A Double-Edged Sword: How the Prosthetics Industry Perpetuates Mental Health Disorders

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction

Every year, approximately 3.6 million babies are born in the United States (Thompson, 2021). According to the CDC, 1 out of every 1,900 babies is born with limb differences (Centers for Disease Control and Prevention, 2020). At a young age, children with congenital limb differences tend to find prostheses unnecessary because they have never known what it is like to have that limb and are thus more likely to develop any psychological problems stemming from not having the proper prostheses available later in life. Conversely, children with acquired limb differences are more likely to develop psychological problems such as body dysmorphic disorder in the early stages of life (Fisk, 2002). Presently, many insurance plans do not fully cover prostheses, and if coverage is provided, cosmetic prostheses that may alleviate body dysmorphic disorder do not qualify. Additionally, most functional prostheses do not account for the original shape of the lost limb nor the skin tone of the patient (McLarney, 2021). The failure of functional prostheses to meet the cosmetic needs of their users has directly contributed to rising mental health disorder rates in the limb-different community (McLarney, 2021). An analysis of how the inaccessibility of body image-affirming prostheses affects the rate of mental health disorders in the limb-different community will highlight the importance of redirecting commercial development efforts towards inclusive prosthetic solutions. The analytical framework of technological determinism is used to characterize the limb-different community, demonstrating how the community is directly affected and shaped by the current availability of prosthetics, their capabilities, and overall cost. The shortcomings of social development under prosthetic-driven technological determinism are identified through literature review, providing a novel exploration of the root causes of mental health disorders in the limb-different community. In order to mitigate these mental health issues from the early stages of life, the following question must be

addressed: how does the prosthetic industry's failure to consider body dysmorphic disorder in the prosthesis design process affect the psychological development of children with limb differences?

Methods

This research question is addressed by a comprehensive review of different prosthesis literature, personal blogs, hospital journals, and insurance company coverage information. These personal blogs will be able to highlight several important considerations for future prosthesis design, and demonstrate the way the prosthesis industry can help the psychological development of children with limb differences. Soft Technological Determinism (TD) will be used to illustrate how different prosthesis technologies have a large effect on a specific social group, and how the industry shapes said group. However, this group still has a say on what the industry needs to produce, since they are the main target audience (Smith, 1994). Some of the main key words for this research paper are: prosthetics, prosthesis, psychology, upper limb, lower limb, limb differences, amputation, soft prosthetics, exoskeleton robotics, wearable electronics, phantom leg, and technical determinism. Through this literary analysis, this paper will present a comprehensive review of the psychological effects of limb differences in children, and how the prosthetics industry affects their lives with the current products in the market.

Background

There are about 1.9 million amputees in the U.S., and approximately 185 thousand amputations every year (McGimpsey). From 1990 to 2002 111.6 thousand children younger than 18 years old were treated for amputations (Hostetler, 2005). Birth defects play a large role on these statistics, since about 6,000 children end up needing long-life prosthetics devices every

year (McGimpsey). The design and manufacturing of these prosthetic limb devices can become extremely expensive, especially for children. For example, a prosthetic leg can cost anywhere from $5,000 to $50,000, and the average child needs the prosthetic to be changed every six to twelve months (Seager, 2012). This economic burden can result in unimaginable stress for both the caregivers, and patients. Adding on to the stress created by necessary constant modifications to prosthetic devices, the federal amputee care budget has decreased by 20% from previous decades (McGimpsey). This lack of funding means the financial hardship for this specific group of children and their caregivers has been drastically increased, therefore increasing the likelihood of stress and thus mental health disorders, demonstrating how the prosthesis industry perpetuates mental health disorders.

