

Memories and Re-Memories of My Mom's Eye Bandage: Trans-Relation Among the Norms,
Otherness, and Resistance

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Abstract: A mother and daughter from South Korea construct re-memories about the mother's visual impairment. The paper uses the concept of re-memory that Toni Morrison uses in her novel, *Beloved*: the act of revisiting a memory in order to reconstruct "past realities." The aim is not to "tell" the story of what it means to live as a person with a visual impairment while being a single mother and working as a special educator in Korean society, or what it means to live as the daughter of that person. There is no attempt to claim an authoritative version of "our stories." Instead the goal is to recognize our own social construction and cultural conditioning through re-reading our shared memories. Conceiving ourselves as sites for cultural critique and social change, the presentation will interrogate the ways in which mother and daughter have been constituted by historically, socially, and culturally specific discourses. The presentation will interrogate the ways in which our memories and experiences are enmeshed in a web of ableism, classism, sexism, and ageism. Finally, the paper will discuss what ethical work mother and daughter may/can do on themselves as educational researchers and teacher educators.

Disability has been reduced to an "object" of discovery, learning, and practice. Non-disabled researchers have strived to establish systematic knowledge about disability. Through the authorial knowledge, disability has been *created* as a biological and psychological reality, which is fixed and explorable. James Charlton's (1998) book entitled, *Nothing About Us Without Us*, reveals the positioning of people with disabilities in the process of knowledge production. However, with the current debating surrounding the ethical and political questions of ethnographical representation of "the researched" (Britzman, 1995; Fine, 1994; Denzin & Lincoln, 2000; Miller, 2005), the conventional way of inquiring about disability has been reconsidered (Couser, 2005). With recognition of costs and limits of ethnographic representation of disability, increased attention has been paid to the genre of autobiography, autoethnography, and memoir authored by those who are subjected to the category (Biklen, 2005; Biklen & Burke, 2006; Blackburn, 1999; Mooney, 2007; Mukhopadhyay; 2000). Yet, the stories of individuals with disabilities are often read as if they portray transparent and generalizable "reality" of their experiences. Questioning the modernistic notion of a fully conscious, rational, and coherent story teller, in this article, we produce family narratives about a visual impairment that one of us, Jong Lye, "has."

We – Sujung, a doctoral student who studies teacher education from a disability studies perspective in the United States and her mother, Jong Lye, who is a professor of early childhood special education in South Korea – interrogate our own memories around the visual impairment. We do not aim to "tell" our stories of what it means to live as a person with visual impairment while being a single mother and working as a special educator in Korean society or what it means to live as a daughter of that person. We do not attempt to claim an authoritative and completed version of "our stories." Instead, our goal is to recognize our own social construction and cultural conditioning through de-familiarizing and de-naturalizing our own memories.

Specifically, we question why the absence of Jong Lye's right eye has deprived her from the opportunity to give an account of herself, why she has been coerced to normalize herself even when the norms demonstrate its arbitrariness, and why she has actively produced ableist discourses to resist it. Conceiving ourselves as sites for cultural critique, we seek to interrogate the ways in which our experiences have been formed by historically, socially, and culturally specific discourses.

It is important to note that we have encountered tensions while reconstructing new meanings of our memories. The tensions come from the irreconcilable struggle between the voices of Sujung who has experienced her mother's disability as a witness and Jong Lye who has been dealing daily with material and ideological effects of her disability; between Sujung's epistemological stance implicated by Disability Studies and Postcolonial Studies and Jong Lye's one shaped by constructivism and a conflicting blend of special education and Disability Studies; between our lived experiences and their transformation into written texts; and between our original transcript written in Korean and its translated English version. Therefore, our autobiographical narrative should be read as conditional, contradictory, partial, and in tension. Based on our lengthy and emotionally driven conversation, we craft the script in a dialogue format and organize it around the three themes: production of otherness through fixity, ubiquitous and yet arbitrary norms, and paradox of agency. Each section begins with Sujung's vignette of her memory and follows with our conversation about it.

