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## **Deformography: An Autoethnography of Syndactyly**

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### **Abstract**

The author of this paper uses autoethnography to explore some of her experiences being born with the congenital malformation syndactyly, calling the process her deformography. She engages in this process for two reasons: a) to move syndactyly out of the medical literature, and b) as a step in a self-empowering process towards acceptance. In so doing, the paper explores social ideologies of difference that have affected her in her lifetime, with particular focus on Ancient Sparta and Nazi Germany. The paper concludes with the author's realization that although she understands how difference "works" on a cognitive level, she has more to do on her healing journey.

### **Keywords**

syndactyly, autoethnography, congenital malformation, upper extremity, Aktion T4, Nazi Germany

## **Deformography: An Autoethnography of Syndactyly**

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### **Introduction: A Long Hard Road**

Simply stated, “syndactyly is a congenital malformation in which two or more fingers are joined because they fail to separate or fuse during limb development” (Gallego & Avedillo, 2016, p. 1). Syndactyly is a condition I understand intimately and expertly, despite not being a doctor (of medicine or philosophy [yet]). Being born with syndactyly means that I have physically and culturally experienced the world differently than persons who do not have the condition, particularly those who do not have an upper limb difference. Indeed, having been born “deformed” has distorted my understanding of normalcy. Deformography was introduced by Marilyn Manson in the form of a song title on his *Antichrist Superstar* (1996) album and used as a chapter title in his autobiography *Marilyn Manson: The long hard road out of hell* (1999) to explain his transition into a performer. In both instances, the word is referred to rather than being explicitly described or explained. I thus acknowledge Manson’s creation of the expression but have utilized it for my own purpose: *deformography* is a portmanteau of the words “deformity” and “autoethnography,” which I use to explain how I have come to terms with myself being born differently in a world that treats difference as a deficiency, (Ghosh & Abdi, 2013).

The purpose of this paper is to bring syndactyly away from the medical literature and into qualitative scholarship using autoethnography. This is a valuable endeavor for two reasons. First, I consider it important for academics who aren’t physicians and/or scientists to research and

write about medical conditions; in other words, it is vital that disrupt the medical model of disability that is so prevalent in society. This positionality of disability within the medical model facilitates the binary oppositions of healthy/unhealthy, abled/disabled, and normal/abnormal, ultimately resulting in a discourse that marginalizes people with certain conditions like syndactyly. As Brisenden (1986) observed, “our opinions, as disabled people, on the subject of disability are not generally rewarded with the same validity as the opinions of 'experts', particularly medical experts” (p. 173). This is not a denial of the so-called “objective” nature of the sciences, but rather serves as a reminder that disability cannot “be adequately interpreted from a strictly medical point of view” (Brisenden, 1986, p. 173).

Second, I am providing an autoethnographic account of my experiences as a person with syndactyly and a disability as part of a therapeutic process (Ellis, Adams, Bochner, 2011). This reflexive act exemplifies my journey in identifying as someone with a dis/ability - something I did not begin to do until after I started my doctoral program. Important as part of this therapeutic process, as noted elsewhere, is my purposeful and aesthetic choices to use dis/ability or dis/abled rather than disability or disabled when referring to myself. I do this for two reasons: “First, the slash operates as a means of disrupting the detrimental notion that to be disabled is to be in some way “less than” someone who is not. Second, the slash acts as a visual marker that identifies the ways in which my ability levels may be impacted by any number of other factors—this is to say, my having a dis/ability, like many others, is representative of a spectrum of ability rather than a binary” (Lorenz, 2017, p. 82)

