Operation Disturbance: Questioning Cleft Lip and Jaw Corrections

Ella Hillström, MA Anthropology New School for Social Research

When my mother was pregnant with my youngest sister, she went to consult a cleft jaw and lip expert in London. She lay down on the brits, lifted her legs up and peered at him as he glared at the black and white image. She had done these checkups before; I was also born with cleft. But the uncertainty of my sister's wellbeing unnerved her anyways. The expert muttered to himself, shook his head and asked:

"What have you done?" He scoffed. "I mean, what possible drugs could you have taken?"

Cleft lip and palate are a result of undeveloped facial tissues. Around day 23 of the fetus's life, five (soon to become) "bones" fuse to create the structure of the face. One bone stretches down from the "forehead." Two jaw bones, left and right, grow down to meet the two jaw bones that grow upwards. Push your tongue against the palate to feel the scar of the merging. When a child is born with cleft lip, jaw and palate, the fusion was incomplete, leaving infants with a gaping hole that stretches from their lip to their nose. Cleft palate is the most severe and impacts the ability to eat, breath and speak. Lip and jaw cleft, however, which I and my sister were born with, lead to an aesthetic disfigurement and sometimes a nasal tone.

There are various causes for cleft. It can be impacted by drug abuse during pregnancy. It can be genetic but unpredictably so; parents with symmetric faces can create the deformity while asymmetric parents can birth children without. In addition to the two causes, my aunt, who is an orthodontist with an expertise in cleft, mentioned that the disfigurement could also be "random" i.e. with no traceable causalities. The Doctor was aware of the arbitrariness behind the disfigurement but implied that my mother should be ashamed over her unborn daughter. To save the abject, and to save my mother from having to witness the deformity, he recommended her to do the corrective surgery instantly after the delivery instead of waiting for three months, which is the standardized practice. Some surgeons even perform cleft lip and palate surgeries inside the womb, claiming that "it affords the potential to provide a scarless repair" (Lorenz and Longaker, 2003). It also prevents the parents from seeing their disfigured child.

The desire to stitch the open mouth, and the Doctor's need to express disgust and shame my mother for his affective response, opens up space for generative inquiry. Who are the surgeries of cleft palate for? What is it with the open face that disturbs culture? To question the axiomatic corrections, I will use Sarah Ahmed's critique of the politics of happiness. I will also argue that the correction is located in a politics of care that tries to alleviate the immediate "suffering," rather than curing the structures that allow for suffering from aesthetic deviance.

Sarah Ahmed argues, in *The Cultural Politics of Emotions,* that emotions are not psychological states independent on context, but cultural artefacts created in a valued relation. From this perspective, sentiments have genealogies that allow for political mobilities. Currently, Ahmed argues that the global North and its political economy are driven by "a politics of happiness" and consequentially asks: Why is it wrong or undesired to feel disgust and discomfort? Why are certain people shamed? Why and how are these affects politicized? She convincingly argues that politics use

the reluctance towards discomfort to mobilize war, segregation, disappearance etc., in order to further the politics of happiness[1].

In the case of cleft lip and palate, the political emotions that are present and will be explored in this essay are disgust and shame. The Doctor was disgusted by the sight of the ultra sound and shamed my mother for his affective response - a feeling that is later embodied by the child.

Shame is the feeling of "the subject being against itself," Ahmed writes (2014, 103). The Doctor shamed my mother for creating disturbing life, and the cleft child later grows up to either feel ashamed over their appearance, or question themselves, *Should I be ashamed?* Not knowing what the other might think of one's appearance, leads to an internalized oppression. One takes the viewers unknowing opinion into consideration as one creates a self-(dis)regard.

When my 20-year-old sister went for a consultation on her wonky nose – a residue of cleft-, she explained how the cleft-children, in the waiting-room, hid under their hoodies. They were hiding and ashamed of themselves. She told me with a tonality that meant, *are you saying that they shouldn't have this surgery?* Similarly, my cousin, who did the same nose-surgery, explained that upon seeing another person with cleft, she doesn't want to affiliate herself with them. She lifted her arm and pushed away. It was an embodied response. She was not them, and they were not her. My sister, cousin and the other cleft-children in the waiting room were turning away from themselves. Shame is an affective response inflicted upon the subject, as a preemptive interpretation of what others might think– hide, hide, hide. You might be a freak.