Production of Otherness Through Fixity

A small bandage has covered Umma's right eye for as long as I can remember. I believe that she started to wear the bandage to avoid the unwelcomed attention that an absence of one eye brought. I still do not know whether she was born without the eye or lost it by an accident when she was young. I have never asked about her impairment because seeing her "difference" has been taboo in my family. When I was growing up in Seoul, Korea, most of my friends and their parents went to a public bathhouse every weekend. Taking their kids to a public bath was a weekend routine of most Korean families in 1980s and in the early 1990s, when hot water systems were regarded as something luxurious. Whenever Umma took my younger sister and me to a public bathhouse, she was interrogated about whether her right eye under the bandage was infectious. She used to respond to them by explaining that she injured her eye in an accident. She would not forget to add that she would be okay soon. That has been the way that I have also learned to satisfy other people's interest, curiosity, or concern.

SJU: Umma, I don't know where and how to start our conversation because we have never talked about your eye. Why haven't we talked about it?

JLW: Maybe I never wanted to have conversations about my eye? It has been something that gives me some sort of pain whenever I have to dredge up the issue.

SJU: I think I know what you mean... But, let me ask why it has to give you the pain.

JLW: My right eye is something I have strived to hide so that nobody could see it. I was born without my right eye. I have a crooked nose probably because the eye was not formed. The

right side of my nose went up a little bit. Ever since I was young, I have been something that other people stare at. I was, and am still, sick of being looked at in disgust, pity, or even curiosity.

SJU: I'm amazed by how the simple act of looking can be a tool of violence against you.

JLW: It also worked as an efficient technique that taught me how strange, different, and abnormal I was, and still am. Any time people looked at me in "that way" they were pivotal in constructing the way I saw myself. When I was a little girl, I would play with my image... I would place a mirror next to the image of my face so that my left side, my good side, would be reflected up... this would make a perfect face for me to see. My perfect face—I thought I was beautiful.

SJU: I cannot find any words to describe how shocked and disturbed I am by this story. Since you were young, you've been learning what is normal and abnormal and which category you belong?

JLW: That is right. When I was in 7th grade, I started to wear an eye bandage. I do not exactly remember where I got the idea. But most likely, I was looking for a tool that could help me start over in relationships when I would meet new friends and teachers in middle school. I truly enjoyed the fact that I could decide whether or not to disclose my disability... although, I did not open it up in most cases. With a small eye bandage, I avoided being labeled as disabled as soon as they saw me.

SJU: Why have you strived to liberate yourself from the category of disability?

JLW: I did not want to allow the label to explain what or who I was and am. I felt that I was fixed as something undesirable, pitiful, or monstrous by a simple stranger's look.

SJU: You did not want to be associated with stereotype of disabilities. According to Bhabha (1994), the stereotype is an "arrested and fetishistic mode of representation" (p. 109) in the field of identification that always *fails* to account of someone. The strategy of the stereotype has been central in creating "the disabled" as a fixed social reality. You've resisted the ableist discourses that attempt to lock you in the rigid category.

JLW: You're right. I have tried to avoid being defined by and with the essentialized label. I did not want to be one of the objects sitting in a glass case at a museum and being explained with a small label and a short description.

SJU: I find it interesting that disability has been regarded as an object which people can establish complete knowledge about even though there has always been anxiety over the unfamiliar and ambivalent category. For what purpose and for whose benefits have the category been being mummified?

JLW: I don't have the answer to the question, but one thing I can tell you is that the determinist and essentialist stance plays a vital role in "othering" people who do not conform to hegemonic cultural and social norms.

SJU: I agree. If we put it in other words, it is a vital component of privileging those fulfilling the norms. Going back to your metaphorical statement, I could read the way in which epistemic violence (Spivak, 1987) was exercised against you by positioning you as a knowable object, not a knowing subject.

JLW: I haven't framed my experiences in that way, but I thought it was unfair that I would be explained with the label of disability while other "normal" people would be the author of the account for themselves. Maybe I have used the eye bandage to have the authority to define myself, although; it also has been a survival tool, which has allowed me to live in the ableist society.

SJU: Your eye bandage has such complex meanings... So, using the eye bandage as an instrument to control your body and identity, you have resisted to the epistemic violence. Would you explain what it means to use it as a survival tool?