## **Methodology**

### *Disrupting Science as Value-Neutral*

Though my deformography requires me to utilize medical literature in order to explain syndactyly, it is at the same time pertinent that I problematize the belief that the sciences are value-free, a position often purported by scientists. To do so, I use scholarship from Indigenous academics in an act of solidarity against the normative settler colonial processes that value certain bodies (read: white, male, cis, able-bodied) over others. nehiyaw Indigenous Studies scholar Shawn Wilson (2008) described research as being led by the ontological, epistemological, and axiological values of the researcher; in other words, the researcher's ways of knowing and being as well as their values impact what (and who) is seen as important. Problematizing the notion that only certain kinds of learning count as "knowledge," Linda Tuhaiwai Smith (2012), a Maori educational scholar, asserted that Eurowestern research paradigms were created in order to reinforce hierarchies of knowledge, and in this case in order to subjugate Indigenous peoples to settler populations. Building on the work of Smith, nehiyaw educationalist Margaret Kovach casted further doubt on the subjective possibilities of research and indicated the existence of the "epistemic privilege of the scientific paradigm" (2005, p. 21). More simply, Kovach stated that scientific methods are promoted as being "the right way" (or the "only way") to conduct research. In sum, as Anishnaabe scholar Kathy Absolon and nehiyaw scholar Cam Willet (2005) declared, no research—regardless of academic discipline—is truly objective in nature. Non-Indigenous qualitative researchers may also take this position about research. As Sarah Wall (2006) explained, "traditional scientific approaches...require researchers to minimize their selves, viewing self as a contaminant and attempting to transcend and deny it. The researcher ostensibly puts bias and subjectivity aside in the scientific research process by

denying his or her identity” (p. 2). As I have explained previously (Lorenz, 2017), a researcher’s “ontopistemological and axiological orientation is derived from the culture(s) they are from, the place(s) they live, and their experiences in the world” (p. 82) and therefore are rooted in subjectivity. Likewise, my perspective on syndactyly is intertwined with my experience living with the condition: I cannot separate myself from the literature on syndactyly, because, intrinsically, that research is about me even if I am not being treated as the research subject.

### **Autoethnography**

The ways syndactyly has been examined in the literature is focused on the medical field, usually in the areas of genetics, orthopedics, or plastic surgery. Not being trained in medicine, I do not have the capacity to write about syndactyly in the same way as these researchers and medical professionals; however, the experiences of those with the condition are absent from the literature. If patient-centered care is becoming more common-place for clinicians (i.e., Ishikawaa, Hashimotob, & Kiuchia, 2013; Mead & Bower, 2000), perhaps then there should be a focus on including patients within the literature that is about them.<sup>1</sup> This subjective approach to syndactyly—which I am encapsulating within an autoethnography—will ideally give medical professionals some insight.

Autoethnography emerged out of critiques of the scientific method applied to qualitative research, the lack of ethical care given to participants of the Tuskegee Syphilis Study, and the tendency for outsider researchers to have arrogant opinions of those deemed as Other (Holman Jones, Adams, & Ellis, 2013). As a combination of autobiography (writing about oneself) and

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<sup>1</sup> This approach is demonstrated in Jackson and Spencer (2017) where the former encouraged the latter, an eight-year-old budding entomologist, to write about her experiences being bullied by her peers in their peer-reviewed article *Engaging for a Good Cause: Sophia's Story and Why #BugsR4Girls*.

ethnography (writing about sociocultural contexts) autoethnography is the process by which the researcher writes about the sociocultural situations they participate in and the revelations they have as both participant and researcher (Allen-Collinson, 2013; Ellis, 1999; 2004; Ellis et al., 2011; Holman Jones et al., 2013; Méndez, 2013). For Poulos (2013) even though the stories come from one person, they are really about society as a whole; as Ellis explained, they are about “a way of being in the world” (2013, p. 10). The focus on stories and storytelling in autoethnography is very different than how research is conceptualized in the sciences and medicine: instead of compartmentalizing or ignoring subjectivities in the sciences, the subjectivity of the author is the focus of the piece (Ellis, 2004; Ellis et al., 2011).

For many autoethnographers, writing and research can be part of emancipatory processes; as Brown and Strega (2005) asserted, there can be transgressive properties to research. The relative uniqueness of autoethnography as a method in the academy speaks to this as well. The autoethnographic practice as a first-person narrative disrupts “the conventional separation of researcher and subject” as Belbase, Luitel, and Taylor (2008, p. 88) clarified; these thoughts are echoed by Chang (2008) as well as Jones and colleagues (2013). Moreover, critical reflection—which is an essential part of autoethnographic writing—has transformative properties which can lead to the production of new knowledge about a topic (Boud, Keogh, & Walker, 2013; Mezirow, 1998). In sum, there is no other research methodology that I can use that allows me as both researcher and subject to situate myself within the paper while simultaneously permitting me the space to critique normative, able-bodied society.

