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Prosthetic Identity: Understanding the Relationship Between The Self, Prosthetic Design, and Society

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PROSTHETIC IDENTITY: UNDERSTANDING THE RELATIONSHIP BETWEEN THE SELF, PROSTHETIC DESIGN, AND SOCIETY

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ABSTRACT

This manuscript will explore the intersection of perceived disability due to limb loss and self-identity. The research is centered around the work in the Limbitless Solutions laboratory, where clinical research is providing children with customized prostheses. This research applies a focus on how customization can lead to positive identity construction. By facilitating active engagement in the design process a stronger connection is formed between the participant and their prosthetic device.

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CHAPTER 1: INTRODUCTION

As the conversation surrounding accessibility continues to grow, in both an academic and private setting, providers of accessibility devices need to engage with their intended users throughout their research and all the way through their product design and development. Helping to frame this work, the statement by Stella Young (2009) offers an exemplary standpoint: "My disability exists not because I use a wheelchair, but because the broader environment isn't accessible." How can we, as a society, work towards a world that provides access to people unconditionally?

Understanding the relationship between a person and their prosthesis entails a multi-perspective approach to research. The analysis below emphasizes three viewpoints to assist in understanding the relationship between an individual and their prosthesis: self-identity, prosthetic design, and expressive design. In so doing, it seeks to provide a unique approach to understanding identity development in relation to prosthetic design, this research adopts a sociological approach to identity, prosthetics, and society while incorporating psychosocial aspects to better understand self-identity development in children with congenital upper-limb differences. By narrowing the focus of the prosthetic relationship to the three aforementioned particular viewpoints, the measurement of what makes a prosthetic 'useful' shifts from solely a focus on mechanical functionality to a focus on psychosocial growth. This shift allows for the consideration of the user's perspective. To measure this psychosocial growth, an early line of communication can be formed between a researcher and a user to support communication of the user's growth. (Guha, et al., 2013) Through the use of survey tools, interviews, and observation, the user is included in the development of the device that aims to support them.

As prosthetic design has largely focused on the degree to which it can replicate a fully-formed biological arm, the design process aims for an unattainable goal that negatively affects the impact

a prosthetic device can have on a user's self-identity (Hilhorts, 2005). While such functionality is a baseline necessity, it can limit the actual possibilities for prosthetics and the children co-creating what that prosthetic means to them in their identity development and lives. (Walker et al., 2019) I find that children are incredibly resilient, (Zolkoski and Bullock, 2012) such that having an upper-limb difference does not inhibit their capacity to feel empowered in independently completing everyday tasks and going above and beyond them. (Sims, et al., 2020)

Modern technology and dedicated researchers have together facilitated significant advancements in prosthetics technology, but users are still faced with the struggle of obtaining these devices. The range of prosthetics is wide, ranging from still/non-moving devices to myoelectric powered arms, and all the way to nerve-integrated prosthetics. (van der Riet et al, 2013) (Cordella et al., 2016) The ability to access and afford more advanced prosthetics is much more difficult than alternatives such as myoelectric prosthetics which still come at a high cost to those in need. However, many muscle-powered devices have the potential to be built using common hardware, and 3D printed parts obtained from and schematics published online. This allows those with access to provide themselves with prosthetic devices that are otherwise inaccessible. (Prince, 2013) The open access to these prosthetics has encouraged people with limb differences to engage with the production and development community in an open-forum setting over the internet. (Novak, 2019) Many groups have been formed for parents and older users to discuss, troubleshoot, and inspire new designs that best fit the individual user building their prosthetic.

The last of the devices mentioned seeks to help the user 'blend in' with others with a technique called cosmesis, a medium in which artificial limbs are made to look lifelike, which can create a multitude of identity and body-image issues (Crawford, 2015). To avoid these issues, space can be made for the inclusion of artistic principles and user participation in prosthetic design.