JLW: With the eye bandage, I have been able to use the identity strategy of passing to gain inclusion into the ableist spaces around me. Many people think I am temporarily sick or injured rather than permanently disabled. I've learned that the way of interpretation allows me to be less alienated. With the simple device, I could manipulate people's interpretation of my difference and break free of the constraints imposed by the "abnormality."

SJU: With the eye bandage, you seem to have been able to transgress the limits imposed on you to create a little space where you can be partially empowered and temporarily liberated. Yet, why have you been culturally and socially coerced to seek a way of "normalizing" yourself even when your normalization tool, the eye bandage, is a reminder of your "failure" to meet the expectation of normality?

Ubiquitous and Yet Arbitrary Norms

I had believed that people could see much more clearly from their right eye than from their left one like they could use their right hand more easily for chopsticks. One day, in third grade I realized that it was only me who could barely see from my left eye. In Korea, once a year, students from third grade take a physical checkup to measure their height, weight, eyesight, and hearing. On that physical checkup day my teacher called my Umma to share the unfortunate news that my left eye sight could not even be measured since I could not read any letter on the board. The next day, Umma took an early leave from her school and came to my classroom to pick me up to go to see an eye doctor. We spent almost half of the day in the hospital to figure out what was wrong with my left eye. My eyes were tested over and over with a number of different machines. After endless tests and a long wait, my name was called, and a nurse took us to the doctor's office. The doctor told Umma that my left eye was amblyopic and kindly explained what it meant. Umma looked ready to cry. As soon as we came home, Umma started crying bitterly as if she wanted to be compensated for holding up her tears on the way. I felt

terribly sorry for Umma. Maybe it was because I remembered she mentioned how much she was relieved when I was born with two eyes.

JLW: When your dad wanted to marry me, your grandma disapproved at first. The only reason was that I had a disability. She feared that a disabling condition might be passed on to a child. I was worried about it as well. When you were born, the first thing I did was to check your eyes. You had two, beautiful eyes. I cannot forget the feeling of profound relief. But, when I was informed that your left eye did not function well, I had a strong feeling that I could not describe. Complete sorrow and guilt... I suspected your eye abnormality was caused by me even though I never knew if my condition was genetic.

SJU: Wow... you've been dealing with various cultural expectations and norms as a woman, as a mother, and as a person with disability. Although it is painful to know that my dear grandma was part of the discriminatory discourse, it is not surprising to me that she as a shi-uh-muh-ni [mother-in-law] had the clearly set expectation on your role as myuh-nu-ri [daughter-in-law]: bearing "healthy" children with preference for a son, who can carry on the family line. The clear cultural expectation that having children *is* a natural and inevitable part of being a myuh-nu-ri seems to rob you of your rights over your own body.

JLW: What was more interesting to me was that no one regarded my disability as a reason that the cultural norm needed to be reconsidered. At that time, I was working in a special education school for students with intellectual disabilities. A main concern of the teachers and the families was how to "protect" our middle and high school female students from becoming pregnant. One of the underlying assumptions was that they should not be mothers since they would not be able to take care of their child. Disabled women in many societies, including ours, often encounter pressures not to be a mother. Korean government currently allows abortion if the person or her partner has genetic mental or physical disabilities under article 14 of The Maternal and Child Health Act (2010). Interestingly, I wasn't persuaded not to have a baby despite your grandma's concern about the genetic possibility of my disability.

SJU: Ableism creates a fundamental paradox of the discourse of reproduction and motherhood. Why do you think that you were not discouraged from being a mother?

JLW: Probably, I was assumed to have the ability to fulfill the cultural expectation of motherhood especially since I was a teacher, which is considered a nurturing and caring job. It also resulted from your grandma's firm belief that it was my responsibility pass on the family line, especially because your dad was the eldest son. The complex interplay of sexism and ableism, which are grounded in blending of traditional cultural beliefs shaped by Confucianism and Western ideologies, shaped my experience of having you.

