

2019-01-01

## "Nací De Nuevo:" Examining The Functions Of A Prosthetic Limb Through The Lived Experiences Of People In México

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*“NACÍ DE NUEVO:”* EXAMINING THE FUNCTIONS OF A PROSTHETIC LIMB  
THROUGH THE LIVED EXPERIENCES OF PEOPLE IN MÉXICO

ROGER ANDREW RENTERIA

Master’s Program in Sociology

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Stephen L. Crites, Jr., Ph.D.  
Dean of the Graduate School

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by

Roger Andrew Renteria

2019

## **Dedication**

I would like to dedicate this thesis to the “village” that has brought me to this point in my life.

Thank you to my parents, my brothers, family, mentors, friends, and others that I have met on my academic path. Thank you, Lorena for your help and guidance through this process. You are a source of inspiration. To all the people that shared their life stories and experiences with me, thank you. I can never repay you for all you have shared with me. I hope that you see this thesis

as a token of gratitude. This is yours.

*“NACÍ DE NUEVO:”* EXAMINING THE FUNCTIONS OF A PROSTHETIC LIMB  
THROUGH THE LIVED EXPERIENCES OF PEOPLE IN MÉXICO

by

ROGER ANDREW RENTERIA, B.A.

THESIS

Presented to the Faculty of the Graduate School of

The University of Texas at El Paso

in Partial Fulfillment

of the Requirements

for the Degree of

MASTER OF ARTS

Department of Sociology and Anthropology

THE UNIVERSITY OF TEXAS AT EL PASO

Fall 2019

## **Acknowledgements**

I would like to thank Dr. Aurelia Lorena Murga for her unwavering support through this process. Thank you for guiding Juan, Todd, and me. I know it was difficult, but you did it. I am, and I know Juan and Todd are, forever grateful for having you as our mentor. To my research committee, Dr. Ophra Leyser-Whalen and Dr. Patricia Juárez Carrillo, thank you for the guidance and support you have offered me as I wrote my thesis. I appreciate the time and energy that you lent to me. Thank you, Mom and Dad, for instilling the importance of education in my mind as a child. I gave it my best attempt because of you both. I hope that I made you proud. This degree is as much yours as it is mine. My brothers, Ryan, Charlie, and Christopher, I am so glad to have you in my life. We are each other's closest links to our past. Never forget that I love you unconditionally. Through thick and thin, you all have been there for me. Thank you. Thank you, Enrique Gonzalez and Juan Mendoza, for your friendship. I would like to think that we livened up the cubicles with our laughter and conversations. Our group really helped me with all the stress and fears that I had about the grad program. I am grateful to call you my friends. Thank you, LIMBS, International for funding the project that provided the information for this thesis. Thank you, Oscar Gonzalez-Montoya, for your help through this process and I send my thoughts and energy to you and your family. Thank you Deyana Lozano for introducing the team to the organizations and for joining us in our travels through México. Thank you, Sergio Armendariz, for being a part of our research team. We both learned a lot through this experience and I am glad that I was able to share it with you. Finally, thank you to all the participants of this study. I am happy to have met you and I am humbled by your openness. I still think about you and reflect on our conversations. I hope that our paths cross again one day under different circumstances. This thesis belongs to you.

## **Abstract**

80% of the people living with a disability live in developing countries (WHO 2018). With this being said, there is limited social research examining the experiences of this population (Connell 2011; Meekosha 2011). This thesis seeks to gain an understanding of the broad functions of a lower-limb prosthesis through the lived experiences of people living in México. Through the use of qualitative data collected from participants living in Oaxaca, Guadalajara, Mexico City, and Cuernavaca, the conversation on the “functionality” of a prosthetic limb has been expanded to include the social function that the prosthesis serves in the roles of navigating social spaces, social re-integration, and social pressures of living as a prosthetic limb user.

## Table of Contents

Dedication.....	iii
Acknowledgements.....	v
Abstract.....	vi
Table of Contents .....	vii
Introduction .....	1
Literature Review.....	3
Sociology of Disability: Disability Studies.....	3
Disability in the Global South .....	6
Wellbeing and Social Meaning of Prosthesis .....	8
Summary of Literature Review .....	11
Theoretical Model.....	13
Methods .....	14
Study Context .....	14
Positionality .....	15
Participants and Setting.....	16
Data Collection .....	17
Photovoice.....	19
Data Analysis.....	20
Presentation of Findings.....	21
Findings .....	23
Navigating different terrains: Darío and Francisco .....	23
Darío.....	24
Francisco .....	27
Social Rebirth and Re-integration: David, Mateo, and Ramón .....	32
David.....	33
Mateo .....	36
Ramón .....	38
Social Cohesion and Support: Lucero, Luis, and Mateo.....	41



Lucero .....	41
Luis .....	43
Mateo .....	45
Social Stressors, Blame, and Barriers: Hernando, Pepe, and Karla .....	47
Hernando.....	48
Pepe .....	50
Karla.....	52
Study Limitations.....	55
Discussion.....	57
Conclusion .....	62
References .....	64
Appendix .....	69
Table 1: Causes of Amputation .....	69
Table 2: Participant Demographics .....	70
Table 3: Amputation/Prostheses Information .....	71
Vita	72

## **Introduction**

The ability to walk is something that many people take for granted on a daily basis. For instance, able-bodied individuals do not have to think about walking independently, that is, with the use of any ambulatory assistance. The everyday experiences of navigating through different physical and social spaces are often an afterthought because walking is, in many ways, a common involuntary action. The topic of my thesis revolves around the lived experiences of people that do think about the function of walking. Or, in the case of the participants of this study, the function that a prosthesis plays as part of their lived experiences in the physical and social environments that they traverse on a daily basis.

The participants in this research not only navigate the act of walking, but also deal with internal thoughts and social comments about the absence of a leg or ideas around a “normal” body. For some people this is particularly upsetting since limb loss occurs at different points within their life span. For example, some people have experienced limb loss at a young age (e.g., during childhood) while others experienced the loss of a limb later in life (e.g., adulthood). Moreover, coupled with, at times, the physical pain of limb loss, are expressions of sympathy from people as part of everyday interactions in different environments. Still, having a prosthesis allows people to navigate diverse physical and social worlds a bit “easier.” For instance, the ability to walk provides some people a sense of independence that they did not have since the loss of their limb.

My work elucidates the functions that a lower-limb prosthesis serves for people living in México. In this research I address functions that are beyond the physical efforts of being able to walk or stand and the ways in which they respond to these situations. There is limited sociological research in the literature of disability dealing with physical disabilities (Lucas,

Greenberg, and Bevan 2018). Likewise, there is limited work being done among disabled populations within the global South. For this reason, my research in México fills an important gap in the literature about living with a disability in Latin America.

According to the Instituto Nacional de Estadística y Geografía (INEGI 2017), the equivalent of the U.S. Census in México, as of 2014, 6% of México's population live with some form of disability (2017). That makes up approximately 7.1 million people throughout the entire country. Of those people who have a disability, 64.1% fall under the disability type that is classified as hindering their ability to, "walk, get up and get down using your legs" (INEGI 2017: 28). This is noted as the major form of disability for people living in the country. The main cause of disability in the country is recorded as "illness" at 41.3% with the chronic illness of diabetes being the most prevalent among the population.

In the next section, I introduce the literature background of disabilities, a discussion of the global South, and issues of wellbeing and social meaning for prosthetic limb recipients. I use these three literature themes to inform my analysis of participants' experiences in my study of the functionality of a prosthesis in people's lives. My goal is for this research to provide a deeper understanding of the ways that people with a physical disability (limb loss) navigate their social worlds in México.

## Literature Review

### SOCIOLOGY OF DISABILITY: DISABILITY STUDIES

When examining topics under the umbrella of disability studies it is useful to begin with a discussion about the models that are used to conceptualize, understand, and analyze disability. Medical and social models have been used in the study of disability. The medical model views disability as a deficiency or something that is wrong within an individual's mind or body that should be cured (Weitz 2015: 123). According to Lucas et al. (2016), the idea of the "disabled" body arose during the Industrial Revolution. The body was seen as a means of production and this thrust value onto the body. This is to say that there was (and is) a certain type of body that was valued by society.

During this time, the same idea gave rise to the eugenics movements (in the U.S. and in western European countries) as a way to preserve and give value to certain bodies. A by-product of these ideas was the concept of the "sick role." When individuals are identified in this role they are seen as deviant and not able to assimilate to what is perceived as "normal" (Parsons 1951). People who fit the "sick" role have a legitimate reason for not fulfilling their obligations and are not held responsible for the reason(s) that they are sick. However, it may be thought that the individual should strive to get well and seek/follow medical advice in order to resolve an ailment. Still, this concept does not take into consideration the effect of chronic conditions that cannot be resolved. It also only looks at the interactions between the "ill" and the mainstream healthcare system, which "form only a small part of the experience of living with illness and disability" (Weitz 2013: 117). As such, the "sick role" is limited in its application when it comes to understanding the experiences of people with illnesses and disabilities. Because of this, the use of the concept has declined over time (Weitz 2013).

The study of disability has been under-researched in the social sciences, specifically in sociology (Lucas et al. 2018). For this reason, a more critical response toward the centralized medical model of disability began to take shape. The development of a new model examining disability began in the mid-1970s (Oliver 2004). This social model addressed certain topics that were ignored by the medical model in regard to disability and illness. The social model of disability was adopted by sociologists and disability activists as a way to understand and define disability. In this model there are social barriers that “create” disability. Oliver (2004) states that:

the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, mental or intellectual. The barriers disabled people encounter include inaccessible education systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media – films, television, and newspapers (21).

In this way, people using this model note how people within society play a role in disabling individuals. This is the accepted model that social scientists (e.g. medical sociologists) have used to study disability or illness in a more critical way.

One of the critiques of the social model is that it is found to be, “unhelpful in understanding the complex interplay of individual and environmental factors in the lives of disabled people” (Shakespeare 2013: 220). For this reason, disability scholars expanded on the social model of disability with the Social Relational Model of Disability. The Social Relational Model of Disability (this is the model that I use to frame my discussion) views and defines disability as the lived experience of the body. This model is used to note how disability is created on the basis of unequal social relationships that undermine the wellbeing of people labeled as “disabled”, and that this label is imposed on individuals through restrictions in social relationships and interactions (Thomas 1999; 2001).

Disability Studies scholars have pushed to view disability as an identity to be examined as a form of oppression, much like the social constructions of race, gender and sexuality. In this way, disability would be understood as an identity that is rooted in a position of subordination, social oppression and exclusion. This differs from the social deviance paradigm that is usually used in the medical sociology of disability by remaining critical of the oppression of people with disabilities in an ableist society (Thomas 2004; 2012). This “other” way of looking at disability would mean that there is an –ism at work here. Disablism, as defined by Thomas (2012), focuses on imposing an oppressive and inferior view toward people with disabilities. Disability is defined differently by academics in disability studies. Per Thomas, “impairments do play some role in causing disability, that is, the body and embodied states are of relevance to ‘being disabled’ (2012: 573).