The Doctor also expressed disgust. Whilst shame is an internalized emotion by the oppressed, disgust is an affective response asserted upon an external object. Psychologist and biologist Paul Rozin together with psychologist April Fallon, argue that disgust is evoked when the interior and exterior are interpellated. They define disgust as: "revulsion at the prospect of oral incorporation of offensive objects" (1987). Disgust is therefore connected to vomit – an, often, involuntary act that exposes the interior. By connecting disgust to this instinctive reaction, they claim disgust to be a timeless and universal emotion. Following Rozin's and Fallon's argument and lens, the institutional concealment of cleft lip is because the open lip reveals an interior that "should not" be exposed. The disfigurement creates an *instinctive* reaction of disgust from the observer.

Sarah Ahmed, amongst others, question Rozin and Fallon's a-priori conception of disgust. She instead understands disgust as a cultural artefact that is performed upon a border object that disturbs the boundaries of inside and outside (2014, 87). Yet, she argues that the line between the inside and the outside is a negotiated border. A border which needs to be collectively agreed upon. Borders fluctuate. They move and are unruly, yet we try to control them in an attempt to know

1 Affective politics for Ahmed goes hand-in-hand with an affective economy, where the desire to experience positive feelings creates massive economic markets, but also drives cultures further into *homophily – love of the same*, which marginalizes the other even further (Chun, 2018). The other becomes a symbol of discomfort and disturbance, and the undesired emotions drives society towards correction/assimilation/segregation/discipline/certainty. Ahmed thus argues, that valuing discomfort could lead to new ways of being with each other and finding new modes of politics. She calls for ways to refuse the terms of allegiance.

what belongs and what doesn't, as we determine who we are. The fluctuating line, between the inside and outside, becomes a border object, which can both be a thing (a wound) or an event (e.g. separating two sticky objects from each other). The deformed face is instinctively human yet different and becomes a border object. From this perspective, the open mouth is not a disgusting object. It's a line that confronts the viewer and asks: What are the possibilities of life?

Days after leaving the hospital with my newborn and "unrepaired" sister, my mother visited my primary-school. Passersby and teachers pulled towards the trolley and then back at the site of the baby. Some teachers expressed concern for their students. Would seeing this "unrepaired" human frighten them? My mother doubted her decision to bring my sister into the public, disrupting the cohesion of normal faces. She entered the classroom. Seven-year-olds peered at the newborn, asked questions and held her fingers.

When I explain to adults that I was born with cleft lip, they often state that they had no idea, or that they can't notice it. But, when I encounter a child, I'm struck by my own appearance: *Why do you have a scar, or What happened on your lip?* They immediately ask. Children are curious and seemingly more accepting to difference. They see the scar as a symbol of an event that demands causality, but they are not afraid. They don't assert the value that Ahmed argues is present in our culture.

For Ahmed, exposing those marked by difference is a way to refuse the "terms of allegiance" (2014, 100). Ahmed sees potential at the moments when the border between the inside and outside is negotiated, or when love emerges out of discomfort. My mother, by bringing my unrepaired sister to my school, was doing that, and I want to believe it was a performative act that declared: With all your faces, you are loved.

Besides from when the child has difficulties breathing or eating, the main reason behind cleft surgery is the assumption that uncorrected cleft children will be rejected and outcasted by society. These forms of surgeries can indeed be traced back to China 350BC and the bones of discarded children with cleft lips can be found in most regions (Wright, 2012). Yet, there are also accounts of communities where clefts are seen as blessings and an opening into a world beyond. For example, amongst the indigenous communities in Central South America (2012: 25). There, the communities see the open mouth as a spiritual bridge to the animal kingdom, the Gods and supernatural powers (2012, 38). Being born with a cleft lip in these regions are not just normalized or accepted but considered an opening into a world beyond. Hence, similar to how our understanding and ability to define emotions change, responses towards difference do too.