SJU: This story clearly shows that we are caught up in a realm of social norms. Our subjectivity and our experiences are socially and culturally constituted through the norms intertwined with relations of power. Remembering the day that I realized the "abnormality" of my left eye, I have been hunted by a question: why have I *not* been constituted as "the disabled"? I use only one eye to see the world, and so do you. Yet, I cannot recall any memories of

battling with the ways that other people look at me, resisting the stigma associated with my “abnormality”, and being tortured with the paradox of having to accept marginalized status along with the pressure to demonstrate normality.

JLW: It is an interesting point, but it also brings me relief as your mom. You would be diagnosed as a class-6 visual impairment according to the Disability Rating Scale of Ministry of Health and Welfare in Korea (2003) that defines class-1 as the severest and class-6 as the mildest. I am categorized as a class-5 visual impairment.

SJU: Our impairments do not seem much different based on the “severity” according to the Korean government’s definition. Why has my amblyopic eye colored my life experiences radically differently than yours have done?

JLW: It probably lies in the invisibility of the “issue” of your eye. The absence of one of my eyes surprises, fears, disgusts, or saddens other people because it does not fit in their frame of reference; however, your eye does not challenge their idea of what normal eyes look like.

SJU: That is exactly what I am intrigued by. What governs the politics of (in)visibility? Why is your non-existent eye visible while my amblyopic eye remains invisible?

JLW: I believe the notion of normality plays out in a relation to the politics of (in)visibility. The socially and culturally constructed concept of normality, which defines who has disabilities in a “common-sensual” way, has been taken-for-granted. Thus, people do not even know that the standards they often use to sort differences from sameness, ability from disability, and normality from abnormality are something that can be questioned. Our vision seems to be subjected to the hegemonic power.

SJU: The concept of normalcy leads people to assume that the categories of “the disabled” and “the abled” are mutually exclusive. But, my way of being is disrupted by *and* disrupts the assumption. I am conceived as non-disabled in my day-to-day contexts and, simultaneously, as disabled in Korean legal and policy contexts. I am positioned both as one of “the able-bodied” citizens who conforms the hegemonic cultural norms and as a person with disability who would need extra resources and supports from the Korean government. I am located in-between the presumed mutually exclusive subject categories. Isn’t my body one of a number of examples revealing the ambivalence of the categories and the arbitrariness of notion of normalcy? Is my case not an exception of the borderline condition but the nature of the concept of normalcy? What ethical work we may/can/should do to disrupt the ableist discourses that constantly defend the boundaries and attempt to define what belongs within the realm and what does not?

Paradox of Agency

Umma has always been a smart and strong woman. Her mom, my grandma, used to say how she was exceptionally smart compared to her siblings and other kids. I was always proud of introducing Umma to my friends because she was a career woman who had earned advanced degrees unlike most of my friends’ Ummas. Overhearing her conversation with her coworkers, I

also knew that her outstanding competency at work was admired and valued by other people. While she has always been my pride and my hero, I was often suffocated by her overemphasis on ability and smartness. To speak more correctly, I was frustrated whenever I encountered her normalized yardstick measuring someone's ability and smartness. She wanted me to get along with those who get good grades at school. She was unhappy about my boyfriend who did not attend a top-ranked college. While struggling with her overemphasis on ability and her unfair standards, I cannot deny that I have been privileged by her tendencies. When I received admission from a prestigious university in the U.S., Umma did not hesitate to allow me to accept it and to use our limited family resources to pay the awfully expensive tuition. She thought that not only would the college polish my talent, but its diploma would also serve as an indicator of my smartness, like a small warranty label guarantees quality of the product.

SJU: Umma, where do you think your strong emphasis on being intelligent and smart came from?

JLW: I don't know exactly, but I think it came from my family background, my social location, and who I am as a person. When I was young, my family was not affluent, actually poor. My parents migrated to Seoul from a rural area, wishing to establish your grandpa's tailor business in the big city. But, settling in the new area was not easy. They raised six kids with the limited resources, and they had to plan how to use the money for their children's education. Your grandpa decided to support his eldest son and me to receive college education. His rationale was that his eldest son would need the college education to lead the household, while I would need it to compensate for my disability and to live independently.

SJU: What did you think of his rationale?