The findings below suggest that when applying artistic principles to prosthetic design they should

be used as a way to communicate the user's identity, and not in a way that is attempting to achieve the unattainable goal of cosmesis that can result in the Uncanny Valley sensation. (Sansoni et al., 2015) As the world of prosthetic design works to embrace the inclusion of artistic principles, there should be consistent communication with the user. How people choose to present themselves is an ever-changing decision. A decision that can be influenced by the use of fashion, hairstyles, and accessories. Athlete, Aimee Mullins opened a door to this discussion by saying, "A prosthetic limb doesn't represent the need to replace loss anymore... It can stand as a symbol where the wearer has the power to create whatever it is they want to create in that space, so people that society once considered to be disabled can now become the architects of their own identities and indeed continue to change those identities by designing their bodies from a place of empowerment" (Mullins, 2009) While there have been options to color or wrap previous prosthetics with a carbon fiber pattern, options such as these are limited and costly. A number of movements are being dedicated to creating access to and spreading knowledge about 3-D printed accessibility devices, has given users the ability to customize and stylize prosthetics in a personal manner.

Challenges involved with incorporating artistic design have been further exacerbated by the rise of STEAM, a movement created to incorporate art into the booming field of STEM (science, technology, electronics, and mathematics). (Hunter-Doniger, 2016) As many products try and fail to understand how art can be integrated with their design, development, and production, a new approach must be considered. (Mejias, 2021) Since these products opt to merely cover themselves with 'artistic designs' in an effort to meet the perceived requirements of STEAM without truly making artistic considerations in the design process, they ignore the true purpose of the inclusion of artistic principles for user expression. In Mullins' quote cited above, she uses the word 'architect' to describe the desired role a prosthetic user should have in the development process. Reworking the current design process and bringing the user in at an earlier point than paint and finish can lead to new designs, ideas, and ways of construction that better fit the limb different communities.

(Grocott, 2007) End-user engagement in the design process lays a foundation for nurturing the bond between user and device and creating an avenue for positive self-identity growth. When the idea of utilizing self-expression in bionic design is well-executed, it turns the device into a tool of communication for both the user and those around them by initiating positive inquiry. This positive inquiry is key to allowing users to find or create their self-identity in a safe environment. (Bergold, 2012)

This manuscript will explore the intersection of perceived disability due to limb loss, self-identity, and expressive design. This study will engage with the following questions: (RSQ 1) How can personal customization of a prosthetic affect self-identity development in children with congenital limb differences? (RSQ2) How can personalized prosthetics facilitate positive social interaction? (RSQ3) How is expressive design used as a tool of communication? How can customization promote human object integration? The research is centered around the work in the Limbitless Solutions laboratory, where clinical research is providing children with customized prosthetics.

CHAPTER 2: BACKGROUND

Prosthetic design can be found hundreds of years ago, either for purely situational matters such as completing daily tasks or in a socially centered manner. (Bennet, et al., 2016) The beginnings of these devices have a torrid history, the hook prosthetic that was developed in 1912 aided in users' daily function allowing for more access to the world around them, however, the devices created a social dilemma for users. (Khan, 2015) The hook prosthetic is represented in pop culture quite often, most frequently surrounding a character that is associated with fear or terror. These media portrayals aid in the societal stigma cast upon the limb different community, by adding to the narrative that limb difference is something to be scared of – the most recent example being Witches by Warner Bros.– the discussion and advancement of prosthetic design is threatened. (Owoh, 2020) When we, as a society, design something whether that be a physical building, a piece of code to run an app, or a theoretical construct there is a bias built-in by the creator(s). (Wachter-Boettcher, 2017) It was not until the late 1990s after the crawl on the capitol steps that the ADA was formed, adding accessibility to the code of building throughout America. The road to passing the ADA was difficult, it took years to be passed as a bill and has been subject to sanctioned limitations through Supreme Court rulings. (Mettler, 2020) The fight for accessibly rights has a long history in America, before the 90s 'Capital Crawl' in 1977 protesters gathered for the 504 sit-ins to fight against disability discrimination in federal aid programs. (ADA National Network, 2021) The book, Technically Wrong by Wachter-Boettcher, (2017) works to show how tech can unknowingly participate in racism, sexism, and ableism. Scholars throughout the world continue to study The Humanities in pursuit of understanding how we can continue to build a better world, representing each walk of life that adds to our society.

