight into the second question. In asking if short term goals should precede long term goals of systemic change, Murphy seems to pose the question of whether the strategies used by international craniofacial NGOs constitute the “master’s tools.” Findings from this study show that, as the NGOs currently operate, the goals of “short term awareness” and “financial support” act as the “master’s tools.” Until international craniofacial NGOs can develop strategies for raising awareness and funds that align with long term goals of systemic change, I argue that short-term goals should not take precedence. Doing so perpetuates hierarchical power relations that contribute to the lack of access to medical care, stigmatization, abuse, and infanticide of children with facial differences.

I encourage Ethnic Studies, Feminist Studies, and Disability Studies scholars to actively resist the problematic marketing approaches of international craniofacial NGOs. Although this study focused primarily on representations of children with facial differences, it still reveals the oppressive ideological underpinnings that inform the direct interactions between the NGOs and the children they treat. Transnational disability justice shows us that surgically altering children to meet hegemonic Western norms “will never enable us to bring about genuine change,” as Lorde (1984, p.112) would say. While I recognize that incredible positive changes have come out of the work of international craniofacial NGOs, I urge the NGOs to fundamentally restructure the ways that they view their role in Third World communities, their short-term and long-term goals, and the way they represent children with facial differences.

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APPENDIX A: VISUAL DISCRIPTION FOR MCDA

Step one of the data analysis involves visually describing the sampled data. This chart, adopted from Wang (2013) displays the categories and subcategories used for the visual description.

Table 1: Representation of Visual Meaning Making

<i>Category of Description</i>	<i>Sub-Category of Description</i>
Representational Structure	Action process
	Reactional process
	speech process
	conversational process
	symbolic process
Interactive meanings	contact
	social distance
	horizontal angle
	vertical angle
	modality
Compositional system	↑
	↓
	←
	→
Salience	

APPENDIX B: DATA

Table 2: Data Collected from Social Media Posts

<i>Name</i>	<i>Source</i>	<i>Photo</i>
Photo 1	Little Baby Face Foundation, Facebook	
Photo 2	Operation of Hope, Facebook	
Photo 3	Operation of Hope, Facebook	



Photo 4	Operation of Hope, Facebook	
Photo 5	Operation Smile, Facebook	
Photo 6	Operation Smile, Facebook	

Photo 7

Operation
Smile,
Facebook



Photo 8

Operation
Smile,
Facebook

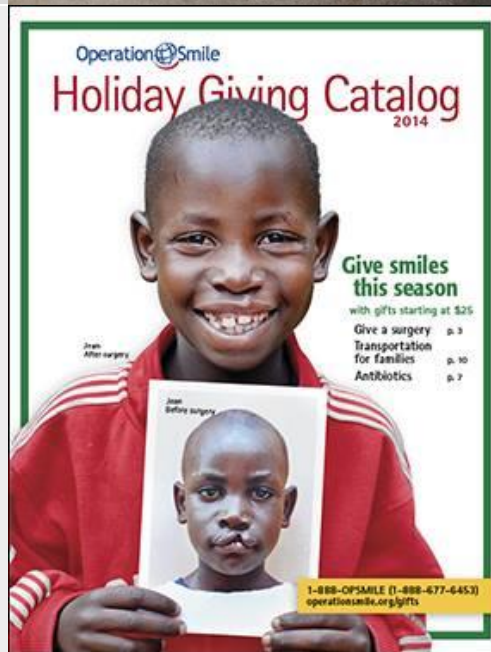


Photo 9

Operation
Smile,
Facebook

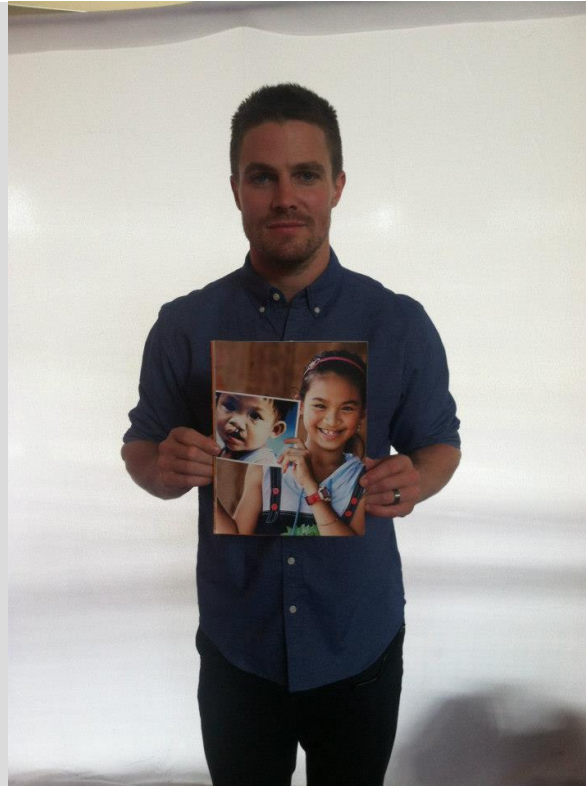


Photo 10

Operation
Smile,
Facebook







Photo 11	Smile Train, Facebook	
Photo 12	Little Baby Face Foundation, Facebook	
Photo 13	Smile Train, Facebook	
Photo 14	Smile Train, Twitter	 <p>“Everyone smiles in the same language.”</p> <p>UNKNOWN</p>




Photo 15	Smile Train, Twitter	
Photo 16	Smile Train, Twitter	
Photo 17	Smile Train, Twitter	

Photo 18 Operation of Hope, Twitter



Photo 19 Operation Smile, Twitter



Photo 20 Operation Smile, Twitter