Similarly, a study in 2020 by the International Society of Prosthetics and Orthotics shows that there are about 14,000 children in the Market-Scan database who had major lower limb loss out of the 36.5 million children in the database (McLarney, 2021). According to the same study, there are about 38 cases of insured children per 100,000 cases of insured children with lower limb loss This group is broken down into 84% from congenital deficiencies and 13.5% from trauma (McLarney, 2021). Although there are not many in-depth studies on the effects of children needing a prosthetic limb, there are many components that affect people who belong to this group, regardless of deficiency category. One of the main challenges these children face is finding a prosthetic that fits their necessities and capabilities. There are many different types of prosthetics designs, divided into two main sub-groups: functional and cosmetic. Not having prostheses that fit both these requirements hinders the mental state of many children as they grow up because their appearance and capabilities are so important during early stages of life for

emotional and psychological development, especially those that need them after a traumatic experience.

The Atlas of Limb Prosthetics has a chapter introducing a couple of the main difficulties limb-different children face. The first difficulty relates to children who have lost a limb after birth. These children usually go through a long period of grief before acclimating to the idea that they will never be able to use that extremity like they used to. These children want to immediately recover full physical autonomy, which is usually not possible given the fact that they must undergo rehabilitation, including prosthetic fitting, physical therapy, and counseling. On the other hand, children who have missed this limb from birth are not always eager to get fitted for a prosthetic; they do not feel like they have lost something when they are young, so they try to live their life as the other kids around them. This is something that not many kids want for the mere reason of it being uncomfortable, or difficult to control. For example, if they have lived without this limb their whole life, they might never have had to use a specific set of muscles.

Technical Determinism

Technological determinism (TD) is the concept that societal development is shaped by technology rather than the other way around (Smith, 1994). In this case, soft technological determinism best describes the relationship between the prosthetic industry and the children who use it. The main difference between TD and soft TD is that TD is the main catalyst leading to one radical change, and soft TD is when the technology is considered an enabling or facilitating factor (Chandler, 2014). For this paper soft TD is used because there is still human freedom that shapes the prosthetics, but these new technologies place limitation on this specific group of people. Prosthetics are a technology that need to adjust and adapt to the users, however, since the

advancements that have been made are not widely approved by the different insurance companies, many of these technologies cannot be accessed by the people who need them. For example, soft robotics is an amazing advancement in the world of prosthetics but they are still being developed, and there is not enough funding for them to be distributed at a cheaper rate. Most research papers and projects done are with the help of current patients in need of prostheses, which is one way in which the group can still talk with engineers and alter the final product, but the technology itself and its capabilities at the end determine the product.

Prosthetics is a technology that is as socially relevant as it is scientifically. In a technologically deterministic sense, there have been several innovations in prosthetics that have helped children participate in different social activities such as sports, playing music, and participating in theater (Hall, 2020). Some critics of TD say that technology is socially determined, that as social structures evolve together, they are not deterministic and that the effects these technologies have depend on the social structure already established (Technological determinism, 2013). Other critics of TD argue that technology itself is socially determined, that technology and social structures co-evolve in a non-deterministic, emergent process, or that the effects of any given technology depend mainly on how it is implemented, which is in turn socially determined. Given the proliferation of new technologies in modern capitalism, the TD debate is continually renewed. Because the evolution of prosthetics is both influencing and being influenced by societal factors it cannot be argued that hard TD is the correct framework to analyze the problem between the prosthetics industry and its patients.

Results & Discussion:

Aside from their functional purpose, prosthetic limbs also serve as an extension of users' personalities. While prosthetics have a substantial effect on the mental health of limb-deficient

individuals, the prosthetics industry has failed to support an equitable prosthetic design process. The inflexibility of the prosthetic design process to accommodate for patients' preferences increases the rate of mental health disorders in children, no matter how a child's limb was lost in the first place. By taking into consideration factors like patients' skin tone, cosmetic preferences, and material preferences, the prosthetics industry can improve the prosthetic design process to mitigate the mental health issues of the limb-deficient community.

According to Carroll, there is little to no emphasis on psychological rehabilitation after losing a limb and while getting adjusted to wearing a limb prosthesis. In this study, they looked at the different levels of satisfaction with finger prostheses (Carroll, 2005). The Attitude to Artificial Limb Questionnaire shows patients' comfort with the shape, color and material, as well as how the patients felt about their prosthesis and how they thought people perceived them in comparing silicone to non-silicone prostheses (Fisher, 1998). This test showed that people preferred silicone over non-silicone material. Although, statistically speaking, the difference was not significant between the silicone and non-silicone group, demonstrating that the questionnaire needs to be improved in order to obtain better answers and results for comparison. This questionnaire showed a key deficiency in the way scientists and engineers obtain data on body image, since it was mainly focused on how the patients feel about their body image as opposed to long term psychological reactions.