With mean rejection rates for upper limb prosthetics being from 45 percent to 35 percent, prosthetic design has a long way to go. (Biddiss and Chau, 2007) While a fair amount of adolescents using

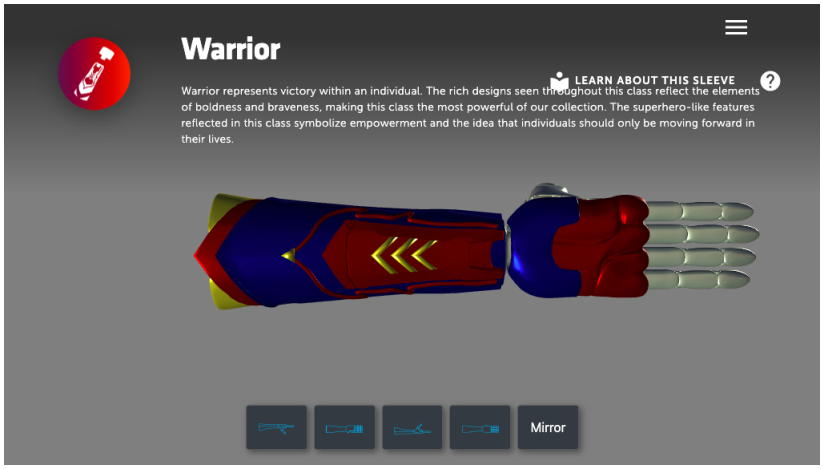

Figure 2.1: Customization page

prosthetics abandon the device due to issues like function and discomfort, many reported 'other' as their reason. (Wagner, 2007) The work being carried out at the Limbitless Solutions lab aims to understand what comprises the 'other' section. Incorporating each participant in the design process the lab hopes to aid bionic children in creating their own narrative pertaining to how their limb difference plays into who they are. Through the use of customizable and interchangeable sleeves, a magnetic attachment provides a 3-D design and custom paint-job to each prosthetic arm.

Each child begins the design process by selecting two sets of sleeves, which can easily be popped on and off the bionic arm, allowing for identity exploration. The customization process provides a simple user interface, enabling the children to envision their design in a 3D setting showing real-time changes for sleeve choice and color, presented in Figure 2.1. Creating this type of accessibility and interaction promotes user engagement throughout the process (Corno et al., 2015).

Working on the paint team at Limbitless, experiencing the differences in the interactions between the bionic children before and after they received their bionic arms sparked an interest in how the artistic aspect of the prosthetic device directly affects the children's lives. The work being

conducted in the lab uses various methods including 3D printing, thermoforming sleeves, and automotive air-brush painting to bring the designs created by the bionic kids to life. The design process allows the bionic kids to use artistic principles as a form of communication, it is the Paint Teams' job, using their Studio Art backgrounds, to translate the expression in the children's designs using tools such as; form, line, shape, color, and texture. Researching the influences of identity exploration and developmentation by using a customized bionic arm with both a sociological and artistic lens allows for a unique stance.

CHAPTER 3: THE STATE OF THE ART

Identity and Society

The scope of identity research is endless, different lenses are used depending on how we seek to understand identity construction. This research strongly relies on sociological theories and frameworks while also incorporating psychological theories to build knowledge upon childhood identity development. Stets and Burkes', A Sociological Approach to Self and Identity (2012), provides a clear outline of how the construct of self-identity came to be discovered and defined by scholars throughout the years, discussing how the Self and Identity are affected by both internal and external forces. As individuals interact and communicate, a new expression of self is formed, and as these interactions continue to build up, they work to develop and reshape the individual's self-identity (Ashmore and Jussim, 1997).

Initially, the concept of self-identity largely drew from that of self-esteem, one's self-identity must be built upon how one feels about themselves. As research continues, self-esteem is put under the umbrella of identity. Rather than being viewed as the predecessor, the ideas of self-concept - an individual's defined opinions and/or beliefs - and self-esteem - how much one values themselves - are working together to better understand identity development. (Rosenberg, 1979)(Stets and Burke, 2014) Self-esteem is therefore also related to empowerment., simply meaning to give power to. While self-esteem can oftentimes be grounded in the individual themselves, empowerment offers a bridge to help individuals - and particularly children - develop the self-esteem that can carry them through such difficult encounters as bullying and/or challenges that arise with life changes. (O'Moore, 2001) Seeing how identity is multifaceted, it is no surprise the way individuals express their identity is equally diverse – engaging with fashion, beauty, accessories, lifestyles, and more allows people to communicate with others through presentation and action. (Gonzlez, 2010)