Within the text, I disrupt a more academic writing style with critical reflexivity that has come about as I have written, edited, re-written, re-edited, re-re-written, and finessed this paper over the past five years. Truthfully, though I knew it was important have this manuscript

published, I was underconfident in submitting it for quite some time. To signify reflexive praxis, I enclose italicized text within two virgules. I do this for two reasons. First, the slashes act as a pause between two different types of writing, allowing for my more personal and reflective thoughts to be clearly articulated to the reader. Second, I employ this left-leaning stroke within the text as a type of visual transgression: I am purposefully distorting normative academic standards of writing as a part of my pedagogical praxis of engaging in autoethnography. / *This is not going against the (academic) status quo just to be contrarian.* / To me, this two-fold rationale embodies /*as much as text can on a virtual page* / how subjectivity in research writing can manifest as a method antithetical to so-called objective writing.

When the history of research is guided by principles of “objectiveness” and situates the Other as something to be studied, the introspection and reflexivity of autoethnography is in direct opposition to the norms of quantitative, and sometimes qualitative, forms of research. Yet, because it speaks in specifics rather than generalities, autoethnography is often dismissed as a valuable method of inquiry. Three frequent criticisms, as outlined by Chang (2008), include the lack of academic rigor, a shortage in methodological legitimacy, and too much focus on autoethnography’s subjective nature. Similarly, as Denzin (2014) specified, “autoethnography has been criticized for being nonanalytic, self-indulgent, irreverent, sentimental and romantic”; it has also been problematized as being “too artful,” “not sufficiently artful,” “not being scientific,” and lacking theory, concepts, and hypotheses (pp. 69-70). /*But I’m not doing science. I’m not hypothesizing either. This is my story. Mine.* / Despite these criticisms, the subjective nature of autoethnography is what gives it the greatest appeal: like McDonnell (2017) I see myself “as my own research subject,” and thus “I can rely on my interpretation of the data and avoid any risk of



appropriation of voice or culture” (p. 60). This makes autoethnography the best method for my deformography.

As expressed prior, the purpose of this paper—and thus why I am drawn to autoethnography—is to generate an interest in syndactyly within the research literature that is not wholly based on work from the sciences and medicine. In this way, it seeks to create space for other (read: non-medical) opinions of syndactyly. Part of my practice as an educator comes from how I articulate myself as a person in the world: compared to many others I have a great deal of privilege as a straight white ciswoman, a settler-colonizer on Indigenous lands, and someone who is highly educated yet deals with income precarity as a PhD candidate. */Who has been taking too damn long to finish./* Intrinsically my social location makes me “both oppressor and oppressed” (Potts & Brown, 2005, p. 258). This intersectional understanding of who I am within bigger systems of power and privilege allows me to navigate these structures in an effort to do meaningful academic work. */I hope./*

Part of my pedagogical praxis as an educator endeavors to create space for others in places where I have privilege, and to fight for myself in places where I do not. To reiterate, we must not only note the importance of diversity in scholarship, but as social researchers we must stress that our experiences as individuals have merit:

We know that erasing the alterity and diversity of the voices of others emaciates our stories. It produces scholarship that sustains hegemonies. Erasing our inner voices does the same thing. It is a lie of omission. We participate in this lie because we like to see ourselves as coherent, knowledgeable and safe, just like our scholarly voices sound. We can't just barf our mess onto the page. In order communicate effectively and look smart, or at least not pathetic and crazy, what we say has to be deftly written and make sense. (Tamas, 2009, para. 11)