JLW: I agreed with his idea that education was the instrument that would help me survive as a disabled woman with low socioeconomic status in the society. In the 1960s and 1970s, it was not the norm that women entered into the job market. Most women would become housewives and be supported by their husband. However, nobody in my family including myself thought I would get married due to my disability. Accordingly, I had to be prepared to have a job to support myself. The available jobs for women at that time were secretary, nutritionist, nurse, and teacher. I decided to become a teacher and therefore needed a higher degree.

SJU: Educating yourself was not a choice for you but an actual survival tool in the social context. Then, where do you locate your standard of smartness that I've always battled with as your daughter?

JLW: In school, I was a "model" student who got good grades and was adored and valued by teachers. Through my schooling experiences, I learned that my ways of thinking and learning were understood as smart. In addition, I've been growing and living in this society that decides people's smartness and their value based on what college, high/middle school, and even elementary school they graduate from. Wouldn't it be strange if I was not "contaminated" by what I have been seeing and learning?

SJU: I agree, Umma. We cannot be dependent on ourselves; we are always subject to the contexts in which we are located in nonlinear, unpredictable, and messy ways. While watching, experiencing, and living with you as your daughter, being “smart” seems like a driving force of your life. Umma, what does your “smartness” mean to you as a person with a disability who lives in this ableist society?

JLW: If my bandage is a “shield” that protects me from being “othered,” my smartness is my “weapon” that challenges others’ doubts about my ability associated with my “abnormal” appearance. While wearing the eye bandage, I could never get rid of the feeling of defeat. I sometimes see myself as a coward who is hiding behind the eye bandage, rejecting to “talk back” to the oppressive world. However, with my smartness, I could more actively challenge the ableist assumptions that other people might have about me. I could gain the respect of others and prove my worth. When I started my teaching job in the 1970s, the workplace operated in a male-centered way even though women were more numerous. Most female teachers easily gave up competing with their male colleagues for promotion. I was different. I would compete. I enjoyed having my intellect and capacities recognized. My smartness has not been merely a tool that offset my disability. Rather, it has been the foundation of my self-esteem. Yet, I am also aware of the paradox of my challenging ableism by (re)producing ableist discourses on smartness.

SJU: I would like to discuss the paradox. Your conceptualization of smartness, which has proven your value, might be the foundation of justification of other’s worthlessness. Doesn’t this paradox expose the nature of agency in subordination? You could interrupt the presumed fixed relationship between the label of disability and its connotation by demonstrating how capable and smart you are. As you make the label somewhat enigmatic or even inappropriate to explain who you are, you could question the discriminatory knowledge on disability. However, like you mentioned, while justifying your way of being, you might have been actively engaged in reproduction of cultural hegemony. Leonardo and Broderick (2011) conceptualize “smartness” as systems of ideology that operates simultaneously to privilege some people and to marginalize others in both material and ideological ways. Hasn’t your way of resistance disrupted *and* constructed the mythical category of disability?

JLW: If I look at someone very closely and deeply, I often see what I have never noticed in the person. If I turn the interrogative gaze into myself, I notice “the problem” that I’ve strived to contest within myself. I am finding myself as the oppressor through the interrogation of myself as the oppressed.

SJU: Why does it remind me of Mamdani’s book title, which brings me deep sadness, *When Victims Become Killers*? Your example complicates the conceptual opposition of the oppressor/the oppressed and reveals their complex relation. It seems that the categories do not exclude each other but rather blur with each other. Why have you had to turn yourself into a producer of ableist discourses in order to be free from it?

Through this autobiographical writing, we inserted ourselves into our past and “re-experienced” it although we acknowledge that the past is not something to which we can simply “return.” We did not aim to merely unearth what we had not been aware of; rather, we sought to construct new meanings of our experiences. As we revisit and interrogate our memories, we could read the partial “finger prints” of social and cultural conditions left on our “personal” experiences. In this section, we want to discuss what we have learned and what implication our leaning has for social researchers committed to production of counter-narratives in order to “create vision and imagination for what could be” (Weiss, Fine, Wessen, & Wong, 2000, p. 56).