Syed and McLean work inside a psychological framework, their research provides an excellent overview of Erik Erickson a psychologist whose research is considered foundational in psych identity research (McLean and Pasupathi, 2012). Expanding upon Erikson's identity integration work, Syed and McLean's research highlighted the need for a focus on person society integration – the idea that a person's identity can be influenced by internalized structures of social culture and how an individual reacts and interacts with social expectations and/or norms (Erikson, 1968) (Syed and McLean, 2016). Emphasizing a focus on the societal role in identity integration, their work recognizes the importance of social engagement. Going so far as to say that mastery of different types of integration's, such as temporal and contextual, are connected. In turn, having a strong temporal identity integration correlates to a strong contextual identity integration, yet the same is not true for person-society integration, meaning that confidence and assurance in oneself does not always translate to the ability to navigate social settings easily (Syed and McLean, 2016).

Design and Prosthetics

Communication is a fundamental form of expression; how one expresses themselves can take shape in many different varieties such as verbal language, facial movements, body language, fashion, and hairstyles. (Kaiser, 1991) Through personalized expression, people possess autonomy over how others perceive them. However, it is typical for expression to be overlooked when designing products that are accessible (Pullin, 2009). But Designing for Disabilities (Pullin, 2009) has created a substantial shift in fashion (Gwilt, 2014). In the 1950s, designer Mary Brown spearheaded the shift by creating a line of clothing for children with cerebral palsy. She incorporated function and expressive design into each piece, deepening the accessibility of the clothing line without compromising the artistic integrity. Fashion designers have continued to show their understanding that disability should not deter self-expression, with a number of designers educating themselves about

daily prosthesis use (Watkins, 1995). Open Style Lab, a non-profit organization in NYC continues to push for accessibility in design by creating an interdisciplinary team to approach issues in new ways.(Chichisan, 2015) While fashion designers adapted their platform to be accessible for those living with disabilities, there is still a lack of attention surrounding the aesthetic design of prosthetics due to the separation of the design process and artistic expression created by prosthesis manufacturers as previously discussed.

Determining the relationship that forms between a prosthetic and the user is critical in assessing the impact of a prosthetic and evaluating the impact of changes in the prosthetic design approach. Research conducted by Carole Fraser aims to discover if an artificial limb becomes part of the user found that artificial limb use leads to similar movement and motion between the artificial limb and the user's organic arm; therefore, the prosthetic can become a part of the user (Fraser, 1984). Fraser's research was conducted by observing the user's movement rather than personal recounts of the user's time with the prosthetic (Murray, 2008). While the movements imitate those of the user's organic arm, it is unknown if the users truly felt the prosthetic is a part of their identity. Craig Murray highlighted the lack of personal account through Fraser's research, ensuring to provide research derived from direct communication with prosthetic users throughout his work. Murray's Being Like Everybody Else: The Personal Meanings of Being a Prosthesis User, studied interactions between prosthetic users to better seek an understanding of the lived experience of prosthetic use. Taking a more holistic approach to determining the user-prosthetic relationship by viewing both the user's use of the prosthetic as well as their interactions with other users may lead to a better understanding of how a prosthetic can serve as a vessel for self-expression.

Self-expression has however not been properly implemented in prosthetic design yet. Throughout the years, different companies have designed 3D printed myoelectric prosthetics, opening the accessibility to cost-effective prosthetics for growing children. Yet, few companies offer integrated expressive design as a tool to promote human-object integration. Prosthetic user, Elizabeth Wright,

describes a special relationship with her prosthesis, believing that while design and aesthetics are still lacking, the idea of human-object integration took hold. (Wright, 2009) Human-object integration provided Wright with a sense of ownership over her prosthetic, prompting her to explore how the interaction between body and object affects her identity. Wright discusses a variety of prosthetics users throughout her paper including track and field athlete Aimee Mullins's affinity for expressive prosthetic choices. The effect of this object and body interaction may be derived from the interaction of art and body that has existed for many years.