In current time, in the time of political happiness, axiomatic corrections are weaved into a language of care. This is apparent under the mission statements of NGOs, such as Operation Smile and other similar NGOs, that perform cleft corrections in impoverished areas. Operation Smile's first trip was in 1982 and today the organization has teams in "25 countries and have operated on well over 100,000 children" (Mc Gee, 2008,60). Operationsmile.org writes:

"The majority of these children are unable to receive the medical care they need because it is too costly, far away, or specialized. Because of this, being born with a cleft condition can be fatal. If a child survives, they may face bullying and social isolation."

Operation Smile Sweden writes (authors own translation):

"We could have been called Operation Survival, Safety, Confidence, Friends, School, Love, Hope and Future, but that would be a bit long. So, we are called Operation Smile. And that's what our work results into, more smiles."

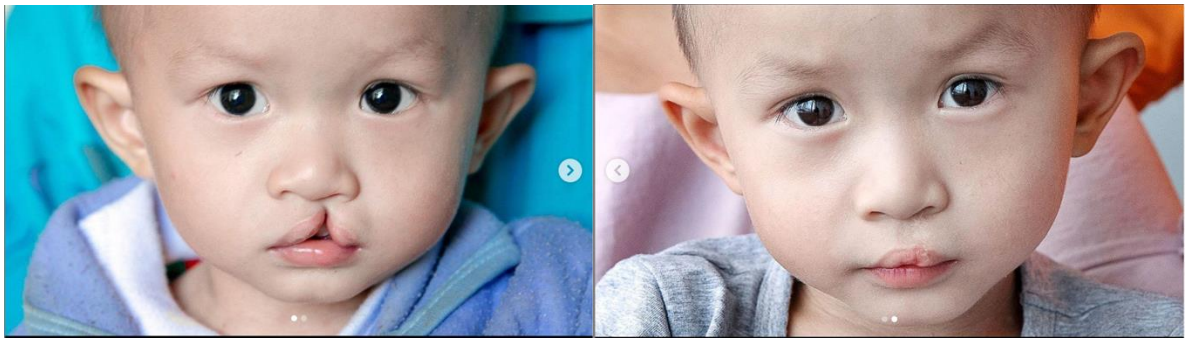

Figure 1 Iimage from Operation Smile Sweden's Instagram post: https://www.instagram.com/p/CEmKmtPJwz4/. I am startled by how innocent this child's deformity is. It also makes me wonder where the boundary is.

There are various accounts of plastic surgeons' missionary and almost spiritual experience working with the NGO. For example, the British nurse Jackie writes about a mother who was abandoned by her husband because of her son's deformity. Jackie later explains how moving her son was:

"He touched our hearts as all the children do. As a mum and a nurse, I feel privileged to be part of Joshua's journey and all the beautiful children Operation Smile helps around the world. The charity's philosophy is to change children's lives forever through a simple operation; their goal is to give local partners the tools and training to treat children independently, through education, research and self-sustainability. I can draw parallels with the NMC's Code of Conduct, championing the care of individuals with respect and dignity, promoting health and wellbeing. Care, compassion, communication and commitment translates across the international Operation Smile community, making a real difference to lives in less privileged countries" (2014).

NGOs', like Operation Smile, mission is to make cleft lip and palate children smile. Technically though, despite having a hole stretching from the lip to the nostril, children with cleft palate can smile and therefore succeed in fulfilling one of the most important function of a face: to communicate emotions and establish immediate relationships. This was later confirmed in a study by Harriet Oster who studied observers' abilities to interpret the emotions of infants with facial anomalies, including uncorrected cleft lips. She concluded that the observers' ratings were "highly accurate" (2003). Even children with uncorrected cleft palates succeed in communicating their emotions. Their humanness is still recognized, even if they are

unrepaired.