Viewing disability as a form of oppression requires an examination of the intersections of oppressive systems that provide individuals with differing experiences. This seems to be the way in which disability studies are heading and has caused discussion and debate between medical sociologists. These scholars take on a more qualitative approach in examining the lived experiences of people with disabilities. In the process, they are also using theories from other branches of study, like feminism, in order to gain an understanding of the research in an interdisciplinary way (Meekosha 2011; Thomas 2012). In summation, people focusing on disability studies want to mark the study of disability as a central subject of sociological thought. This would challenge the traditional stance of locating disability studies under a subfield of medical sociology (Thomas 2012).

## **DISABILITY IN THE GLOBAL SOUTH**

Meekosha (2011) states that current disability studies are centralized in developed countries in the global North and this has caused a one-way transfer of knowledge about disability (top/down). Because of this, countries located in the global South are under-researched and the experiences of those living there are underrepresented in any sort of research revolving around the topic of disability (or any social research for that matter). The greater issue around this is that the majority of people living with disabilities are located in the global South with a reported 80% of the 1 billion people worldwide living with disabilities residing in these countries (WHO 2018).

Both Meekosha (2011) and Connell (2011) stress that we must acknowledge the power relations between the global South and global North. We must also recognize the role that the global North has in the role of “disabling” the South. It remains paramount to recognize the role that colonialism has had in the idea and construction of disability in these areas. During the colonization of these countries, disability was used as a way to institutionalize individuals who were seen as “abnormal” (Meekosha 2011). This is important because these people in positions of power wanted to control those they were colonizing. What better way to do this than to separate and institutionalize people placed into subordinate positions of power? The other role that the global North has had in this is the dependence that the people of countries in the global South have on the colonizing powers. With the role of arms and wars, pollution, and other factors that capitalism has had in the role of producing physical disabilities among people in the global South, the global North should acknowledge its role in producing disability and take an active role in the prevention of impairments (Meekosha 2011).

The access to medical care and prosthetics is also different in the global South than in the global North. In the case of Bigelow et al.'s (2004) study in Haiti, they found that most people experienced limb loss because of a lack of access to medical care. This resulted in the leading cause of amputations. For instance, often times, people have a cut on their leg that developed into an infection that would then lead to amputation of the limb. The majority of people interviewed by Bigelow et al. (2004) were not able to secure a prosthetic limb as a result of cost, lack of prosthetic limb makers and not being able to travel to the cities where prosthesis shops are located. Those who did have a prosthesis had issues with using it because there was a lack of prosthetic treatment and rehabilitation. The researchers conclude that a more “holistic” and “universal” prosthetic treatment for the people of Haiti requires a prosthesis that is economically feasible to acquire and easy to repair. The authors also argue that in order for the situations of people experiencing limb loss to improve there needs to be public awareness of limb loss throughout the entire country. With this, Bigelow et al. (2004: 251) note, “prosthetic treatment in Haiti can be successful.” Overall, people that have experienced limb loss in the global South share common experiences related to economic barriers and access to medical care that need to be addressed in order for their situations to improve.

There has been limited sociological research that examines the functionalities, outside of the pure physical function, of prosthetic limbs and even less research for those prosthetic limb recipients who are located in the global South. This is a significant issue to address since individuals living in the global South are disproportionately impacted by living with a disability. This is the goal of this thesis, to expand the conversation of the lived experiences of people with disabilities living in the global South. In particular, addressing the lived experiences of people who have lost a limb and are living in México.



## WELLBEING AND SOCIAL MEANING OF PROSTHESIS

The majority of the literature focusing on prosthetic limb users revolves around the increase of perceived wellbeing. The majority of the literature examines the roles of a prosthesis in the perceived wellbeing of prosthetic limb users. Findings from this literature show that there is a positive increase in the perception of wellbeing in people's lives after receiving a prosthetic limb(s). The majority of these studies have used quantitative measures to gain knowledge on the wellbeing of "patients." Additionally, the majority of this literature is found in medical journals with scarce research being done by social scientists. Webster et al. (2012) found that people who used their prosthesis, more often than those who did not, were less likely to experience depressive episodes. They also found that older individuals had greater functional restrictions when it came to full-range use of their prosthesis. This makes sense since our mobility becomes more limited with age. This also addresses the total physical functionality of the prosthesis. The limb was created with the purpose of "returning" mobility back to the client, but what if the client cannot walk after the limb has been given to them? Has the prosthesis then served its function, or can people find another purpose for it?

Norlyk et al.'s (2016) qualitative research looks into the period when an amputee is learning to use the prosthetic limb. Researchers found that in this "in-between" stage (becoming a prosthetic user) there was a disconnect between people's lives before and after living with a prosthetic limb. This "in-between" stage is understudied when it comes to prosthetics and the people who use them. Norlyk et al. (2016) found that their participants were living on "standby" until they were able to walk independently. Participants often wanted to again completely stand on their "own two feet." The parting discussion of this study leaves us with the importance of looking beyond the physical and medical worlds of the individual. The authors stress the

importance of understanding people's experiences as a way to recognize the new life that a prosthetic limb user is now living as, "the initial critical phase in which they have lost their former life and need to re-conquer life as a prosthetic user" (Norlyk et al. 2016: 8).

Literature examining the psychosocial impact that limb loss has on individuals has also been documented. In Coffey et al.'s (2009) study of individuals who had lost their limbs due to diabetes they found that individuals may continue to experience episodes of physiological distress involving high levels of anxiety and depression. The researchers stressed the importance of following up with people who have lost a limb and advise offering follow-up care after amputation.

While the majority of the research addressing the wellbeing of people who have experienced limb loss is situated in countries of the global North, there are some studies illustrating the wellbeing of people living with prosthesis in the global South. Arias Vázquez et al.'s (2018) quantitative research in Tabasco, México focuses on individuals who received a prosthetic limb after amputation. They found a prevalence of suicidal attempts and depression among their sample. The researchers examined whether functionality correlated with, and whether it was an indicator of, depression. The researchers found that 27.5% of their sample had attempted suicide while 92.5% of their sample experiencing depression. Arias Vázquez et al. (2018) found that as functionality was down the chance of depression was high. They concluded that it is beneficial to view the process of rehabilitation in a holistic way where the individual is given both physical rehabilitation so they may experience full functionality as well as psychological therapy in order to assist people with depression and suicidal thoughts.

Gallagher and MacLachlan's (1999) study with forty-four participants addressed the psychological adjustments and coping mechanisms of adults with prosthetic limb users. They

found that individuals that had lost a limb due to trauma used “avoidance” as a coping strategy significantly more than those who had lost their limbs as a result of disease. They also found that those who were experiencing “stump pain” tend to develop a greater sense of despair and withdrawal from social support when compared to people who had not been experiencing stump pain. Gallagher and MacLachlan (1999) found that participants more often experienced stump pain if they lost their limbs as a result of trauma. Researchers concluded that avoidance as a coping strategy affected participants’ physical and psychological wellbeing. They conclude by stating that limb loss is a multifaceted experience that requires consideration of both the physical and psychological adjustments that individuals have to make as well as the reason for amputation.

Murray’s (2004) study on the embodiment of the artificial limb found that individuals can experience the prosthesis as a part of their body. For example, participants experiencing phantom limb, which is when a person feels that the amputated limb is “still there,” were able to project this feeling onto the prosthetic limb and have the prosthesis as a part of the phenomenal body. The embodiment of the prosthetic limb was also more likely to happen after practiced use with the prosthesis and if the individual had a decreased awareness of the prosthetic limb. Decreased awareness is defined as, “walking with a prosthetic could resemble the intuitive nature of walking of the pre-amputation, able-bodied self” (Murray 2004: 968). In other words, walking with a prosthesis without having to think about the process of walking. Therefore, creating the decreased awareness of the prosthesis by the prosthetic limb user. These individuals were considered by researchers as “successful” prosthesis users while those that “rejected” the prosthesis were identified as not “persevering” enough to be thought of as successful prosthesis users.

Murray (2005) has previously addressed the social meaning of the prosthesis. “Social meaning” is defined as, “the use and experience for the person concerned of prosthetics, and the prosthetically enhanced body, in relation to social occasions and relationships” (Murray 2005: 428-29). In their work, Murray (2005) looks at the way that prosthetic limb users were able to navigate their identity as a person with a disability and found that people were able to “conceal” their disability to others with their clothing. Prosthetic limb users were also “skillful” in their use of a prosthesis, thereby controlling who knew of their disability and, when, or if, they were likely to disclose this information to others. In this way, prosthetic limb users were managing the stigma attached to having a disability and able to better facilitate social integration. Prosthetic limb users were able to choose who they wanted to disclose their disability to and managed disclosures at their own time.

#### **SUMMARY OF LITERATURE REVIEW**

In this chapter, I presented three literatures introducing the sociology of disability: disability studies, disability in the global South, and wellbeing and social meaning of the prosthesis in order to illustrate the limited research conducted on prosthetic limb users. Bringing the three literatures together highlights the ways in which people experiencing disabilities are affected by the framing of their experiences within research and academic literatures. There is also a need to expand our conversations, views, and research centering on prosthetic limb users who are rendered vulnerable as a result of their positions within the global South. For instance, members of these communities face the structural causes of impairments (e.g., war) as well as the institutional barriers to acquiring a prosthetic limb (e.g., medical services). Lastly, addressing literature on the wellbeing and social meaning of prosthesis elucidates the dynamic ways in which people, for example, personally or socially navigate the loss of a limb.

In the next section, I present the Social Relational Model of Disability. This model guides my analysis of the experiences of people living with an amputation and who are prosthetic limb users in my study.

## **Theoretical Model**

I use the Social Relational Model of Disability (SRM), developed by Thomas (2001; 2004; 2007), in this study in order to frame my understanding of the experiences that people have as a result of being a prosthetic limb user. This model takes what both the medical and social models (introduced in the previous chapter) have to offer in order to understand and problematize disability and people's experiences with disability. The SRM takes into consideration the effect of "impairments" on the lives of people. As proposed by Thomas, this model of disability reflects on the social and environmental factors that influence the lives of people with disabilities and also considers the functional implications of having an impairment (2001; 2004; 2007). Arguments for the use of this model have been made by disability scholars in order to expand the studies and conceptualization of disability (Thomas 2012; Martin 2013; Cologon 2016; Reindal 2016). Through analyzing the experience of impairment and of disability we may be able to better understand the lived experiences of individuals with disabilities.