Looking at different prosthetic design processes, only one of the links yielded results relating to skin tone and attempting to simulate the missing limb (Prosthetic Process, 2015). Most of the processes mainly focus on measuring for the socket, asking about the patient's lifestyle and physical needs, testing the socket, and gait test, but never mentioned anything about cosmetic additions such as skin tone. Gait is the way a person walks. By doing a literacy review

of new proposed adjustments to the betterment of limb prosthesis, most articles focus on the biomechanics of the prosthesis, such as how to better develop sockets, materials to use that are cheaper, as well better fitting for patients; however, these documents never mention anything about how the patient's psychology is affected by the proposed changes. Additionally, these documents do not portray how not having a limb that simulates their normal limb is also a hinders their psychological recovery (Ballit, 2020).

The cost of a basic prosthesis, not a leg prosthesis as mentioned before, can range anywhere from $100 to $20,000, demonstrating the disadvantage low-income communities (Blough, 2010). When thinking of children and how fast they grow, they need to get a new prosthesis every 3-6 months, depending on how young they are, since not only are they growing and needing larger prostheses, but their extremities are also growing, meaning that they also need a whole new socket, and a whole new fitting, making it increasingly expensive, since they would need to start from the beginning. Similarly, in the prosthetics design process, it is recommended to see the prosthetic doctor every 6 months to make sure that the prosthesis fits correctly and make any adjustments, meaning that they need to pay for those appointments that are not usually covered by insurance. There are six different types prosthetic devices used for the lower limb: microprocessor, hybrid, mechanical, sporty, water proof, and cosmetic (Blough, 2010). The microprocessor option is the most expensive one with a base cost of $45,000. The cheapest option for a functional lower limb would be about $9,000 to $15,000. For people who qualify for Medicare, which is one of the most affordable insurances, will only cover 80% of the total cost, meaning that if someone needs a lower-limb they would have to pay at least $1,800, which can be a great strain on many people, especially when considering that children need their prosthesis changed often (Ledbetter, 2021).

Some people prefer to deal with the difficulties of just wearing a cosmetic prosthetic instead of an efficient one, because it leads to people asking fewer questions, and that ultimately helps the person's emotional state (Schairer, 2014). On a similar note, women tend to prefer cosmetic prostheses over functional ones, because society tends to care more about what they wear and how they look, whereas men tend to perceive the metal-looking prosthesis as something cool to talk about, like having an "upgrade" (Schairer, 2014).

Carroll's study compared the effects of prosthesis aesthetics on body image and wellbeing by comparing if the patients prefer non-silicon or silicone prosthesis. The study found that those with silicone prostheses had a lower score for depression and anxiety (Carroll, 2005). When prostheses are not congruent with how normal body parts look, most people develop mental problems, especially children, since they are in an essential time of growth. This is can been seen in the Hospital Anxiety and Depression Scale questionnaire, in which we can see a statistically significant difference in the depression scores, showing that people with the non-silicone prosthesis had a higher level of depression than those with a silicone like prosthesis, and one reason for this is that silicon can simulate the softness of skin more closely than a metallic prosthesis.

The Atlas of Limb Prosthetics has a chapter on introducing the main difficulties and differences from being a child and an adult with limb differences (Fisk, 2002). One of the biggest differences to take into consideration is that many children have parents and siblings who are also directly affected by anything that happens to the limb-deficient child. Taking into consideration the difference in experiences between congenital and post birth limb differences is essential to know how to suit their needs better. For example, children who become limb-different after birth have a harder time with their mental health at an earlier stage than children

with congenital limb-differences (Fisk, 2002). Similarly, there is also a difference in the mental health implications that needing an upper limb vs a lower limb prosthetic has, since a lower limb prosthesis is more necessary for mobility purposes than an upper limb prosthesis. On a similar note, congenital limb different children tend to reject upper limb prosthesis because they don't really find them necessary, additionally, parents usually have a hard time accepting the limb difference, and prefer a cosmetic prosthesis for their child instead of a functional one, because to them that is more natural, but for the child that does not make sense since to them, it is like having something unnecessary to carry around. Children mostly prefer something durable instead of something cosmetic, since they are indeed children, and are more likely to break since children are not careful.