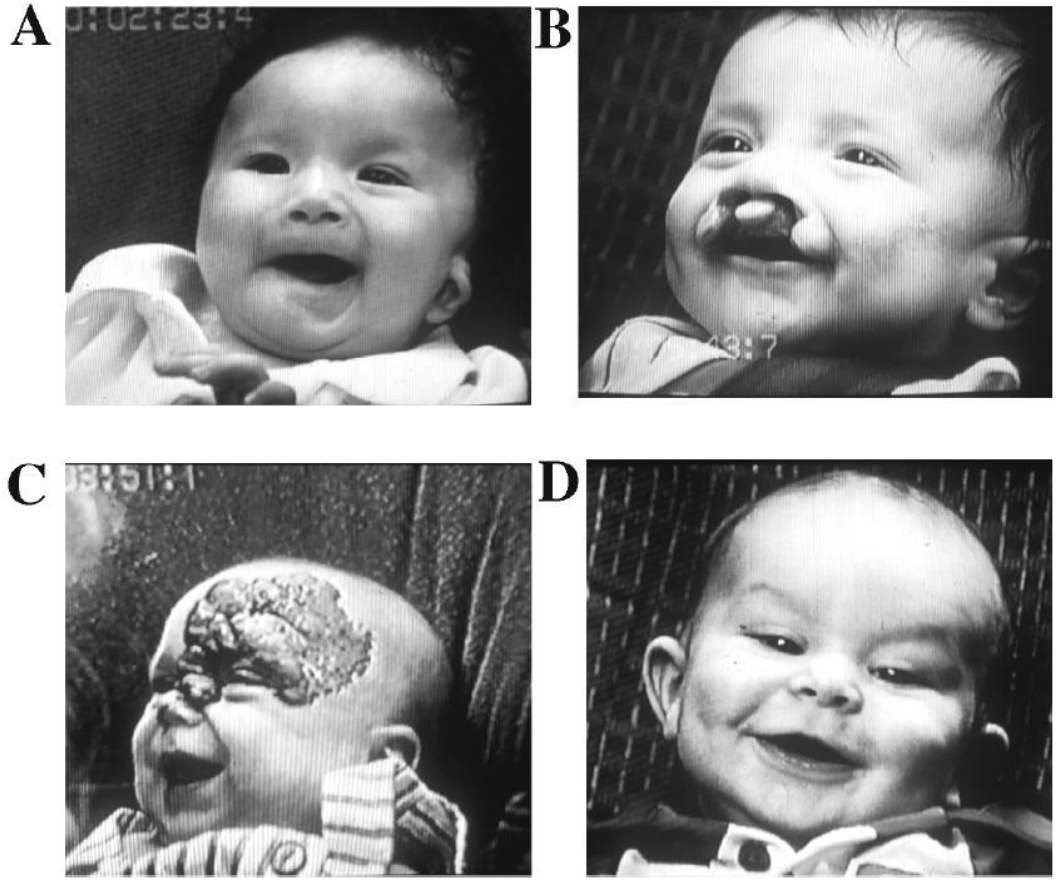

FIGURE 1. Examples of slides used in the observer judgment study. All slides were classified as smiles and were rated 6 on the 7-point intensity scale by objective Baby FACS criteria. The numbers following each infant's group and diagnostic category are the mean ratings and (in parentheses) standard deviations across 38 naïve judges on the 7-point emotion rating scale. (**A**) Goldenhar's syndrome (CFA), 5.71 (0.649); (**B**) bilateral cleft lip (CLP), 5.89 (0.863); (**C**) hemangioma (HEM), 5.89 (1.25); (**D**) comparison (COMP), 5.97 (0.563).

Figure 2 Oster Harriet, Emotion in the Infant's Face: Insights from the Study of Infants with Facial Anomalies, Annals New York Academy of Sciences, 197-204(2003).

Might it be possible then to question Operation Smile's agenda through the lens of postcolonial care theory? Do the NGOs make the child smile, or is the operation for the observer to smile? What forms of politics do these organizations care for?