## **Methods**

In this chapter, I discuss the different parts of the methodology of my work. I address how I was introduced to the research topic, my positionality in the research process, and introduce the research participants and settings. This study implemented a mixed-method approach to research. That is, it integrated quantitative and qualitative research within the same project. Below, I introduce each part of the collection of data, including: ethnosurvey, semi-structured interviews, and photovoice. For the purposes of this thesis, I only use the information gathered in the ethnosurvey and semi-structured interviews for the findings portion of the thesis and will use photovoice at another point in time.

### **STUDY CONTEXT**

LIMBS, International (N.d.) is a non-profit organization based out of El Paso, Texas that provides low-to-no cost prosthetic limbs to individuals that live in developing countries in Latin America, Asia, and Africa. The organization has been providing prosthetic limbs to clients for the last 16 years. The organization contacted the Department of Sociology and Anthropology at The University of El Paso (UTEP) in order to conduct exploratory research examining the impact that their work has had in the lives of their clients. As a result, I, along with Dr. Aurelia Lorena Murga agreed to conduct the project during summer 2018 in México. México became the country that provided the setting for data collection due to its proximity to El Paso, Texas and because of the researchers' knowledge of language and culture. Along with the creation of an assessment tool, LIMBS, International (LIMBS here forward) was also looking for an independent (not affiliated with the organization) research team that was interested in the construction and administration of surveys and analysis of findings.

Data collection occurred during summer 2018 over the span of two weeks. The research team traveled to four locations that included Oaxaca, Guadalajara, Mexico City, and Cuernavaca. LIMBS served as the contact to the five affiliated local organizations and churches that the research team visited. Through these contacts, the local organizations and churches facilitated interview meetings between the research team and the participants of the project.

### **POSITIONALITY**

Before and during traveling to México, Dr. Murga and I spoke about our positionalities in this research. Positionality, is referred to as the “standpoint judgement of the researcher” and how they relate to their participants (Parker and Lynn 2002). I knew that my own social location would affect my rapport and connection with research participants. As an able-bodied, young, Mexican-American, male researcher, I have to acknowledge the set of privileges I had when compared to our study participants. It was important for me to think about how my positionality would impact my interactions with participants, the data collection process, and my analysis of the data.

I am an outsider to the experience of living with a disability and navigate both social and physical worlds differently than my participants. Their daily experiences are different than my own. I do not have to navigate my life as a prosthetic limb user. As a result, my social and physical experiences are quite different than those of my participants. Nonetheless, I felt accepted by the community of participants that were a part of this study. I was able to have conversations with people about the situations in both the United States and in México. The current events occurring in the U.S. and México were one way that I began to build rapport with participants. These conversations usually revolved around President Trump and his anti-immigrant rhetoric, presidential elections that were occurring in México at the time, and the



FIFA World Cup (i.e., soccer games were playing in the reception areas of organizations while people were waiting to be interviewed). I used the translation of my name from “Roger” to “Rogelio” in order to make it easier to interact on a first-name-basis with participants and members of the five organizations. As a cisgender male, I interviewed women about their experiences with a prosthesis and found that their interactions with me were similar to their male counterparts. As part of the demographics of the study we did not ask about sexuality, and this was never raised as a situation affecting people’s experience as prosthetic limb users.

As a social scientist, interviewer, and young researcher living in the U.S., I was learning about the experiences I had only previously been informed about through research literature. Overall, being able to speak Spanish fluently allowed me to have an “in” in this community. Additionally, my Spanish surname, knowledge of Mexican culture, and being considered as a *paisano* (even if I did not live in México) helped my interactions with participants. These shared commonalities—Mexican heritage, language, cultural connections—along with being receptive to participants’ life narratives provided me the opportunity to gain an understanding of people’s lived experiences as I use their words to illuminate their stories in my work.

## **PARTICIPANTS AND SETTING**

Participants of this study were recruited as a convenience sample (Singleton and Straits 2017). As previously mentioned, participants were asked by local organizations affiliated with LIMBS to take part in a survey and interview that solicited information about their lived experiences as prosthetic limb recipients. In return, if they had any issues with their prosthesis, they could have technicians or doctors look at them and provide adjustments during that time. Data collection occurred in the office spaces and vacant areas of the affiliate organizations. Interview areas were limited to participant and interviewer. Pseudonyms were provided for the

five organizations and churches visited by the research team. The names and locations are as follows: *Ayuda* (Oaxaca), *Pies Unidos* and *Herramientas* (Guadalajara), *Alas* (Mexico City), and *La Puerta* (Cuernavaca).

Forty-five participants were recruited for the study. Out of those forty-five, four participants were in the process of receiving their prosthetic limb. Their responses are included in this study as part of the overall sample. Thirty-nine men and six women, between the ages of 19 and 73 (Avg. 48.51, S.D. of 14.024 years), participated in the study. Participants that were employed and provided their annual income earnings ranged between \$14,000 and \$120,000 Mexican pesos (\$59 and \$512 US dollars per month respectively-average exchange rate of \$19.5 pesos per dollar in December 2019). The average annual income for the participants is \$48,408 pesos (roughly \$2,500 USD). Frequencies and percentages for the reasons that lead to amputation are shown in Table 1 (see appendix) with diabetes being the major reason for amputation. The majority of participants reported completing their education up to middle school or less (56%), with 7% reporting no school at all, 29% completed elementary school, 27% middle school, and 24% completed high school or technical education. Only 13% reported college education. Participants reported living with a limb loss for 7 years average (ranging from 1 to 37 years before having a prosthesis). Tables 2 and 3 (see appendix) detail the demographic characteristics of each participant.

#### **DATA COLLECTION**

Before data collection began, Institutional Review Board (IRB) approval was granted by The University of Texas at El Paso (UTEP) and the research team received permission from UTEP for conducting international travel/research. Prior to the formal interview, participants received verbal and written information that introduced the study, its purpose, the right to

withdraw from the study at any time, and the confidentiality of data. With the consent of the participants, the interviews were audio recorded, transcribed verbatim, and were analyzed for themes. Pseudonyms were assigned to participants (some chose their own) and organizations in order to maintain confidentiality throughout the research process. Data for this thesis was collected through two research instruments: ethnosurvey and in-depth interview guide. These data gathering instruments were compiled by the research team. The survey was designed as an ethnosurvey. Ethnosurveys began their use in migration studies. This research design was created as a response to the complexity of the migration process and to address questions that could not be answered with existing data sets (Massey 1987). As stated by Kaczmarczyk and Salamońska (2018: 460) “the term ethnosurvey derives from two elements—ethnographic study combined with survey methods.” The method is developed as a way of collecting both quantitative and qualitative data simultaneously as, “ethnographic and survey methods inform one another throughout the study” (Massey 1987: 1505). The goal is to follow a “naturalistic” conversation where the administrator has a guide and is interweaving survey measures into the flow of talk.

As part of this survey method, the first portion of the study asked participants to provide demographic information, which included age, educational attainment, marital status, gender, and income, to name a few. Some survey questions were adapted from the Centers for Disease Control and Prevention (CDC 2018), the Behavioral Risk Factor Surveillance System Survey (BRFSS) Questionnaire (2018) and the Quality of Life Assessment Survey developed by MarketResponse International (2001), plus additional questions developed by the research team. Participants were asked to reply to binary questions (yes/no), ordinal responses (1-5), scale responses, and open-ended questions. The survey was divided into ten sections. These sections

were titled: Demographic information, Prior to receiving a prosthetic limb, Receiving a prosthetic limb, Overall health questions, Mental health, If has Diabetes, Independence, Integration, and Inclusion. Open-ended questions were used to elicit more nuanced information about the experiences of the participant that could not necessarily be quantified or explained through the answers provided in the instrument. This form of survey methodology allowed for participants to elaborate on survey responses. Selected responses to the ethnosurvey are examined in this thesis. A more complete analysis of all the responses of the ethnosurvey will be part of another report by the research team.

In conjunction with the survey, participants were asked to participate in a semi-structured, face-to-face, in-depth interview. The transition between the two methods was fluid and was only broken by the switching of guides. The interview revolved around topics such as medical care experiences, access to healthcare/medicine, experiences of being a prosthetic limb user, social circle, and current occupation. This portion of the study allowed for more nuanced replies and reflection to previous survey responses. Responses to surveys and interviews were audio recorded. Interview sessions averaged 1 ½ hours.

## **PHOTOVOICE**

Photovoice, a qualitative research method, was also implemented as part of this mixed-method research project. This qualitative method approach allows participants to elaborate on their everyday experiences through the use of photographs. Participants that agreed to take part in this section of the study took pictures of anything that they wanted to share as part of their experience of living with a prosthetic limb. Examples of these pictures included images of themselves, their daily routes and physical environments, pictures of themselves working, pictures of the waiting room areas of their doctor's office, to name a few. In addition to the

sharing of the photographs, participants were asked to explain what these images meant to them using the SHOWeD method (Wang 1999). This method asks that participants address the following: 1) What do you See here?; 2) What is really Happening here?; 3) How does this relate to Our lives?; 4) Why does this situation, concern or strength Exist?; and, 5) What can we Do about it? This method of data collection allows participants the freedom to express their lived experiences as prosthetic limb users in any way they feel comfortable. Thirteen people participated in this part of the research project sharing seventy-three photographs in total. For the purposes of this thesis project, the photovoice element of the data collection is not included in the analysis. Instead, I will be working with Sergio Armendariz, the undergraduate student that took part in the summer research, on a separate writing project.

## **DATA ANALYSIS**

Survey responses were imputed into SPSS v.24. Surveys included demographic information and descriptive statistical analysis was done to gain an understanding of the sample (gender, age, annual income, and educational attainment). The qualitative portion of the study provided more nuanced information about the participants' lives. As per Hartley and Muhit (2003: 112), "qualitative research has a particularly valuable role to play in the development of relevant research about disability in majority world countries by virtue of the fact that little is known about this area and that the stakeholders are a very vulnerable group."

Interviews were listened to in Spanish and were transcribed in Spanish. I used ATLAS.ti v. 8.1 qualitative software to code and analyze the interviews. Inductive analysis was used when coding. This type of analysis consists of, "...closely examining qualitative data in the form of documents, field notes, or interview transcripts..." and through this "...the researcher locates patterns and commonalities" (Roulston 2010: 150). Transcriptions were reviewed and through

this process I developed codes for the data. The coding and analysis of data took part in stages (Strauss and Corbin 1988). Initially, interviews were grouped and categorized into themes that were defined as the greater “social,” “emotional,” and “promise/hope” functions experienced by participants. I then conducted a second review of these coded interviews in order to identify sub-themes. This process allowed me to untangle the functions that I had previously noted. I ended up with some of the following sub-themes: “navigating physical terrains and built environments,” “rebirth and reintegration,” “social cohesion and support,” “social stressors and barriers.” Lastly, I conducted substantive or selective coding in order to refine codes and build storylines around specific themes. I translated the sections that were used for analysis into English. The narratives used in this research highlight some of the collective experiences shared by the participants of this study.