Denzin (2014) described this in relation to autoethnography as being “interventionist, seeking to give notice to those who may otherwise not be allowed to tell their story or who are denied a

voice to speak” (p. 6). /*Oh, hey there.*/ Consequently, “Even with the best of intentions, relatively privileged researchers can wittingly or unwittingly silence, mute or distort the viewpoints of the relatively underprivileged communities to which they are attempting to give voice” (Allen-Collinson, 2013, p. 289). /*AKA The road to hell is paid with good intentions.*/ As such, this deformography cannot and should not be seen as speaking for others: I am writing about my life, my experiences, my hand, and my feelings. My choice to use autoethnography as the method to frame my deformography comes from its utility as an emancipatory practice that “gives voice to the culturally muted” (Crawley, 2014, p. 222) as well as providing “a discursive and representational space” that poses “a direct challenge to hegemonic discourses” (Allen-Collinson, 2013, p. 290). /*Me.* /

## **Literature Review**

The term syndactyly comes from the Greek language, where *syn* means “together” and *dactyl* means “digit” (i.e., finger or toe); combined, syndactyly means “together digits” (Jordan, Hindocha, Dhital, Saleh, & Khan, 2012; Łatkowski, Wysocki, & Siewiera, 2011; Malik, 2012; Schmelzer-Schmied, Jung, & Ludwig, 2011). More specifically, the term refers to fingers or toes being conjoined. Someone born with syndactyly will often have skin between their digits; in some cases, this resembles webbing. Webbed toes, a condition that is known outside of the medical literature (e.g. celebrity gossip magazines like *InTouch* reporting Ashton Kutcher has webbed toes [Sitzer, 2014]) is the most-well known incidence of syndactyly. Isolated syndactyly of the feet, Kim, Kim, and Kwon (2016) indicated, citing the earlier work of Castilla, Paz, and Orioli-Parreiras (1980), occurs four times more often than isolated syndactyly of the hand, wherein *isolated* refers to syndactyly that does not occur as a result of a genetic syndrome.

Syndactyly happens during embryogenesis (the process of development an embryo goes through) when the hand plate (“an expanded, flattened area of tissue... which develops into the hand” [“Hand Plate,” n. d.] and rather resembles the fin of a fish) does not form normally; in particular, tissues of the hand do not separate, causing two or more fingers to be fused together (Dy, Swarup, & Daluiski, 2014; Goldfarb, Steffen, & Stutz, 2012; Jordan et al., 2012; Łatkowski et al., 2011; Lifchez & Sen, 2010; Schmelzer-Schmied et al., 2011; Young & Hansen, 2010). There are many different types of syndactyly, some the result of syndromes or genetics, while in others the cause appears to be random (Dy et al., 2014; Łatkowski et al., 2011; Lifchez & Sen, 2010; Schmelzer-Schmied et al., 2011; Young & Hansen, 2010).

Syndactyly can be complete (digits being joined together with skin to the fingertip), incomplete, complex (bones joined together) or simple, with other visible or invisible conditions impacting the presence and/or appearance of joints, tendons, muscles, or fingers (Dy et al., 2014; Goldfarb et al., 2012; Jordan et al., 2012; Lifchez & Sen, 2010; Malik, 2012; Oda, Pushman, & Chung, 2010; Schmelzer-Schmied et al., 2011; Tonkin, 2009; Young & Hansen, 2010).

Depending on the severity of the condition surgical intervention may be necessary: the interdigital skin is cut, and skin grafts are applied to increase the functionality of the hand (Dy et al., 2014; Jordan et al., 2012; Łatkowski et al., 2011; Lifchez & Sen, 2010; Oda et al., 2010; Schmelzer-Schmied et al., 2011). Other forms of treatment include splinting, limb manipulation, band stretching, tendon transfers, physical therapy, skin grafting, and prosthetics (Lifchez & Sen, 2010).