The anthropologist Miriam Ticktin argues that a structurally unjust world is, paradoxically, organized through a "politics of care" (2011). She locates this politics of care to the wave of *new humanitarianism* which the NGO "Doctors without Borders" initiated. She writes: "Rather than change the conditions in which people live and thereby improve human life on a broader scale, the focus is on alleviating pain in the present moment" (2011: 62). Consequentially, since the politics of care focuses on alleviating immediate pain, refugees are harming themselves to cross borders, revealing that the politics of care is oriented around a subjective process of

recognizing suffering. By applying Ahmed's critique on the politics of happiness to the hiding of clefts, the unpleasant feelings, which the NGOs like Operation Smile care to alleviate, is not because of the nature of the disfigurement, - most children that they operate have already survived and so are independent beings – but because they are serving a politics of happiness that values certainty and positive feelings.[1]

Yet, it would be naïve of me to not recognize that the politics of happiness does set up borders with real consequences. I for example, wouldn't be able to access the spaces that encouraged me to write these words without a corrected face, and even I can be surprised by images of uncorrected clefts. I am startled by seeing myself. And the parents who bring their children to the NGOs want their child to be able to cross borders within hegemonic structures, not be defined by them. Yet, assimilating difference enforces the borders of normalcy and happiness even further. It marginalizes those who live within the borderlands, between the inside and outside, even more, and they will keep existing. Because, despite all the technologies of repair that are produced to control us, the abnormal slip through, leaving traces in the form of scars and uncanny reactions, reminding culture of its fragility. The queerness of humans disorients us, and assimilative care located within hegemonic politics will not cure this disorder.

Instead of assuming that correction is axiomatic, saves lives and prevents bullying, what would happen if we questioned this common-sense correction? Could we move towards a political order where "human" is considered a broad and unruly spectrum. Where difference was valued instead of shamed. Where uncorrected children were offered a platform to be honored, instead of hidden, and where the primary concern behind corrections were *what is lost* (Wright, 2012), instead of *how well can we hide them?*

1 This is an argument made by several postcolonial theorist. They raise the critique that care does not mean unequivocally positive feelings but that positive feelings, normally equated with care, "work with and through the grain of hegemonic structures, instead of against them." (Murphy, 2015: 719).

References

Ahmed Sara, 2014, *The Cultural Politics of Emotion,* Edinburgh University Press, 2nd edition.

Chun Wendy, 2018, Queerying Homophily in *Pattern Discrimination* by Apprich, Chun, Cramer and Steyerl, University of Minnesota Press: Minneapolis, London

Lorenz & Longake, “In Utero Surgery for Cleft Lip/Palate: Minimizing the “Ripple Effect” of Scarring.”*Journal Craniofacial Surgery* 2003, 14(4):504-11 https://pubmed.ncbi.nlm.nih.gov/12867864/

Magee Bill, *Management of Cleft Lip and Palate in the Developing World.* Edited by Michael Mars Debbie Sell and Alex Habel © 2008 John Wiley & Sons Ltd, ISBN: 978-0-470-01968-9

Matthews Jackie. "Operation smile: screening for birth defects." *Community Practitioner*, vol. 87, no. 10, 2014, p. 38. *Gale Academic OneFile*, https://link-gale-com.libproxy.newschool.edu/apps/doc/A394685469/AONE?u=nysl_me_newsch&sid=AONE&xid=37ee01f6. Accessed 16 Sept. 2020.

Murphy Michelle, Unsettling Care: Troubling Transnational Itineraries of Care in Feminist Health Practices, *Social Studies of Science,* vol.45, No.5, Special issue: The Politics of Care in Technoscience (October 2015), pp.717-737

Oster Harriet, Emotion in the Infant’s Face: Insights from the Study of Infants with Facial Anomalies, *Annals New York Academy of Sciences,* 197-204(2003).

Rozin .P., Fallon .A. A Perspective on Disgust, *Psychological Review,* 1987, Vol. 94. No 1. 23-41

Ticktin Miriam, 2011, *Causalities of Care: Immigration and the Politics of Humanitarianism in France,* University of California Press.

Wright, Shelley, 2012, *Toward the Mouth of the Abyss: The Indigenous Nature of Cleft Lip and Palate,* Dissertation submitted to Pacifica Graduate Institute.