Art and Expression

Art as self-expression can be seen throughout human history including, body markings and modifications to decorative tombstone designs depicting one's entire self-identity through decoration and design (Deter-Wolf, Diaz-Granados, 2013). Lucy Shiply discusses the use of art throughout the Etruscan and Roman eras as a form of developing civic identity and solidifying a ruler's status through their ability to procure and produce art for their society (Shiply, 2013). By using art as a form of communication and status reinforcement, these rulers recognized their society's need for art and the impact it has on identity formation whether it be civic or self. In today's time, there are still those who recognize the importance of art in life, especially the introduction of art in early childhood and adolescence to promote self-expression.

Research covering self-identity, prosthetic design, and expressive design as individual points is expansive, however, research engaging within the overlap of the three is narrow. This research aims to participate in exploring intersections of prosthetics, design, and identity to better understand the experience of prosthetic users.

CHAPTER 4: RESEARCH DESIGN AND METHODS

This section presents the steps used in creating the testing plan and the steps taken to perform the created plan. The execution of this plan enabled the exploration of the following concepts: the analysis of how expressive design can be used throughout the prosthetic design process to affect the day-to-day use of the participants' prostheses and how the changes in a user's daily interactions with others are identified and analyzed. This section explains this plan by first providing an overview of how identity growth is measured throughout both this research and existing research. It then presents the qualitative methods used to collect data. It does so by providing insight into the design of the questions used to gather the data and define the processes used to extract meaning from the data. (Brinkmann, 2013) Previous research surrounding the measurement of identity growth has yielded tools to perform this measurement and has provided the knowledge needed to develop new tools to quantify identity growth.

Qualitative data is being collected through interviews to assess the relationship between a child with a congenital upper-limb difference and their prosthetic. Focus is being placed on the effect of this relationship on a user's self-identity, how expressive design affects this relationship, and how expressive design is used for personal identity communication. This study collects the qualitative data throughout the length of the participant's enrollment in the LSI (Limbitless Solutions Inc.) clinical trial with OHSU (Oregon Health and Science University.) As this study is being completed in support of the LSI clinical trial, the interview questions contain sections that are not directly aimed at this research. However, with semi-structured interviews allowing impromptu conversation, the answers to these questions provide supporting data and lead to engaging conversation.

The data collected for this research was obtained through the use of semi-structured interviews

designed to create an open discussion between the participants and the interviewers. As these interviews were a part of the LSI trials, each interview took place after a technical assessment of the prosthetic device. The interview included a total of five LSI members who were on the call for the recorded psychosocial interview section. These inactive participants kept their web cameras off and their microphones muted. Active participants of the recorded interview session including the author, their thesis chair, and the participant and their family member(s) used their web cameras and microphones to participate in the interview.

Six families were interviewed for this study. This created a sample size of 14 total interview participants. It is important to note that the initial research plan has been affected by the COVID-19 outbreak. COVID-19 caused the LSI clinical trial to be slowed down and it was extended for additionally years. Due to travel restrictions and health safety precautions, all interviews were held over Zoom. The interviews were originally planned to take place during assessment two for the larger clinical trial. They are performed in-person, with each family coming in for three to five hours over a three-day time span, following the same structure as the initial delivery assessment for the LSI trial that provides participants with their bionic arm. Aside from the shift to Zoom, many of the families lived in different timezones making scheduling the assessments difficult and restricting the sample size to the number presented in this paper.

The author is an active member of Limbitless Solutions, with completing human subjects training requirements per the IRB, they were granted access to the data. access to the data collected throughout the trial, all data collected, viewed, and stored complied with HIPPA guidelines and is treated with extreme sensitivity. Consent to be recorded was obtained before each session. After the meeting ends and the recording is finished, each recording is saved on a password-protected, encrypted USB drive. Since the request has still not been granted the author used audio from the recordings to hand transcribe selected interview points for use in this paper.