The exact frequency of syndactyly is not reported with consistence in the medical literature. For syndromic types of syndactyly, the literature suggests ranges from one in 2,000 births (Goldfarb et al., 2012; Jordan et al., 2012; Jose, Timoney, Vidyadharan, & Lester, 2010,

citing Kay, 2005; Oda et al., 2010; Tonkin, 2009) to one in 2,000 to 2,500 births (Kim et al., 2016). For isolated cases, the frequency decreases significantly, though is still not consistent: ranges from to seven in 10,000 births (Lifchez & Sen, 2010), 3-10 in 10,000 births, (Malik, 2012) or one in 10,000 births (Malik et al., 2005) have been reported. Syndactyly is considered one of the most common hand malformations (Goldfarb et al., 2012; Jordan et al., 2012; Jose et al., 2010; Łatkowski et al., 2011; Lifchez & Sen, 2010); nonetheless, malformations of the hand and wrist are considered statistically rare or uncommon in the general population, occurring in about 1 of every 600 newborns (Oberg, Feenstra, Manske, & Tonkin, 2010; Schmelzer-Schmied et al., 2011).

In dysmorphology—the study of congenital abnormalities—syndactyly is recognized as a malformation, or “an abnormal formation of a body part or complex tissue,” whereas a deformation “occurs after normal formation” (Oberg et al., 2010, p. 2072). The difference between the two is that the former was never considered “normal,” whereas in the latter something changed to make the body “abnormal.” As much as definitions are useful because they can precipitate understanding, they can also be injurious.<sup>2</sup> The etymology of “deformity” (coming from the French “*deformité*”) has the capacity to be hurtful and is a world that I have negative associations with. Synonyms for deformity include “marred,” “disfigured,” or “unsightly” (“Deformity,” 1989). */Like Frankenstein’s monster. I guess I best incinerate myself in “the Northernmost extremity of the globe,” too. /* By the time I was of school-age I had an understanding that being marred, disfigured, or unsightly was something relegated to “the bad

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<sup>2</sup> The colonial practice of naming and defining, Young (2005) explains, was a way for nineteenth century philosophers to describe racialized persons as deficient. If we are relying on definitions to elicit understanding in the present, we are therefore relying on colonial practices, and privileging Eurowestern knowledges over those of Indigenous peoples and other racialized persons. As such, the procedure is not without complications.

guys” in the media I consumed: but I didn’t want to be seen like that. There wasn’t anything wrong with me: I was just a little different, that’s all.

## **Deformography**

### *Deformography in Childhood*

I was born with complicated syndactyly of the left hand. As Kozin (2001) explained, “complicated syndactyly is a broad category that encompasses many difficult forms of abnormal web space connection and bony abnormalities” (p. 7). For me, this means that the soft tissue in two of my fingers are conjoined. Additionally, I am missing a number of muscles, ligaments, joints, and bones throughout my hand as well as my index finger completely. I’m covered in scars from skin grafting and the four surgeries I had between nine months and thirteen years of age. These scars serve as another indicator of my physical difference: my hand is covered in scars from the grafting, and I have a scar on my thigh where skin was taken to use on my hand. / *What happened to you, people ask. Nothing happened, I reply. This is the way I am. /*

Often, those born with syndactyly “often are the subject of ridicule by other children that can lead to low self esteem” (National Foundation for Syndactyly, n.d., para. 3). /*Yup./* I must have understood very young that I was physically different than my peers; as a preschooler, I would not have understood how my syndactyly made me into a subject, but I did understand the pointing, and the questions from other children (and adults). / *I am forever watching people’s eyes. If they notice my hand, they will pause, just a second too long. And then I know that they see./* A *subject* is an ideological construction created by a particular society (Althusseur, 1971/2014). This, Smith (2004) reminded us, is something that happens in such a way that we are unaware of it. The dichotomy that exists between abled and disabled, Garland-Thomson (2011) argued, is ideological: “it penetrates the formation of culture, legitimating an unequal

distribution of resources, status, and power within a biased social and architectural environment (p. 17). Since societal constructs of ability and disability exist in a binary opposition—rather than recognizing them as a spectrum—persons who are considered “abled” occupy a privileged position as “normal” people (Smith, 2004). In this way, I began to understand—or perhaps internalize—that I was seen by others as being abnormal, and therefore, lesser than my peers. The ideological construct that surrounds the idea of difference, exists always-already, Althusser (1971/2014) confirmed: I was different in the eyes of everyone else without knowing I was.