Pediatric limb loss can be due to many different things, including birth defects, tumors, or accidents, affecting not only the children but their loved ones emotionally. Losing a limb involves accepting the disappearance of that limb, leading to a huge struggle with body image issues, and learning how to use this new prosthetic device. Children and families need to understand that no prosthesis will give their child their touch back. Every family's experience is different, and therefore there are programs and support groups to promote acceptance and spread awareness about limb loss, opening doors for children in athletic events, and increasing accessibility and accommodations in schools (Napolitano, 2018).

About 30% of amputees are diagnosed with depression, and it has been observed that people have a decreased self-esteem, distorted body image, and significant levels of social isolation in both short and long term (Physiopedia, 2022). The anxiety caused by missing a limb can also be connected with phantom limb pain, PTSD, and coping mechanisms. After the amputation, people with an acquired limb difference have concerns about their safety and

different fears caused by the traumatic experience. There is also a large difference between the in-hospital and the in-home rehabilitation. In-hospital rehabilitation tends to go better most of the time because patients have access to a whole team of people supporting them, while once they get home, they don't have the same supportor accessibilities that they still need (Physiopedia, 2022).

There are different coping styles that people go through after an amputation; some maladaptive coping styles include overcompensation, surrender, and avoidance. Some people refuse to seek or accept the help they need, not leaving their sick role and continuing to stay in bed, or they are in need of high attention from caregivers and experience psychological withdrawal (Physiopedia, 2022).

There are four stages in adaptation: preoperative, immediate postoperative, in-hospital rehabilitation, and at-home rehabilitation. The preoperative stage only applies when the patients are informed that there is a need for amputation, and they have time to grieve and think about what this will mean for their future. During the immediate postoperative stage, patients are scared for their health and are afraid of possible complications. During in-hospital rehabilitation, not only is the patient being challenged to accept they've lost a limb, but the pressure is also on the family and the care team, for the patient needs to learn how to reintegrate in society, as well as learning how to use the new prosthesis, adjusting and overcoming this stage is crucial for the at-home stage. The at-home rehabilitation stage is when the patients fully understand what they've gone through, and that they cannot do the things they were used to. Some patients experience resent when anyone asks them for simple tasks, being fully aware that they can do this, but this is when one of the maladaptive surrender copying styles comes into place. During this stage, the at-home caregivers experience the most pressure, and they have to be able to take

this and at the same time help the patients learn how to be themselves after losing a great part of themselves (Physiopedia, 2022).

There are many factors affecting the psychological reactions of acquiring a limb difference including age, personality style, economy and vocation, psychosocial support, health, reason for amputation, prosthetic rehabilitation, and team approach, among others. During prosthetic rehabilitation, having the right prosthesis as early as possible can decrease the degrees of anxiety, sadness, and self-consciousness the individuals can feel during rehab. As previously mentioned, age has a great impact on how people react to missing a limb, children with a congenital different limb tend to adapt more easily to their reality, since they don't really know better. For contrast, children who acquire the limb difference later in life, like during adolescence, have a harder time, since they are more receptive to peer acceptance and what others think of them. Something particularly hard for younger children is their inability to play and explore as they used to, which often leads to frustration and depression that they cannot learn about the world the way they used to be able to. In the past, it was believed that older people with acquired limb differences had a higher risk of psychiatric disturbances, however recent studies have demonstrated the opposite (Physiopedia, 2022). A study showed that there are significant differences in depression, anxiety, hostility, paranoid ideation, psychoticism, global severity index, and positive symptom distress index. These differences demonstrated that the younger group had a higher index of psychological disturbance, showing that as time since amputation increased, the younger group's Back Depression Inventory increased. This study demonstrated that a majority of amputees who checked depression can be categorized in the younger group (Frank, 1984).