The questions composed for the interview provide insight into how the participants use principles of design while customizing their arms to communicate with others. Further exploring how this communication can be fostered and lead to positive interactions with others, ultimately leading to positive identity construction. Following the initial review of the data, coding was used to identify themes and locate areas of similarity across the six different interviews. (Rabinovich and Kacen, 2013) The interview recordings were loosely transcribed to extract quotes and context, in addition, the author repeatedly reviewed the video and audio to be fully familiarized with the data. As the analysis was conducted, seven themes began to arise across the entire group of participants; creativity, connection, design, independence, individuality, participation, and storytelling. These themes will be used to illustrate the larger picture that connects the participants' answers to their development in regards to their prosthetic.

CHAPTER 5: DATA ANALYSIS

Creativity

Throughout the interviews, themes of creativity are found in each of the participant's responses; there are many ways that creativity can be represented or reflected by an individual. One participant's response encapsulated a literal manifestation of the theme – "I kind of wanted to [make a] change that gives it a flair or good look, add more of my perspective... my grandpa hydro dipped it for me... we made it orange." This participant is using creativity as a tool for communication and also as a way to foster device attachment by adding personal touches. By altering their first poly-colored prosthetic, the device no longer serves only as a mechanical aid but also as a visual representation of what the users view a prosthetic as– an extension of oneself.

In the following interviews, the design process continues to solidify its place of importance in the process of using a prosthetic device. Certain parents recall past experiences with prostheses– "the next option that someone I had talked to about a prosthetic was you know– this big Barbie doll blob of whatever". This parent approaches prosthetics as a way to provide self-expression, not as a way to blend in and conceal their limb difference. They go on to highlight the importance of customization, saying that "being able to have some fun designing his own hand, trying to see what it's going to look like, he has his own story that he puts into everything". Connecting stories and characters to items allows for children to use creativity in a less literal form and explore what it means to be creative. Certain participants turn to fantasy worlds to express their creativity. Depicting specific characters through their sleeves is a form of expressive design. Participants choosing to reflect superhero or fantasy world characters identify ideas, traits, or values that they find admirable. By choosing these characters, the participants are also defining what their ideals and values are, they are choosing to share those with others by incorporating those icons into their

prosthetic design.

For those participants who don't have specific characters in mind when designing their sleeves, many of their influences have similarities, some participants choosing to represent their family's Naval history with a navy blue color palette. When using expressive design to create their sleeves the participants are able to develop a prosthetic that embodies their stories and experiences. One participant reflected upon a specific moment when asked about designing their arm– "we were driving in the car and I was writing a letter to my grandma drawing a tree. I started adding swirls to it, and turned that into an arm." The participant later goes on to describe the look of their prosthetic in a unique way: "It's not even a look really, it's more like a feeling of this design and the feeling is just ethereal I guess". This level of personal connection to the device increases the user's affinity and affection for their prosthetic, granting the device somewhat of an aura.

Connection

Certain participants explore creativity and their prosthetics as a way to create connections, one user's parents goes on to say "she's very funny, she has a little name for her arm and she and her friends, they make little jokes and characters, not like anything bad, just silly and fun". Creating connections with friends in a way that includes their limb difference or prosthetic device is important, another parent notices how the prosthetic arm provides a way for their child to start conversations with other people, especially others with a disability. They said "that helps him more than the arm in certain stages more than the arm did." Yea it makes his day when he sees somebody with a prosthetic, he's like oh that's so cool or he'll go and talk to people and it's a conversation starter." This family notices how the device can shift between being a physical and psychosocial support tool, in some cases almost acting as if it were a shield– "the arm didn't even have to do anything; it just looked so cool everyone was looking at that". Ultimately the goal is not to create

a distraction but to provide an opportunity for self-expression and connecting with others.

Connection with others, groups, places, and items can help shape identity development, the younger one is, the more these connections matter. Not to say that as we age connection is not needed, in fact, it is just as important. However, connection in adolescence is imperative to the formation of identity development. Early identity literature has a strong focus on the 'looking glass self' concept that is the idea that what we know about ourselves comes from how others react and interact with us. (Bailey, 2003) As research evolves and expands we recognize that self-identity and identity construction is influenced by many things and that the 'looking glass self-concept' is one part of the much larger scope of self-identity.

There is significant importance in interpersonal relationships as well as relationships formed with objects. Similar to a child and their blanket, a transitional object, a relationship with an inanimate object can help to support and provide comfort for individuals. During certain stages of an individual's life, transitional objects are utilized to engage in situations and with others while feeling safe. Using customization as a way to create attachment or ownership between the user and the device assists with gaining independence. Once the participant views their arm as theirs, something they designed and created, how they interact with the device changes.