I was teased and ridiculed by other children into my teens; kids I met at the park, the siblings of my friends, my classmates. / *Flipper. Funny Fingers. Freak. Words that still upset me even though they haven't described me in decades* / It hurt then because I couldn't understand why it was such a big deal. / *It shouldn't have been an issue at all.* / Adults were somehow worse: I noticed them whispering to each other and pointing at me. / *Images still burned in my brain that I cannot forget* / Though I grew up in an era without a discourse around safety in school, I was not protected from discriminatory acts from some teachers. I did not receive adequate accommodations in gym class. I was cut from two school teams despite being at least as skilled as my peers. At the time, I was too confused and embarrassed to push back against these two teachers. In hindsight, I should have.

By the time I was seventeen I realized that it had become an unconscious habit at some point to hide my hand. My sleeves are worn long, my hands are often in my pockets, my arms are crossed, or if I was sitting, my hand was between my knees. I still do these things when I'm with close friends, family, my partner, or even when I'm alone. I'm that uncomfortable in my own body all the time; I'm worried that someone will notice. I don't want someone to make a

comment in a negative or hurtful way. */My experiences growing up have irreversibly impacted my self-esteem. At this point I don't think I will ever feel truly comfortable in my body./*

This is not, however, particularly abnormal as Taleporos and McCabe (2001, 2002) have illustrated in their work. If you are treated as divergent in a strictly negative way, you are bound to carry some of that harm with you. Similarly, Clare (2017) briefly outlined the ideological negativity associated with disability:

Over the centuries in white Western culture, people now known as disabled have been monsters, gods, goddesses, and oracles. We have been proof of events that happened during our mothers' pregnancies, demonstration of sin, and markers of evil. We have been evolutionary missing links, charity's favourite objects, the proving ground for Christian miracles. We have been the wild and exotic gist of freak shows, test subjects for the Nazis as they built and refined their gas chambers. We are burdens on society, useless eaters...We are better off dead. (p. 7).

Clare's words ring true when I reflect on how my body—and my syndactyly as a visual marker of difference in particular—is considered within historical contexts.

### **It Could Have Been Me**

In grade eleven I took a history class in ancient civilizations. Peoples from all over the world were covered, but I still think about one in particular: the Spartans. It was there that my teacher told us that as a militaristic culture, the Spartans practiced infanticide, killing all newborns that were “defective” (Fletcher, 1974). I distinctly remember hiding my hand between my knees on that day: I didn't want anyone to notice that I was different. I didn't want my peers to suggest what I felt was a clear correlation. */You should be dead, Danielle./* This is a burden I have been carrying for nearly twenty years. But it is not the heaviest one that I bear.

As an undergraduate student, began to read more about the Holocaust—a topic I had learned about in my K-12 education but not in significant detail—in part because of how major

corporations (e.g., Coca-Cola, IBM) marketed their products to and were consumed by Nazi Germany (Achbar, Abbot, & Bakan, 2005; Bakan, 2004), something that was covered in my Popular Culture class. Years later, in the second year of my PhD, I became more interested in disability studies as an area of academic focus, stumbling upon how people with disabilities were perceived and treated by the German nation-state in the early-to-mid twentieth century. */I still can't believe in all of that reading I did before starting my PhD I did not come across the relationship that disability had to Nazi Germany./*

Gerhard Kretschmar was born in early 1939 with a number of disabilities: he was blind, his leg and part of his arm did not develop in utero */like mine./*, and he was also labelled as mentally disabled (Merrick, 2016; Mostert, 2002). His parents asked he be euthanized by a paediatrician who refused because to do so was illegal (Merrick, 2016; Mostert, 2002). Kretschmar's parents then petitioned Hitler to override the law that prevented them from killing their child; Hitler personally agreed that he would do so (Merrick, 2016; Mostert, 2002). However, eugenic policies in Nazi Germany were already official during Kretschmar's lifetime: in 1933 Germany had passed a law that permitted the mandatory sterilization of those deemed "idiots," "imbeciles," and "irredeemable criminals" (Hepburn, 2014, p. 103; see also Merrick, 2016; Mostert, 2002). The purpose of this law was to stop disabled people from having children, because it was thought that they */we./* were "defective" and would dilute the idealized Aryan race. Though church records indicated that Kretschmar died "of 'heart weakness' on 25 July 1939" at the age of five months, in actuality he was put to death by following a discussion between a number of doctors, including Hitler's personal physician (Merrick, 2016). */I am missing part of my hand, too. It could have been me./* Merrick (2016) and Mostert (2002) argued that Kretschmar's death—known as the "Knaauer case"—was the impetus for state-