#### **PRESENTATION OF FINDINGS**

I use the work of Latinx sociologists in the analysis and presentation of the findings in this study. I present the findings in this study as a collection of narratives or stories that are grounded in the context of individual experiences that address the issues of a population that has been rendered vulnerable by the social and institutional environments they are part of. In *Precarious Claims: The Promise and Failure of Workplace Protections in the United States*, Shannon Gleeson (2016) addresses the limits of labor law as part of the everyday lived experiences of low-wage workers. Gleeson interviews sixty participants as part of her study and presents the story of one or two participants in order to illuminate the collective experiences of her participants. She does this in order for readers to “hear” the voices of those most affected by unequal workplace situations. I root my own presentation of data in Gleeson’s work. In this study, I present the narrative or story of selected participants who have experienced limb loss and

who have become a prosthetic limb user by contextualizing their own experiences while also addressing how their experiences reflect that of other participants in the study. Though each person's experience may be thought of as "unique," people had a number of commonalities related to the ways in which the prosthesis functioned in their lives. Similar to Gleeson (2016), my work elucidates the lived experiences of people who have been through difficult situations and whose voices have not traditionally been represented in social science literature.

## **Findings**

This chapter is informed by participants' experiences in México. By examining these experiences, I was able to expand on the “functionality” conversation of the prosthetic limb and the ways in which it matters for people affected by limb loss. Before heading into the field, Dr. Murga and I met with the founder of LIMBS. As an engineer he explained that the main goal of the knee/limb is for it to be “functional.” Functionality basically means that people are able to use the limb in order to walk--that was its purpose. As sociologists with no background in engineering we found it helpful to understand the basics of what the limb was meant to do. And, we were also appreciative of the fact that the organization wanted to see how the limb had impacted people's lives. Some of what we learned is presented in this thesis.

In the following sections, I provide a brief background of the participant in order to ground their experiences and the functionality that the limb has provided them. In particular, I highlight the stories of ten individuals whose experiences are representative of those of others that we interviewed. As everyday poor and working-class people our respondents were providing their thoughts on their own experiences as prosthetic limb users. In accordance with Gleeson (2016), these individuals were chosen in order to provide an understanding of the functions that the prosthesis serves for the participants in our study who are part of a collective group of people that have received a prosthesis through LIMBS.

### **NAVIGATING DIFFERENT TERRAINS: DARÍO AND FRANCISCO**

Participants of this study brought up their daily routines as a way to talk about how they navigate their lives on a daily basis. The use of public transportation (buses, trains, taxis, etc.), having to traverse unpaved roads, deteriorating sidewalks, crossing roads in busy areas, and poor infrastructure were all common topics of discussion that participants addressed during our



conversations with them. For example, respondents from Oaxaca were primarily living in rural communities outside of Oaxaca City and had difficult experiences when having to navigate their physical environment because they lived in communities that were mountainous. I would also learn that respondents who were living in urban areas also had a difficult time getting around the busy cities they lived in. Indeed, while the spaces that people live in are made up of different terrains, respondents had to learn how to navigate demanding situations as they move about on a daily basis as prosthetic limb users. In the following section, Darío, who lived outside of Oaxaca City, and Francisco, who lived in Guadalajara, address these issues while they offer differing experiences on how they choose to traverse their physical environments. Below, I share their stories in order to highlight the ways that people in my study addressed how they moved around their day-to-day environments.

### **Darío**

Darío was one of the first people that was interviewed in Oaxaca. He was a 20-year-old man, who had traveled with his sister and mother from a small, rural community outside of Oaxaca City to take part in our study. The trip to the offices of Ayuda had taken four hours by taxi. He and his sister, who is also a prosthetic limb user, were going to be able to receive adjustments to their prostheses. Darío's community was located in the mountain region of Oaxaca. There had been heavy rains in the area during the past few days causing major landslides. This had affected roads and peoples' homes in the community. Luckily, he and his family had not been impacted by this, but others from his community were not so fortunate.

As we began the interview, Darío shared that he was not unfamiliar with walking with his prostheses. He reported using his prostheses for a year at the time of the interview. Unlike his sister, who had just been fitted with her prostheses and not interviewed for this project because

she was 17 years old, he was able to walk well using his prosthetic legs. He did not use a crutch or cane when walking even though he had to traverse mostly on unpaved roads that were uneven and rocky. Darío was shy and soft-spoken and explained that both of his legs had been amputated as a newborn. He was born with what he called a “deformity” of both his legs and the doctor advised his mother that it would be necessary to amputate his legs. He had received his prostheses while he was in high school thanks to a faculty member who had heard about an organization in Oaxaca City (Ayuda) that was offering the opportunity for candidates to receive low-to-no-cost prostheses. That opportunity had changed his life since he would otherwise not be able to afford his prostheses.

Now, at the age of twenty, he aspired to become a prosthetist. This may be a long-shot for him. Not only because of the cost of schooling, but because, as the prosthetist that worked with Ayuda informed the research team, people that were interested in studying and getting certified as prosthetists needed to travel to El Salvador for that training. At the time of our interviews a school in El Salvador was one of the only schools in Latin America that certified prosthetic limb makers. Darío’s dream was to become a prosthetist and help those who needed a prosthetic limb. He wanted to be like Dr. Angel, the person who had helped him with his prostheses.

Recently, Darío had been dealing with a great deal of pain and discomfort because he had to wear a belt around his midsection that kept his prosthetic limbs closely attached to his body. He had been having to take the prostheses off periodically during the day in order to rest his body and relieve some of the pain caused by the belt. At the time of our interview he was experiencing extreme pain and bruising from the straps that would go around his waist and this was the most prevalent reason that he was not able to wear his prostheses all day long; it was harming him. Darío shared what it was like when he was not able to wear his prostheses:

I don't feel like doing anything when I don't have my prosthetic legs. I don't want to go out and be with my friends and I get kind of depressed when I can't wear them. It limits me, not being able to wear them.

The experiences that Darío was feeling about not being able to wear his prostheses was impacting his drive to want to do things. It was clear to see the way that this situation was affecting him because it was not only the pain that the belt caused him, but that experience was also creating a strain on his life since being unable to wear his prostheses meant a series of both physical and social limitations that he did not feel when he did wear them. Not being able to use his prostheses limited his ability to be out with friends and created a feeling of depression.

When Darío (and others) found it difficult to navigate dirt roads and uneven terrains they sometimes had the use of off-road vehicles that made it easier for them to get around certain areas. Darío was able to wear prostheses because someone else would be driving the vehicle. In the case of others, one participant used dirt bikes while using his prosthesis since he needed to change gears on the bike using a foot pedal. Another participant could use an off-road vehicle with his prosthesis on since his left leg (the one without the prosthesis) would change the gears on the vehicle. And, one participant had access to an all-terrain vehicle (ATV) that did not require gear changing and in this way, he could have his prosthesis on while riding it.

In situations such as these, Darío, along with other respondents from Oaxaca, found it easier to use their prostheses as opposed to wheelchairs or crutches in these areas. The majority of individuals in these communities were working agricultural jobs. Living in rural Oaxaca meant that respondents found that using their prostheses was more effective in completing work, which required them to be standing and walking through fields for long periods of time. Darío, who was unemployed at the moment because the pain that he was experiencing was too great, hoped that he could pursue a higher education and achieve his dream of becoming a prosthetist.

Though we can see that Darío's impairment was partly "resolved" by the use of his prostheses it was frustrating to hear that in his situation they were also causing him pain. This was an issue that he dealt with on a daily basis. Also, when he uses the phrase "it limits me," we can see how he was experiencing the impairment of limb loss. When he was unable to use his prostheses he felt the limits of mobility by not being able to socialize with friends or navigate the diverse terrain of his rural community. He was unable to take part in his agricultural job, which was already a physically grueling task. Not having his prostheses made this work impossible. The SRM allows for the analysis of the effect that the impairment has on the individual; these are the non-social impacts of having an impairment. His impairment was impacting his ability to take part in certain activities. The prosthetic limb was a way to "remedy" the hindrance of not being able to carry out certain tasks. As a prosthetic limb user he had the ability to access social and physical spaces that he would not be able to otherwise (Thomas 2007). Darío's experiences illustrate some of the issues experienced by other respondents. Despite the pain caused while using the prostheses, the prosthesis was offering a way to have access to places people otherwise would not have access to, thus allowing them to navigate their physical environments more freely. In this way, the prosthesis empowered people to manage the disabling effect of the natural environment and allowed them to traverse areas along with people without disabilities.

### **Francisco**

Unlike Darío, Francisco, a 57-year-old man from Guadalajara, had experienced the amputation of his leg 3 years before our interview and reported receiving his prosthesis months before the interview. Like other participants taking part in the study, he had to have his leg amputated from complications due to diabetes. Francisco had a cut on his foot that would not heal and from that an infection began that spread to the bone in the form of gangrene. As our

conversation began, he was very happy to talk about his experiences and the impact that the prosthesis had in his life. Francisco was not wearing his prosthetic limb at the time of his interview. Instead, it was wrapped up in a black plastic bag secured underneath his wheelchair. He used a wheelchair to navigate around the metropolitan city because he found it to be easier to get around that way when having to travel great distances, especially from one side of town to the other.

For Francisco, moving around the city in a wheelchair was possible due to the availability of paved roads and sidewalks in Guadalajara. Unlike Darío, who lived in a small rural town outside of Oaxaca City, Guadalajara is an urban center that allows people the ability to navigate by wheelchair. Though, as noted in field notes and interactions with participants, the built environment was not the easiest to traverse in any of the cities due to poor infrastructure and deteriorating sidewalks. Moreover, other respondents stated that they were in a wheelchair because they were not comfortable enough or had enough practice to walk with their prosthesis. Still, for Francisco, and some of his counterparts (some used crutches to facilitate their walking), it was more convenient to use a wheelchair than to wear his prosthesis. Once he needed his prosthesis, he would grab it from underneath the wheelchair and put it on. As we sat down to start the interview, he started telling me about what happened on his way over to the offices of Herramientas:

I took the train from my part of the city to get here. When I was getting off the train, I fell and got caught between the train and the platform. Luckily, someone saw what had happened and pulled the emergency brake on the train. I am fine, but someone wanted me to stay so that paramedics would look over me. 'I'm fine,' I told them. These are just little falls that happen from time to time.

I was not sure how to react to this event. I asked Francisco if he was okay and he reassured me that he was although he had some scrapes on his elbow. Francisco was not side-tracked by the

event, though. He explained to me that these were some of the things that he has had to deal with as a result of losing his limb. In fact, he lives in the second floor of his building and every time he leaves and returns to his apartment he sits on each step carrying his wheelchair up and down the two flights of stairs. The event with the train was just another part of his everyday life. Plus, this was likely not to be the last time he has such an occurrence with the train since that form of transportation is not accessible to people with disabilities. Francisco had only received his prosthesis earlier that year and, because of this, had not had enough time to feel comfortable navigating environments with it on. It is possible that his experiences would be different if he had more confidence in the use of the prosthesis, as was the case for other participants. Consequently, navigating through these types of built environments creates daily obstacles that people with disabilities have to consider. Francisco, and other prosthetic limb users we spoke with, spend a great deal of time and energy thinking and dealing with these kinds of challenges on a daily basis.