Not every limb difference scenario is the same. As previously mentioned, some are congenital and others are acquired due to traumatic experiences or health conditions. In the past, literature has mentioned that children with a congenital limb difference do not have a sense of losing a limb they never had, however, what they fail to mention is that as the child grows, they become socially aware that they are different from everyone else and start to question why they were born that way, and that is when they tend to start experiencing depression and grieving their limb difference (Smith, 2017). Children with acquired limb differences have a deeper sense of loss, they have to go through surgery and tend to have a harder time adjusting to wearing a prosthesis.

Some children associate wearing a prosthetic device as a bad thing because it hinders their ability to sense with the covered-up limb and therefore choose to not wear the prosthetic device. However, once they become adolescents, limb-different children go through more severe emotional and intellectual changes than other adolescents. This can lead to wearing clothes that hide their prosthesis better (Smith, 2017). This can also continue into adulthood, since they don't want people looking at them weird or asking questions about their prosthesis. An example of this can be seen when a woman in her late 60s had to wear stockings even when it is hot outside, because the color of her prosthetic leg does not match her skin color (Schairer, 2014). She had a difficult time finding a prosthesis that would match her skin tone, on top of that when she lost her second leg, she could not even find artificial skin that would match the first prosthetic leg, therefore she chooses to go out with just one leg sometimes, so that people will ask less questions. Many prosthetic devices manufacturers don't think about different communities from their own, this can be seen with an African American man in his early 40s, when he was wearing

a footshell that was meant for a white user. Footshells are covers for prosthetic feet to appear more human-like and better accommodate shoes.

"Objects and bodies contribute to human identities and take their own kind of objective in the process" (Schairer, 2014). This is a PhD dissertation that challenges the idea that only having efficient and working prosthesis is enough for patients. Prosthetic limbs become part of the person and have a significant impact on their overall mental health. The interactions between the prosthetic device and the patient show how technology and their own bodies relate. There are weaknesses in the current prosthetic device market, for they do not cater to different people equitably. Implicit technological determinism takes away the "human effort" in the rehabilitation process because it only talks about how the prosthetic device affects the patients, but not how patients put in a lot of effort in getting used to wearing the device, the psychological barriers they have to overcome to accept that their reality now includes daily wearing and management of a prosthetic device. Prosthetic devices not only contribute to the patient's identity, but the device becomes a part of them. The type of device they wear becomes a part of their categorical group and personality, like choosing to wear a prosthesis that does not simulate the leg at all, or choosing not to wear it at all to avoid questions (Schairer, 2014). Understanding that the prosthetic limb becomes a part of the patient, and that patients also have an effect on the demand of the types of prosthesis used, makes this situation fit in under the soft technological determinism framework, instead of just technological determinism.

The prosthetic industry needs to understand the specific needs children have when it comes to limb prostheses. Prosthetic devices for children have not been documented well throughout history, however something that is known is the high need for these devices in places with ongoing or past conflict, landmines being one of the greatest reasons why there is a high

demand for these devices. The majority of devices made for children are light weight and have simple structures, allowing for young children to learn how to use them faster. One great advance is the use of soft prosthetics and 3D printing, which are more comfortable to wear and easier to manufacture. Children have said that they like to wear their upper limb prosthesis to hide their limb loss. The project Hero Arm by Open Bionics is a great example of companies that take into account children's opinions and have empowering aesthetics which emotionally help children get used to their new prosthesis and create excitement when wearing them (Mitchell, 2020).

Going more in-depth into soft robotics, soft robotics are made with soft materials, such as silicone and hydraulic fluidics. Soft robotics is a technology meant to mimic the feel and appearance of a normal human limb, and increase comfort of wearing these devices, mitigating the deficiencies found in the design process. As previously mentioned, most limb-prosthesis design processes do not take into consideration what the feel and appearance of the device will have in the users, especially in children who are in development and in adolescence. Soft prosthetics allows for prosthetic limbs to mimic human motion, which is not only more comfortable, but also more functional than previous devices made with rigid materials (WhatNext, 2021).