First of all, through the interrogation of our memories, we have learned that Jong Lye has not been constituted as “the disabled” by her physical difference. Her “disability” status has been *created* through her daily experiences, which are formulated in the cultural contexts where her difference is conceived as “abnormal.” Her “disabled self” is anchored firmly in the micropolitics of normalcy. The oppressive representation of her visual impairment in her day-to-day contexts must not be read as the reflection of the pre-given biological traits. Instead, through a frame governed by the concept of normalcy, social and cultural signs are arbitrarily but systematically constructed to signify her difference (Bhabha, 1994). It appears that the hegemonic cultural power asserts the fixity of the signs whenever she attempts to disrupt the ableist conceptualization of her difference. We do not claim our story as universal, but a number of people labeled with disabilities struggle with the deterministic and essentialized signs attached to their differences. To disrupt the process of overly determining them with cultural signs, we need to move beyond recognizing images of disability as positive or negative. As researchers, we must produce knowledge that enables us to understand the mechanism of disability subjectification. We must question the very frame through which “the other” is born although it also threatens our own existence (Butler, 2006).

Secondly, we, the researchers, have been haunted by the social and cultural norms. Yet, once we acknowledge how the norms are ubiquitous and yet arbitrary, we become able to see ourselves as liminal beings standing at the intersection of self/other, normal/abnormal, and abled/disabled. I, Sujung, find myself being characterized as “able-bodied” in my daily life while being labeled with class-6 visual impairment in the legal and policy contexts. I, Jong Lye, become more aware of the ways in which my “partial” presence of “the normal” is produced by normalizing strategies. By covering the absence of my right eye with a small bandage, I become “almost the same [as the able-bodied], but not quite” (Bhabha, 1994, p. 127). I, Jong Lye, am also able to cross the boundary of “the normal” partially and temporarily by demonstrating my “smartness” in a normalized sense.

Most people, like us, are framed with various types and degrees of privilege and discrimination simultaneously given by the ambiguous and arbitrary norms. It is important to acknowledge our liminal ways of being because it allows a new form of solidarity for social change to emerge. If we acknowledge our liminality, “Not Self and Other but the otherness of the self” (Bhabha, 1994, p. 63), the social change comes from neither one group’s abandonment of privilege nor the other group’s liberation from oppression. Instead, it is derived from everyone’s active engagement in creative intervention for oneself as an oppressed and oppressive being. The social change also requires our collective efforts to challenge our cultural normative expectations

and re-inscribe social imagination. What we need as researchers is to develop analytic frameworks that enable us to recognize and understand the “in-between” spaces that have potential to revise meanings of the normal and the abnormal.

Lastly, we could acknowledge the complexity of agency through closely scrutinizing our memories. Jong Lye has rejected becoming a pure victim of the hegemonic culture. She has exercised her agency by negotiating the arbitrary concept of normalcy. She could transgress the limits that she encounters through demonstration of her normality. Yet, her act of normalizing herself also reveals that she is clearly marked by the hegemonic cultural power even when she resists it. Our example confirms Bhabha’s (1994) assertion that not only are we constituted by the intersection of various power networks, but we also (re)constitute it simultaneously. He argues that agency is characterized by the tension between people as a priori of their national history and the people as its product. The techniques that Jong Lye has adopted to exercise her agency in her daily contexts challenge our pessimistic understanding or utopian vision of agency. As researchers, we might have put too much emphasis on how change agents work against the system while paying less attention to how they work against and within the system. Thus, we might not fully understand the complex and paradoxical ways in which one, who is not necessarily engaged in an oppositional act with political intention, constantly questions, disrupts, and reinscribes the ableist discourses on a daily basis. We need a more nuanced and complex analysis of agency that will stop dismissing hope for change as a too idealistic faith.

We, Sujung and Jong Lye, hope the narrative we produce here is not understood as a device that makes our personal stories public. We hope that our readers have been engaged in the process of reexamining our memories in the social and cultural contexts with us. While we realize that our work of de-naturalizing our taken-for-granted memories is partial and incomplete, we wish to create a tiny “crack” in the “canonical” discourse of disability.

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