Navigating urban centers was also difficult for participants because, like Francisco, they did not own a vehicle of their own, were not able to drive a vehicle due to their impairment, or have anyone to drive them. When our participants addressed the use of public transit they spoke about similar experiences to those of Francisco. They addressed about falling off of buses and onto the street with prosthesis. In urban areas where there is more motorized traffic, these situations could be very dangerous and something that people had to take into consideration on a daily basis:

Here, you have to be careful. People won't stop for you even if you are disabled. It is as if they come at you with more force. People don't want to wait, it's very dangerous.... You take great risks when trying to cross roads.

These are daily thoughts and experiences that people with disabilities have to take into consideration while traveling. Issues of inaccessibility were part of people's daily challenges. For example, participants had to deal with managing environments where there were uneven steps and steps that were set further apart than usual. Because of this some individuals found it much easier and safer to take a taxi to their destinations. That would mean that they would not need to transfer buses. This would mean that they would not have to get off the bus, onto another, and risk falling in the process. However, not everyone could afford to take a taxi. These come at a high cost since they are much more expensive to take than public transportation. In the case of the participants, spending money on taxis was really a luxury that they could not afford. The act of walking or getting on public transportation is something that able-bodied individuals do not have to think much of. After falling off the train, Francisco had decided to take a taxi the remainder of the way to the office for his interview.

As we began the formal interview, I asked Francisco to tell me about the loss of his limb and he began recounting the amputation of his leg. Similar to other participants, he explained the difficulty of dealing with the loss of his limb:

Look... what happens is that when they amputate you, feel like you get depressed but when you get the prosthesis that kind of uplifts you and as I was able to pick up around my house and people are able to see me as the one that doesn't allow himself to get down. I have a lot to do and keep myself busy.

Francisco faced a difficult time when he learned that his leg was going to be amputated. He experienced what he could only define as a feeling of "depression," but his emotions changed once he received his prosthesis. His spirits were raised because he was once again able to get around and do things for himself. In agreement with Webster et al. (2012) and Arias Vázquez et al. (2018), Francisco, along with other participants, were curbing these feelings of depression with achieving the physical functionality of using their prostheses. Francisco was once again able

to pick up around the house and felt as though people's views of his actions and emotions were also important. He did not want people to see him as letting anything get him down, and this helped raise his own spirits as well. Now, even though he may not use his prosthesis to walk long distances, as was the case for his interview, he could use it whenever he wanted and that made a difference when it came to his emotional wellbeing.

Francisco took very good care of his prosthesis, when he took it out of the bag it looked as if it was new. He said, "I try to take care of it. I want it to last me a long time. I don't know if I'll get the chance to get another one." Like many of the participants, Francisco was unemployed and having access to a prosthesis was financially outside of their realm. The unsureness of what the future held and whether they would be able to secure another prosthetic limb if the current one was to break was something that they took into consideration and brought up during interviews. When our interview started to wind down, Francisco wanted to share pictures of himself standing using the prosthesis. He stood up with a smile on his face, "look my daughter took this picture of me. She said that I was the happiest I had been in a long time."

Respondents faced difficulties that were part of the process of living with a physical disability. Darío, along with other respondents, for the most part, found it easier to move around different physical environments while using his prostheses. He felt they were useful as he walked along a diverse series of terrains in his rural community. Specifically, in the case of people in rural communities outside of Oaxaca City, wearing a prosthesis facilitated their navigation of walking in diverse environments. The prosthesis made it easier for them to do their work because it allowed them the ability to move and stand in the fields. It also freed up their hands to hold tools that they had to use. Those who had better command of their prostheses (had achieved better functionality) were able to address the benefits of having one. Still, they noted that by



having a prosthesis they were not completely problem free. Poor infrastructure complicated their lives as they worked on getting around different areas.

Prosthetic limb users who resided in urban areas seemed to have greater options when it came to navigating their physical environments. Because of the availability of paved roads, sidewalks, for example, they were even able to use other ambulatory devices, such as crutches, canes, and wheelchairs in order to assist them in walking long distances, if needed. This was the case for Francisco and others we met that used crutches or a wheelchair in order to, at times, move with greater ease around the city. However, some of the obstacles that participants in urban areas experienced were also related to poor accessibility to public transportation and buildings. Living with a physical disability, navigating a disabling environment, and having access to multiple ambulatory devices creates complex experiences for participants in our study.

In summation, while examining the impacts that the physical environment that participants had to navigate, with or without the use of a prosthesis, it was not trouble free. They still had to focus and take into consideration accessibility to areas and worry about the dangers of falling and harming themselves. Thus, examining whether a prosthesis is “functional” is highly dependent on context and cannot be answered by a simple engineering definition.

#### **SOCIAL REBIRTH AND RE-INTEGRATION: DAVID, MATEO, AND RAMÓN**

The process of becoming a prosthetic limb user involved periods of highs and lows both socially and emotionally. Examples of lows include depressive episodes and periods of social isolation. Some documented highs were situations where participants were feeling included in social situations. These included invitations to parties, social gatherings, and dancing. In the following stories, I highlight what participants noted as some of these social processes. They often took place following periods of social isolation and abandonment. The stories of David,

Mateo, and Ramón are included in this section and were similar to those experiences felt by others in the study. Interestingly, people seemed to more often have some of these experiences when they acquired the disability in adulthood. This could be due to living an entire life as a person without a disability and now having to deal with the effects that an impairment has on their life and the social implications of living with disability. It is important to note that I included Ramón's story because he lived his entire life as a person who has experienced limb loss, but he had been able to start doing things that he was not able to before because of his prostheses.

### **David**

In Guadalajara, David, a sixty-nine-year-old man who lost his limb due to complications from diabetes walked into the building where the interview was held with a cadence swinging his cane along next to him. He wore shorts with a white polo tucked in and a belt around his waist. The shorts allowed his prosthesis to be exposed. He had been on prosthesis for three years by the time of the interview. David's interview lasted about two hours. His interview would be one of the longest to be conducted with a participant. David liked to talk, joke, and would, at times, lengthen his responses by telling a story. Our conversation began with a discussion of the local cuisine as he asked, "have you had a *torta ahogada* or *birria*? You cannot leave without trying them. I can't really do the spice anymore, but they are delicious. That's what we are famous for," he exclaimed.

As our conversation continued, he was very happy to talk about his experiences and the impact that the prosthesis had in his life. He talked about first receiving his prosthesis by explaining that he felt a sense of "rebirth" when he began to use it. He shared that prior to receiving his prosthetic limb he found himself navigating around different spaces in a

wheelchair. This went on for over three years. Consequently, he found himself at home most of the time sitting in his recliner. David shared that he felt as though he lived in a state of emptiness when his leg was amputated, but would never say that he felt depressed. He also felt that his wife was upset with him during that time. She wanted him to take an active role in doing things around the house because she was tired of doing everything for him. The stress on the family unit was felt by having to care for a person (David) with a disability. Indeed, social relationships are strained in having to care for someone who had previously been independent and could care for themselves.

David and his wife were in a better standing since he had received his prosthesis. He had not stopped moving around and being active in cleaning around the house. David jokes, “sometimes I wish that she didn’t really ask so much from me. Don’t tell her that, though!” In David’s experiences we see that his relationship with his wife had changed when he had his leg amputated. David’s example elucidates how having to care for someone who has gone through a life-changing process such as an amputation can change the social dynamics of relationships. The majority of our participants (42 out of 45) were adults when they experienced the loss of their limb. Where before, participants were independent, in the sense of being able to get up and do things for themselves, after amputation they had to rely on others to care for them. The loss of a limb meant that they now experienced physical limitations or an impairment. For instance, using the SRM, we are able to understand how people who acquire an impairment in adulthood are affected by their inability to take part in activities, such as household chores (as was the case for David). David was now living as a person with limb loss, this affected his physical mobility, and this was causing a social strain in the relationship between he and his wife. Now that David

was more mobile with his prosthesis, and able to do things around the house, his relationship with his wife was returning back to “normal.”

David explained that his daughter was the first to contact Pies Unidos, one of the organizations that works with LIMBS to provide people with low-cost prosthesis in Guadalajara, without telling him. He only found out about this once Dr. Hugo, the orthopedist for the organization, showed up to his house one day. “I didn’t know who they were and what they were there for. I thought they were going to assault me,” David exclaimed loudly. In fact, Dr. Hugo was there in order to measure David’s stump and to see if he was a good candidate for a prosthetic limb. Once David received the prosthesis, he felt as if he was born again. He jokingly declared that he had been in such a bad mood that the doctor who amputated his leg once told him that he had wanted to cut his other leg off. David stated that the doctor (who he became friends with) told him:

I see you totally different than how you looked when you first came into the hospital. I see you as a changed person. He jokingly told me, ‘I wanted to cut your other leg off. You were the worst patient, but I see that you are doing very well now.’

David had not seen this doctor in a while, so he laughed and jokingly exclaimed, “If he saw me now he would probably say, ‘I want to cut off the other one!’” David felt he was now so happy with his prosthesis that his former doctor would joke that David’s other leg should be amputated in order to bring him down. He continued to provide another example of how his emotions changed once he began to use his prosthesis. David shared:

And sometimes I get a feeling of pride, even though it’s a sin. I went to a reunion and they used to see me in a wheelchair, and when they saw me they said, ‘Wow! David, you can walk now!’ I can’t hide it, putting it on made me feel like I had been born again!  
*(Laughing)*

While David had once felt a deep sadness from losing his leg he now felt a sense of pride from being able to walk with his prosthesis. His attitude toward going out and interacting with people

were things that he now looked forward to taking part in, and it made him happy to hear others notice that he was once again cheerful. Having a prosthesis and being able to walk again brought David a sense of “rebirth” and it became something that gave light to the “emptiness” he spoke about in his interview. His impairment had resulted in the limitation of mobility and this had caused conflict in his family life. Now, as a prosthetic limb user he felt a sense of pride. This was visible and witnessed by the research team as we saw him walk out from his interview. He was happy to show off his prosthesis, something that very clearly now brought him joy.