Technological determinism views in the medical industry are unique, because in this case technology is used directly to better people's lives, and therefore technology acts as a force to shape social relationships (Technological Determinism, 2013). In this case, prosthetic-limb devices are used to mold a specific group of people into wearing outdated prosthesis, in this case limb-different people. Currently most of the literature focuses on making more profitable prostheses, with cheaper materials and different types of joints to make them more

biomechanically stable, however there is not much literature on the prosthetic industry that focuses on making different skin-toned artificial skin. Most artificial skin made for limb-prosthesis are made for white users, meaning that those who are from a different background and have different skin-tones are at a disadvantage and will have a harder time during their rehabilitation. This becomes extremely difficult with children, because as they are growing and developing, having an upper prosthetic limb, for example, that looks completely metallic, or non-human, will put them at a higher risk for mental health issues, such as body image. Additionally, as mentioned above, the prosthesis becomes part of the individual, meaning that if the piece does not fit them completely, they will have a harder time accepting it, and will most likely decide not to wear it in order to feel more like themselves, they would prefer to not have a limb at all, than to wear something that looks completely strange to them and be able to use it. As one can see here, technology is the primary moving force in the community, and limb-different societies are curtailed by technological momentum. Technological determinism also relies on human attitudes to demonstrate how this technology has historical influence. One can see this when in the past limb prosthetic research was based on adults, because they formed part of the larger population, and therefore were the ones that were in high demand for these types of devices. However, more recently, the focus was widened into looking at the psychology of the device users, and how different devices mitigate or aid in the recovery process, for example in the silicone vs metallic arm mentioned above (Technological Determinism, 2013).

There are different aspects of technological determinism: justificatory, descriptive, methodological, and normative. In the scenario of limb prosthesis and children, the ones that are more relevant are the last three. In the descriptive aspect, Technological determinism leads to a society change, which is true, the literature of the different technological breakthroughs should

lead to the betterment of the limb-different community, however, there is also the need for this community to speak up, and request these changes, which is why it is not just TD, but also soft TD. In the methodological aspect, the different technologies in the different locations have led to different achievements, for example in the UK and the Queen Mary's Hospital compared to countries in conflict, one can clearly see the difference that having access to these technologies leads to the determination of society. In the normative aspect, moving away from politics in the prosthetic industry, and focusing on the actual technology that is available, and bringing in that technology to the different groups within the limb-different community would be an amazing way to mitigate the current mental health issues caused by the absence of different artificial skin colors, and find a way to combine both efficient and cosmetic prosthesis (Wyatt, 2018).

The limitations of the project included not finding much literature on children's psychological responses to different types of prosthesis, as most of the information found was on adults, and only a few sources were centered on children. This is a huge limitation because the way that children respond to different scenarios is different than the way adults respond. Adding on to this limitation, there was also the factor of obtaining information from parents for several of the studies reviewed, and even though the parent usually knew what was best for their child, or how they were feeling, there is always a range of error, due to the fact that they are children and might not be the best communicators.

For future research, I would suggest creating a study in connection with different prosthetic centers nationwide. This would help demonstrate more accurately the various effects different types of prosthesis have on children, be able to identify differences in gender, age, and more differences and similarities between acquired and congenital limb differences. It would also be worth considering the Wicked Problem framework by involving the different types of

insurance, what the coverage looks like for an average child, and the differences in how children do in rehab in relation to their economic and social background.

Conclusion

Having an efficient and working prosthesis is not enough for patients, prosthetic limbs become part of the personality of the users and have a huge impact on their mental health. The current prosthetic industry does not cater to the different patients equitably, for they only offer certain types of prosthetics and hope that these will collectively be sufficient for everyone who needs one. Some people like wearing robot-like prostheses because they feel cool with them, others prefer not to even wear the cosmetic one because it does match their skin tone at all, choosing to use a wheelchair instead. The prosthetic industry needs to be able to fully understand all of the effects these devices have on people as well as what their needs are in order to develop the best prosthetic device for everyone.

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