The further exploration of independence can help facilitate a stronger understanding of the self and can affect the identity construction of adolescence. Independence can manifest in many different ways, as an individual grows throughout childhood and into adolescence how strongly they seek independence may change as well as how they define it.

CHAPTER 6: CONCLUSION

Outcomes

This study concludes that allowing users to customize their prosthetic devices significantly supports positive identity construction. As personal customization works to reach the participants through emotion rather than function, higher chances of device attachment are likely as the user is able to see a part of themselves in their prosthetic arm. As participants continue to develop this relationship with their prosthetic device, one where they can view the device as a part of them versus an accessory, their chances to authentically be themselves around others increases. In turn, this social freedom to be true to themselves leads to greater self-esteem, ultimately aiding in positive identity construction.

Remaining Questions and Future Works

Future work through the Limbitless Solutions clinical trial will build upon this research and provide additional data sets to understand the influence of prosthetic devices on a larger scale. Hopefully, research expands beyond the focus of customization– exploring how a compilation of elements in the Limbitless program leads to positive identity construction. The data collected throughout this study proved customization holds significance in prosthetic design, now a focus on how that significance manifests is crucial. This research touched upon the importance of participation throughout the entire process, not just in the act of customizing their prosthetic but participation with the program, peers, family, and society. Continuing to find the many different ways personalized prosthetics affects the users' identity construction will be sought out with a new focus placed on customization in the world of prosthetic design.

APPENDIX A: Interview Questions

Psycosocial Questionnaire

Participant Questions:

•How did you get involved in the program?

•How did you choose the color and design of your sleeve (and what helped you make those choices/why?

•How did your parents/guardian help you with the arm?

•What has been your favorite experience with the bionic arm?

• Is there anything that has been hard for you since you started with the program?

•What have been the other kids' reactions at school to you and your sleeve?

•Did they start treating you differently from before and then after you got the arm?

•And how about you - do you see yourself differently since you got the arm (e.g., stronger, more confident, etc.)?

•Do your sleeves make you feel calm, happy, powerful, bold. . . ?

•How do you think the different sleeve designs and colors show others about who you are (like, does the superhero design show how strong you are)? [How does your choice of sleeve design and color scheme represent different parts of you?]

•Do you wear different sleeves for different things or events?

•Or reasons/events for why you may not wear the sleeve?

•What surprised you about the arm or as a part of the program?

•Has the arm helped you to do new or different things?

•What helped you feel more of a part of the program?

• What do your parents/guardians think about the program? How have they been involved?

•Has this (i.e., their thoughts/involvement) helped you? Made you more excited about it? Not really changed a lot? Change the way you see the program (follow-up questions will differ based

on their response)

•What have you liked most about playing the video games through Limbitless? (if you haven't played a lot, that's okay - but let me know more about why you haven't?)

•Do you have a favorite game? If so, why?

•What would you change about the video games if you could (characters, colors, challenges, etc.)?

•Would you want to play as a character that represents you?

•Does playing the video games make you want to play other or more video games? Did you already game before?

•How did you see the arm coming into the program, and how do you see it now?

•Is there anything else you'd like to tell me about?

Parent/Guardian Questions:

•How did you get involved in the program?

•What was the process like for your child learning how to use the arm?

•What was your role in helping your child with the arm and creating the sleeve?

•What has been your favorite experience with the program?

•What has been the hardest thing since you started with the program?

•What helped you feel most a part of the program?

•What do you think helped your child feel most a part of the program?

•What did you least expect to happen as a part of the program?

•How have you seen your child change with the arm? (examples of what they have been able to do, choose to do, etc.)?

•Does it seem like your child feels more independent with the arm? Do you have any specific examples of this?

•Do you see people interacting with your child in a different way since they have been a part of

the program? (tell me more about that)

•Did you notice a difference in your child's interest in going to school or in participating at school?

•Are there any obstacles in helping your child with the sleeve or accessing information on it?

•Has this changed the way you view prosthetics? Or how you may use them in the future?

•Is there anything else you'd like to tell me about the program?

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