### **Mateo**

Mateo, a 53-year-old man, was the first person to show up for an interview at Herramientas, the second of the two organizations in Guadalajara. As the team walked into the reception area of the building we introduced ourselves to the organization’s employees and saw Mateo quietly sitting in a chair. Each member of the team introduced themselves to him by shaking his hand and thanking him for joining us that morning. He stood up and introduced himself and then followed one of the team members to a private office in order to take part in the formal interview. Mateo was wearing what must have been his Sunday-best, a long-sleeved shirt, and a dark pair of pressed slacks. He had been using a prosthesis for one year. His crutches lay by his feet. He looked tired, low-energy with dark circles and bags under his eyes. As the interview began, he explained that he had been using his prosthesis for about a year and stated that it had caused positive change in his life. Still, despite the positive changes, he was going through a tough time. He shared that he had been struggling with depression since he was not able to take part in activities that he wanted to do as a result of his financial instability due to being unemployed. He had lost his job at a local factory due to having a physical disability.

Additionally, Mateo had recently separated from his wife and his grown children did not visit him. He shared:

I have two married daughters but they live far from me. As I was saying, my wife left to not return. Before, I was well off financially, I earned well, we went out, I went out with my wife. And then when this happened to me, I noticed that when she took me to the hospital and all that, she complained a lot. That it was very complicated. That the chair was very heavy, that I was too heavy. And I didn't know anything about that. It occurred to her to tell a sister of mine and my sister told me about. I never told her anything, until once I told her, 'if you don't want to be with me then go ahead, make your own life. I will not be able to give you what you want, what I gave you when I was well.' And then she decided. She decided to leave the house.

Mateo explained that he was alone. There was a moment of silence as the interviewer tried to move forward while thinking about what it meant for the person in front of them feeling this way. With a sigh as an acknowledgement of Mateo's situation the interviewer took a moment before continuing then asked Mateo to recount the ways in which the prosthesis had changed his life. Mateo shared the following story:

It [the prosthetic limb] totally changes your life, I was in a wheelchair for almost two years and well, just being there in your room looking through your window, and without being able to go out because of not having anyone to take me. When I received the prosthesis, well, little by little, I tell you, *me fui animando* (gained a feeling of confidence and felt encouraged) ... little by little, I go walking a block, two blocks and things like that. Now, every morning, I tell you, I go out and walk, even if it's for half an hour, around my house. I get little cuts and bruises from the socket, but I still do my exercises... Anyhow, now that I have the prosthesis, that raised my self-esteem. Not to 100%, but now I have been able to do things for myself. To the social security offices, to go the doctors, things like that. Without anyone having to push me in a wheelchair. For that, I give thanks to God for this prosthesis.

Mateo explained that he felt as though his life had stalled for two years while he spent most of his time in a wheelchair. This was a very isolating time in his life. It did not help that his living situation during that time did not allow for him to freely move around the home or even in the neighborhood. Once he had his prosthetic limb he began to feel, little by little, that his confidence began to rise, and he started going outside to take walks around the neighborhood.

Unfortunately, his socket was causing some discomfort with minor cuts and bruising occurring on his stump as a result of a poor fit, but this did not stop him from wearing his prosthesis. He had begun to try and figure out ways in which he could address this issue. Mateo began to cover his stump in layers of socks in order to protect his stump and have a better fit when wearing his prosthesis. He exclaimed, “When I fill cover my stump with socks and walk, you can’t even tell that I have a prosthesis.” Mateo was no longer isolating himself from the outside world. He was feeling capable of walking in his community and had gained a boost in self-esteem because of his new-found independence.

### **Ramón**

Ramón, a 30-year-old man from Oaxaca, had traveled 6-7 hours via public transportation in order to arrive at the interview. He was very sociable and had a contagious smile. He showed up in shorts and a t-shirt, exposing both of his prosthetic limbs. He let us know that both of his legs were amputated when he was 11 months old. His family had proven to be a supportive network. He reported using prosthesis for two years. Prior to receiving his prostheses, he had lived his whole life without any use of an ambulatory device and, as a result, had learned to walk on his knees. While many believed he would have difficulty learning to walk with both prostheses he had, in fact, quickly learned how to walk with them. He recalled, “I picked it up fast. I wanted to learn how to do it and I set myself to learn.” With this in mind, he began his life as a prosthetic limb user at the age of twenty-eight. Ramón came from a community outside of Oaxaca City and said was small in population size where, “almost everyone knows everyone.”

Ramón spoke positively about his experiences of living as an amputee; this may have partly been because, as he explained, “my family has been very supportive of me.” Like Darío, he was the only other respondent that had his lower limbs amputated as a baby. Ramón shared

that throughout his life his family had been very supportive. This was interesting because many of the respondents that we interviewed had gone through a period where their families felt the strain of having to care for someone who had acquired a disability. It may have been that because Ramón had lived a longer period of time as an amputee and because his identity was that of a person living with the loss of his limbs that this may have impacted his family's supportive actions. His family had a longer time to "get used to" having to care for someone who had been amputated as a baby. Ramón learned to move around by walking on his knees and, with time, this came as a way of adapting to his life. He spoke about how he noticed a major change after the introduction of the prostheses into his life. He told us during the interview, "now I can get somewhere faster, I go out more often and, I tell you, I can do things that I wasn't able to do before." He went on to explain:

Yes, it benefited me a lot, like I was telling you, I've done new things like drive a motorcycle and dance. And yes, the truth is that I feel very happy. I go out to the street and the people are surprised that I don't use crutches. I could put on pants so that my prostheses aren't noticed, but I don't so that they can see. In life, if you want to do something, you do it.

Ramón's social experiences had grown exponentially since receiving his prosthetic limbs. He took part in social events that he did not have experience with before he was a prosthetic limb user. Indeed, he was able to socially interact with others in ways he had not been able to before. Much like the social rituals that Murray (2005) spoke of, dancing is one of them. It serves a function of social interaction and relationship building/reinforcement. The act of dancing is social in nature. Here, Ramón is having an experience that he did not have before with able-bodied people. He is integrating into a group of people performing a social act. He is performing as a social being in a process of integration into a greater community (Goffman 1959).



Experiences, like those that can come easily to able-bodied individuals, like walking, dancing, or being able to stand were important to our respondents. In some cases, it made them feel “normal” when they were able to take part in these actions. As noted by Murray (2005), prosthetic limbs serve social functions when it comes to social integration by allowing individuals the opportunity to perform as able-bodied people. We can see that these physical functions also have social implications. In the case of all three respondents, being able to walk on their own two feet again elicited a social response by those around them. Words of encouragement and admiration were offered to them for presenting themselves as prosthetic limb users (Murray 2005). Unlike the participants in Murray’s (2005) research who concealed their prosthesis through the use of clothing, “masterful” use of the prosthesis, and “passing” as not having a prosthetic limb, Ramón and David did the opposite of this. They actively chose to not conceal their prosthetic limbs, though they probably could “pass” as able-bodied people. Instead, they decided not to do this and took pride in their prosthetic limbs and in the experiences that these afforded them. In this way, they created a different meaning of the prosthesis compared to the participants in Murray’s study. Ramón and David used their prostheses as a way of receiving social admiration and felt empowered in their identity as prosthetic limb users.

Living with a physical impairment limited people’s ability to do things such as being able to walk. The people in this study regained the ability to stand and walk with the use of a prosthetic limb and found themselves doing things they had stopped doing since their amputation. This is something shared by all participants. The prosthetic limb gave them a sense of independence and provided an “uplifting” effect on their self-esteem. I observed and heard from participants that the prosthesis served as a device that facilitated social interactions. Overall, I learned from people’s narratives that the prosthesis functioned as a source of social

inclusion and re-integration as people identified as having a disability and as users of prosthetic limbs.

### **SOCIAL COHESION AND SUPPORT: LUCERO, LUIS, AND MATEO**

The social context and networks that individuals had were also important in the lives of participants. Social groups that offered support were seen as points of strength and necessary for people throughout the study. For individuals that were alone, they stressed how sad and depressed that they felt and this was mostly due to living in isolation. Individuals who were part of a family unit had their support. But, as previously mentioned, there were also stresses and points of pressure that occurred in these units. Outside of the family unit, people were searching for and were involved in groups that offered support and solidarity through a common identity-- the identity of being a person with a disability. In the following sections, examples of what these groups were like and the type of functions that they served for people will be discussed through the experiences of Lucero, Luis and Mateo.

#### **Lucero**

Our visit with Herramientas introduced us to Lucero, a 57-year-old woman, whose leg had been amputated at the age of 15 as the result of a tumor located on her tibia. She reported using a prosthesis for one year. She had grown up in a small rural town and her family had little to no resources available to care for her leg. Her family had tried to care for her tumor with home remedies (peanut based ointments), but these proved to be unsuccessful. One night she was rushed to the hospital because, as she recounted, she woke up, “with blood all around me. My bed sheets were entirely soaked in blood. I couldn’t scream, but was able to call my mother. I passed out and woke up at the hospital.” She had developed an infection as a result of the ointment and this led to the amputation of her leg. This did not stop Lucero from moving on with

her life. As soon as she was old enough, she decided to move away from home in order to continue her education and seek better employment opportunities. She was also one of the participants who had lived the longest with limb loss.

Lucero explained that she had recently received her prosthetic limb from Herramientas. She was having a difficult time walking with it because her socket was a poor fit, but she was still managing to get around. Lucero was someone that showed perseverance in any situation. She recounted a recent experience that was tied to her disability and use of a prosthesis. Lucero explained that during an interview for a job she was required by the hiring supervisor to pull down her pants and expose her prosthesis. This made her feel horrible, but she stayed at the interview in hopes of being hired for the job. She was ultimately not hired by the company, but had received another job in a factory that made brake pads for cars.

Lucero took part in a number of social activities. In fact, her partner, who joined her at Herramientas, cheered her on every step of the way when it came to these activities. Lucero had been playing wheelchair basketball as part of a local sports team for a number of years, and this social function was something she enjoyed. She shared how participation in this group provided more than a physical routine:

Yes, like I was telling you, I have made friends and have a group that I get together with to play sports. We all have physical disabilities and we play basketball, we play it in wheelchairs. We get together and talk about our experiences, people that have more time with being an amputee, and people who have recently been amputated. We share our experiences and show each other things that we might not know about getting around with a prosthetic limb and offer information to those who don't have one. It's nice. It's like having another family.

The group that Lucero belonged to offered a system of support that she had not experienced before. It was made up of individuals that could relate to each other and work toward a common goal of having fun and relieving pressure. Having a community of people that she could share

her experiences with and people she considered her “family” was important to her. She, along with other participants, found that having a network of support was beneficial to their wellbeing. In participating in a sport like basketball, she was working with a group of individuals in a social activity that built relationships. After her (over) two-hour interview was complete, Lucero and the interviewer walked out to the reception area of Herramientas. Lucero’s face turned red as she saw that her partner was showing the rest of the people in the waiting room pictures that he had taken of her and her basketball team. She was visibly embarrassed at this, but humored her partner through the whole ordeal. She even humored him as he took a picture of the interviewer and herself posing together in order to chronicle the interview experience.