sanctioned murder to become legalized, and indeed, the mass execution of persons with disabilities became part of health care practice later than year.

Aktion T4 was the name of the government program that euthanized persons with physical and mental disabilities in the period from 1939-1945 (Burdett, 2011; Hepburn, 2014; Karowicz-Bienias, 2018). Estimates surmise that over 70,000 and perhaps up to 300,000 disabled Austrian and Germans were murdered during those six years (Hepburn, 2014; Merrick, 2016; Mostert, 2002). */It could have been me./* If, by chance of fate, I had been born five decades earlier—around the same time as my Oma (“grandmother,” in German) and her siblings—I would have been killed because of my syndactyly. */It could have been me./* Nationalsozialismus (“National Socialism”) was rooted in the discourses of anti-semitism and eugenics, verified as “fact” using pseudoscientific “theories” based in scientific racism. Deemed as one grouping of many types of “undesirables,” people with disabilities were sent to gas chambers. */It could have been me./* Viewing Aktion T4 as a success, the Nationalsozialistische Deutsche Arbeiterpartei (“The National Socialist German Workers' Party”) began to develop the extermination camp system that would be part of die Endlösung der Judenfrage (“The Final Solution of The Jewish Question”), which would be responsible for the genocide of over 6 million of the Jewish people in Europe and about 17 million people in total (“Introduction,” 2019). */It could have been me. Ich hätte es sein können./*  
*/It could have been me. Ich hätte es sein können./*  
*/It could have been me. Ich hätte es sein können./*

## **Conclusion: Failure of Differentiation**

In 1968, Swanson, Barsky, Entin described syndactyly as “a failure of differentiation.” My experiences suggest that how we look understand difference as a society is wholly dependent on why a person or group is deemed deviant or “less than” another. In the case of my hand, my fingers did not differentiate; here, the meaning of “difference” means a lack of separation wherein my fingers remained together. In this way, my difference is physiological because it is at the root of what is in variation compared to others (being “normal”). In contrast, when we speak of a “difference” in a social sense, my being dissimilar physiologically is an arbiter of social differentiation. In one case, it was “alike-ness” that was the issue, whereas in the other, the lack of “likeness” is the cause of the problem. I am simultaneously not different enough and too different. The juxtaposition between my physical difference and how I am and have been treated socially makes the medical inclusion of “failure” that much more insulting. I did not fail: society fails me, over and over and over again. Considering again the work of Ghosh and Abdi (2013), I interpret the “failure to differentiate” phrasing as an ideological paradigm that has—and in some ways, continues to—construct me as deficient in the eyes of Canadian settler society. If the cause of this difference is rooted in biology—as many of these classifications are for those of us with chronic illnesses and disabilities—there is a propensity for them to become fixed, as Hall (1997) outlined in considerable detail with respect to race. As Hall reminded us, “‘difference’ is ambivalent” (1997, p. 238); it has no value, negative or positive, unless one has been ascribed by a social group.

Despite the numerous revisions and re-writes of this piece, I feel like I am still not done. This deformography is the first part of my story: I have to come to terms with learning in my early thirties that I have symbrachydactyly as well as syndactyly. Moreover, I also carry the weight of recognizing that some of my ancestors could have wanted me dead. If for no one else

but myself, I need to go to the Vaterland (“fatherland”) and to the T4 Memorial and Information Centre for the Victims of the Nazi Euthanasia Programme in Berlin. Germany’s history is part of my history, and despite the fact that I was not personally impacted by Aktion T4, I am nonetheless affected by it.

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