Lucero had a network of friends that she considered to be part of her family. They all shared the identity of having a physical disability. Having a space and people that share a common experience, provided Lucero a sense of solidarity with this group. They all shared a collective identity and, as such, this served as a way to bond with each other. In playing a group sport like basketball, they were interacting and working together as a team. In this way, Lucero was experiencing the benefits of working in a team and sharing a common identity with others. Lucero’s story is unique because she is the only participant in the study that took part in a sports group comprised of people with physical disabilities. In the following stories, I focus on other social institutions and networks that offered supportive systems that participants took part in.

### **Luis**

Luis, a 60-year-old man, lost his leg in a car accident in 2016 and had been using a prosthesis for one year. He came into Alas, based in Mexico City, with a smile from ear to ear. He shared with his interviewer that he was present when the earthquake hit Mexico City on September 19, 2017. In fact, his house was considered condemned due to the ceiling caving in,

but he and his family were still living in it because they did not have the means to move elsewhere. He and his wife were a big part of Alas. In fact, Luis was considered a great asset by the pastor of Alas, church goers, and other members of the community who had lost a limb. The church functioned as a greater support system that allowed for social cohesion (Durkheim 1995) among church goers as they saw each other as “brothers and sisters” in Christ. As noted by Durkheim (1995), religion does serve a function of social cohesion and reaffirmation of the “collective consciousness.” It is rooted in the social world and the church worked as a context to these interactions, but as the pastor noted, people were not required to participate in the church in order to receive a prosthetic limb.

Alas dedicated specific evenings out of the week in order to provide physical therapy for prosthetic limb recipients. Therapies were not focused as times to speak about religion. The pastor stated that they did not want to talk to people about religion during that time. Alas only wanted to provide a space for amputees to speak about their experiences and learn physical therapy techniques. These therapy sessions were specifically for people that had received a prosthetic limb from LIMBS. In fact, LIMBS had worked with people that wanted to assist people through the rehabilitation process. Individuals at these therapy sessions were not certified therapists, but had information and experience to share with prosthetic limb users. Luis was one of the few people that had received extensive physical therapy elsewhere and now offered to be present at therapy sessions in order to provide his knowledge of navigating life with a prosthesis. He even surprised me by showing me why he was such an asset to others:

I have been going to support groups and come here sometimes to show people how to fall and get up after. Look (lies on ground and throws crutches on the ground). I grab one crutch and can pull myself back on my feet...

Luis continued:

I try to talk to people and let them know what I know about getting around with my prosthesis and how to take care of the cuts that you might get from the socket. I would have liked for someone to tell me those things when I was barely starting off and I think that it helps people when we have someone that is going through something similar.

Rehabilitation services were often not something that participants had the opportunity to attend.

These services were often either located far from home or too expensive and unaffordable for the majority of the people in our study. For this reason, Luis was the kind of resource or “physical therapist” that many would have wanted to have as they learned to walk with a prosthesis. It was apparent that it was not only other members of Alas who benefited from Luis’s knowledge, but that he also profited from the social interactions. Luis kept busy by interacting with others and teaching them what he wished he had learned early on about walking with a prosthetic limb.

Even in difficult situations such as his, he was still offering to be there for people and share his knowledge. These experiences resulted in the creation of friendships and having a social group that he was able to interact with even when not related to prosthetic limb talk.

### **Mateo**

Through our interview with Mateo we learned that support group opportunities are offered by the government, however these are provided only to people over 60 years of age. Because of this, Mateo, 53 years of age, had searched for a support group online. One day he stumbled upon a group on Facebook that was made up of people located in México. That is not to say that there are not groups online that do not have an international network, social media facilitates this kind of interaction with people from around the world, but Mateo had specifically noted that this group was based in México. This group, in particular, was not only made up of prosthetic limb users, but consisted of people experiencing different disabilities. In fact, Mateo had built a close friendship with a man in the group named Alex, who was blind. Alex became a great source of social support for Mateo.

The Facebook group became a social experience that allowed him to communicate with people who he otherwise would not come into contact with. Mateo found that the *testimonios* (testimonies) offered by members of the online group related to people moving forward when it came to living with a disability and this was of particular interest to him. He states, “Yes, they try to encourage you and, let’s say, more than anything, they tell you that your life won’t be the same, but you are going to learn and go back to the things you normally used to do.” He found that people like Alex often reminded him of how fortunate he was when it came to his disability and that having a prosthesis allowed him a new lease on life. Alex would remind Mateo that there were people in the group that did not have either of their arms, for example, and that for that reason, he “was in heaven” compared to other members of the group. In fact, Alex, who was blind often compared some of his own challenges to those of Mateo’s.

Being a part of the group was something that Mateo was grateful for and he felt as though he tried to gather all the good that came from the people in the group, including any good advice offered by others. Unfortunately, Alex had passed away three months prior to our interview with Mateo. Before his death, Mateo and Alex were going to begin a project of their own that would revolve around the two sharing their own life testimonios in order to help others. This project was now placed on hold as a result of Alex’s passing, and Mateo was not sure if he would be continuing on with it. Alex’s death weighed heavy on Mateo. Still, the Facebook group remained a source of support for him.

In the case of Mateo, during his time of starting a new chapter in his life as being a person that has experienced limb loss, he sought out a community that understood his experiences as someone with a disability. This community offered the social structure that he lacked in his everyday life. Without the support of his family, he searched for another source of

acceptance and encouragement during periods of difficult times. The online group also provided a venue where he could share his successes and progress as he became a prosthetic limb user. The prosthesis was functioning as a topic of conversation that allowed him to integrate into a community that was new to him. In this way, the prosthesis served a social function that connected him to people that he otherwise would not have been connected with and now served as a central component of this social experience as it did for others.

These participants' stories offer insight into the importance of social groups and support networks in the process of healing, wellbeing, shared identity with people that are also disabled, and becoming a prosthetic limb user. People that had become disabled later in their lives were in need of a support network because of their change of social identity. The majority of people were looking for people that they were able to share their experiences with and support them in the process of learning to use a prosthesis.

#### **SOCIAL STRESSORS, BLAME, AND BARRIERS: HERNANDO, PEPE, AND KARLA**

As identified in previous participants' life stories, there are social stressors, pressure and barriers that individuals who have experienced limb loss have to consider and face on a daily basis. Limb loss is something that is not only felt by the individual, it also has a ripple effect and impacts people's close social groups (e.g. friends, family, etc.). Along with having to live with the effects of their impairments (physical limitations, pain, etc.) our participants also had to deal with the consequences of what it meant to have a physical disability. Participants were impacted by the unsuccessful procurement of jobs, the inability to economically sustain their families, having to deal with other illnesses, and facing the stress/pressure of "mastering" the prosthesis quickly. The following set of participants' stories elucidate these processes.



## **Hernando**

On our last days in Guadalajara, I met Hernando a 62-year-old man with a prosthesis for two years. He wore a green shirt and black pants. He was a shorter man that had a stern look on his face. He sat in the waiting room of Pies Unidos with his wife and older son. I introduced myself to him and his family. His wife was extremely nice. She had blonde hair and had very light skin complexion. His son was much taller than his father and was preoccupied with talking to other people in the waiting room of the clinic. After introductions were made, Hernando and I made our way to a vacant office space to begin our interview. We began our conversation with the progress that the Mexican team had been making in the World Cup. Hernando commented, “if they don’t keep the pressure and work together as a team, we won’t make it.”

During our opening questions, Hernando told me that he had his leg amputated because of an accident that he had on a job site. He had been working on a loading dock on the coast of México and was in charge of making sure that the boats were unhinged from shore, guiding ships to dock, and aiding in loading shipping containers onto the ships. He was in charge of a small crew that helped him in this process. He had recently hired a new employee, “I felt bad for him and gave him a shot.” One day when a ship was preparing to leave the port, Hernando had noticed that the ship was still tied to the port. It was the job of the new guy to make sure that all the lines were disconnected. The ship captain was not aware that this was the case as the ship continued to back out. Hernando then rushed over and tried to remove the tie, but as he was trying to remove it, the tension of the line being tugged by the ship caught his leg against a low wall. He said that he passed out from the pain of having his leg crushed between a wall and this metal braided line. When he came to, he noticed that his leg was crushed and that a helicopter

was coming to lift him off to a hospital. His leg had been nearly severed and required amputation. Luckily, people had been able to control the bleeding, but his leg had been lost.

He was now unemployed and as our conversation progressed, he told me that his wife in the waiting room had recently been diagnosed with cancer and was currently going through radiation therapy. He was unable to financially support his family and the cost of healthcare for his wife was growing. He said that the problem was that he was “un-hirable” in a lot of ways. He commented, “I am an older man. They won’t hire me because I am older and now even less that I am disabled.” He was the main breadwinner in his family and now his wife had to work a part-time job to help with expenses. This really weighed heavy on his mind and was a major stress in his life. He was aware of the added discrimination that he would face for being a person with a disability in an able-bodied valuing society, and knew that this impacted his ability to be hired or regain his position as primary breadwinner for the family. This was a sentiment that was held by a majority of the respondents, especially those who were older men.

His son, who was born with a developmental delay, also worried him. His son was in his late twenties and was dependent on both his parents. With his wife sick and he having lost a limb, Hernando was worried about the future of his son. He reminisced about spending time with him. The following quote is of a job he previously had as a delivery man for a famous bread company in México. His son always brought the company up in conversations with him:

He used to go with me to work. He enjoyed being in the truck with me and putting the bread on the stands in the stores. He loved it. To him, that was his favorite time. Every time we pass by the company he says, ‘Daddy, that’s where you work!’ I have to tell him that I don’t work there anymore.

Hernando was active in his son’s life. He was also trying to regain his mobility to do things that they used to do, like go to the park and exercise. He wants to do things that he used to before he had his leg amputated. Something like taking his son to the park and work out where things that

he looked forward to doing again. He states, “that *cabron* [sic] has gotten lazy. He thinks that just because I am not working and can’t walk properly with the prosthesis yet that he can do what he wants and slack off. Just wait, he is going to pay (*Laughs*).”

The prosthetic limb was giving people hope for the future and regaining what social interactions they had lost. For those who had not “mastered” the use of the prosthesis, their focus was that it would give them the mobility that they used to have and all that comes along with that mobility. Some of the common reasons was that they wanted to be able to economically sustain themselves and their families and be able to have experiences that they used to have before they had been amputated.

### **Pepe**

Pepe, a 64-year-old man, walked into the waiting room using a cane and wore a polo shirt with black slacks. He had to have his leg amputated due to complications of an infection, and had been with a prosthesis for one year when we met. He was a very serious man in both his tone and his demeanor. He was tall and slender and had perfect posture. I introduced myself to him and noticed that his handshake was extremely firm. He settled into his chair and made it seem as if he was pressed for time and wanted to get the interview out of the way. He went quickly through the questions, responded promptly, and did not really want to elaborate on much. As the interview began, he told me that he was a manager for one of the local football clubs in Guadalajara before his amputation. That was his last place of employment and he had not been working since he was “let off” from his work. He shared that his employers had advised him to retire:

At work it really affected me because they [previous employers] no longer wanted to give me work. I wanted and expected to work up until I was 65. But, this happened to me and at my job they started to give a lot of excuses that the insurance and this and all that.

Because it is not really an inclusive company... excuses, excuses... I feel like I can still work, but with certain limits.

Pepe was explaining a process that many individuals had been facing when it came to their place of employment and when being able to procure a job. Similar to Hernando, he was aware of the discriminating impact that people with disabilities experience when it comes to employment opportunities. It is not like individuals get less expenses when they are amputated. With a diabetes diagnosis, socket costs, and other medical costs, economic instability seemed to be an unfortunate reality for these participants.

As our conversation developed, the topic of diabetes, a disease that was the main reason for leg amputation among respondents, was raised. Pepe spoke of the feeling of blame that many individuals felt about their health situation:

We are the only ones at fault for not taking care of ourselves... we can't blame anyone else. *Ay*, 'I got this disease [diabetes] because no one took care of me.' No, we should take care of ourselves. How long have you tried taking care of yourself? Those are the questions we must ask ourselves. One is always at fault. We didn't take care of ourselves [*nos descuidamos*].

The blaming of having a disease, diabetes in this case, was, for the most part, understood at the individual level. That is to say that participants often expressed that their diabetes was a consequence of having poor eating habits (e.g. high sugar, high fat foods) or because they just did not take enough care of themselves (Liu et al. 2017). Since this was also the main cause of leg amputations for our participants, they often blamed themselves for their disability. This was a heavy burden that they placed on themselves.

As the interview with Pepe began to wrap up I found that he had completely changed his demeanor and was a little bit more open when sharing his experiences. One of his concluding remarks was "Yes, and also more than anything, you are the only person that I have had this kind of conversation with.... One day I felt like I would be complete for life, but no." Pepe, along

with others, had taken the route of “avoidance” as a way to cope with their life as a person with a disability (Gallagher and MacLachlan 1999). For instance, whenever someone wanted to talk to Pepe (his family for example) everything was fine, “I’m fine.” Adding this burden of blame when it came to his diabetes and the role it had in exacerbating the infection to his leg, may have made it difficult to engage with others about what he was feeling and experiencing on a daily basis. The stigma that people felt and the blame that they had to carry were all intersecting and creating an experience of both disability and illness.

### **Karla**

The final participant that I would like to focus on is Karla. Karla, a 38-year-old woman from Mexico City, had a tumor that required her leg to be amputated and has been on a prosthesis just recently. She came into the church with her husband, son, and daughter and were warmly welcomed by the pastor at Alas and his family. We settled into our seats and she was curious about how long we had been in the city. I responded that this was our second and last day in Mexico City. As our conversation progressed she told me that she really did not want a prosthetic limb. Out of all the people that we interviewed, she was the only participant that did not want a prosthetic limb. Going into this revelation, she was not particularly interested in receiving a prosthetic limb and it was her family who pushed her to get one. She said that she recalls having a conversation with one of her children and that the child was getting emotional about Karla’s life and her having to live with the loss of a limb. Karla shared:

He came to me [son] and was upset and crying. He was scared about what people would think and say about me when they saw me without my leg. I told him, “look son, I am your mother, nothing will change that. I am more than a leg. Don’t you worry about what people think about me. I love you and you love me. Let people think and say what they want.”

Her story was unique from that of other participants. After revealing this information, she also told me that she received psychological/counseling therapy before and after her amputation. She was one of the few participants that also spoke about receiving this type of therapy. This was the biggest difference from the people that were interviewed as a part of this research project.

Karla's experience with attending counseling services seemed to assist her "adaptation" to living with a disability.

Karla shared what it was like to attend counseling therapy (from a psychologist) for more than a month regarding her limb loss. She told me the following:

The psychologist told me about things that I would be feeling. It helped me to have a professional explain to me what I would be going through. The changes in feelings, emotions, and all that were things that I was feeling. She (psychologist) helped me a lot and I think that it also helped my family to know that everything was going to be okay. She told me to look at myself in the mirror and remind myself that I am still me, I am still a mother, a wife, a daughter, but I have lost my leg.

This experience was unique, Karla had only received her prosthesis earlier that year and did not even want it to begin with. Her family was pushing her to get one. Her child was worried about the social implications and stigma that his mother would have to endure as a person living with limb loss. For him, the limb was a step to being perceived as "normal," but she had accepted that she had lost a limb and was okay with living as an amputee and not using a prosthesis. Social pressures from the family unit had pushed her into getting the prosthesis and becoming a prosthetic limb user. The medical model stresses the need to remedy ailments and impairments. As socialized individuals, we feel those societal pressures to conform and seek these resources. This can be seen in the case of Karla's experience with limb loss. Further, I think that it is important to note that counseling services often costs money and, as a result, were not available to all participants in our study. We saw that with time people seemed to adapt to their situations,

but wonder if their experiences as amputees would have been eased with having attended counseling services if they had been available.

The stories of Hernando, Pepe and Karla shed light on some of the issues of stress, social barriers, blame, and pressures felt by prosthetic limb users in this study. As people with a disability, opportunities were constrained when it came to procuring employment. The impact of this weighed heavily on participants and on their families. Issues of discrimination based on their identity as a person with a disability were commonly brought up as reasons for not being hired, or re-hired, and when being “asked” to retire. People also often dealt with feelings of blame. This was particularly the case for those living with diabetes. They often felt as though they were living with the consequences of not taking care of themselves as well as the added stigma of an amputation. Furthermore, prosthetic limb users felt a pressure to get some sort of device that assisted their mobility (e.g., prosthetic limb). This was often seen as a benefit for people, but it also was something that would benefit their greater social network because there would be less strain of having to care for them. There was also, at times, a feeling to “pass” as an able-bodied person. These social situations were important and stressful for participants and created layering impacts on participants.

## **Study Limitations**

Similar to other social science research, this study had a number of limitations. In terms of generalizability, we only spoke to people who had received a limb through LIMBS. The main disadvantage of qualitative method approaches is that the findings cannot be extended to wider populations with the same degree of certainty that quantitative analysis can. However, generalizability was not the purpose of this study. Instead, we were interested in learning more about the everyday experiences of people that had experienced the loss of a limb and learning how receiving a prosthesis through LIMBS had impacted them. We end up learning that living with a prosthesis was a process of learning how to walk with it as well as having to navigate different physical and social environments as someone who was living with a disability.

It is important to note that our participants' experiences may have been different than that of others who may have received a limb elsewhere or had resources to purchase a "better" prosthetic limb. This study is made up of a convenience sample of participants that were affiliated with a non-profit organization, so we do not know what differences we may have found as a result of that. Also, we were only able to interview people who had received a prosthesis or who were waiting to receive one. With this in mind, it would have been beneficial to expand our sample in order to include people that were not good candidates for a prosthetic limb. What could we have learned from their experiences as people that had lost a limb, but would not be receiving a prosthesis? Our sample of women was also small, so it would have been beneficial to speak with more women in order to get a better sense of their gendered experiences regarding the functionality of the prosthesis. A comparative analysis between men and women may have revealed a difference in experience.



This study was conducted over a two-week period. The research team had to build rapport with participants quickly, just moments leading up to the interview. It would have been good to have more time with participants and being able to interact with them in the environments they navigate as a part of their everyday lives. Also, having a research team that consisted of researchers with differing levels of experience in social research may have influenced the interaction between researcher and participant. Thus, influencing the responses collected for this project. As far as the limitations when conveying the findings of the research, while I only share the stories of 10 participants I decided to present my data in this fashion in order to provide readers with a glimpse of what it was like to sit with someone and conduct an interview. Even though we only had a short amount of time to conduct these interviews, I think that what our participants shared provided an honest insight into their lives. We found that people's experiences were similar as they dealt with the initial loss of a limb (amputation), the processes of adapting to this experience, dealing with the responses of others (family, friends, strangers), and navigating their everyday social and physical environments. Finally, there was only one person (the author) coding the data. It would have been beneficial to have multiple coders for the same data in order to pick up any nuances that I may have missed while coding.

## Discussion

In the analysis of interviews, participants usually brought up the discussion of having to navigate their daily lives as a way of speaking about the poor accessibility of their physical environments. Common themes of discussion were the poor state of infrastructure, accessibility of spaces, the use of public transportation, and the added stress of having to navigate highly crowded, motorized spaces. Interesting differences that occurred in these discussions with participants were the ways in which experiences of using a prosthesis were different depending on where the individual lived (rural vs. urban). As noted earlier, people that lived in rural Oaxaca noted that the prosthesis was beneficial to them in navigating a much different terrain than what is found in urban spaces. There are fewer paved roads, mountainous landscapes, and a much more “natural” environment than that of an urban space. The prosthesis allowed for people to walk in fields and work more freely (with both hands). In these cases, the prosthetic limb was serving a function of aiding in mobility, but the extended functions were that it allowed them to work and engage in social spaces with more ease.

Urban spaces had “better” paved roads, sidewalks, and more options of commuting through public transportation. Though, as noted by individuals, accessibility of the built infrastructure was not the greatest. Falling, having a fear of crossing streets, impatient motorists, and deteriorating infrastructure were all common topics of conversation. But, at the same time, having these options allowed for greater choice of what ambulatory devices people decided to use as a form of assistance while navigating different environments.

Without having access to certain spaces, in a way, participants felt the additional exacerbating effects of having a disability due to the loss of a limb (Shakespeare 2004); however, they found ways of trying to navigate different spaces as people with a physical disability. The

social implications of not having access to spaces can impact the amount of socializing that people have, the type of participation, and the ability to procure jobs (Gray, Gould, and Bickenbach 2003; Iezzoni, Killen, and O'Day 2006; Botticello, Rohrbach, and Cobbold 2014).

After considering the greater social context that participants had to navigate along with being prosthetic limb users, we can see the importance that certain social support systems have in the feeling of social cohesion and overall wellbeing for these individuals. In the case of participants who were part of a church, they already had a system of support in place, if they wished to use it. Sharing their experiences with others and receiving knowledge and support aided in the process of achieving the functionality of the prosthetic limb. That is to say, in having a connection to a greater community they felt better about their outlook and ultimate goal of mastering the use of a prosthetic limb.

The importance of a social group is reflected even in those participants that did not necessarily have a group of support connected to the church. Lucero was able to feel this sense of belonging with her group of people that lived with limb loss. They all shared a common experience of limb loss and were coming together to play sports (basketball). Here, the prosthesis did not really function as the root of social interaction and integration. Rather, a common held identity was the source and this created a sense of group solidarity. People in this study did stress that they wished to have greater contact with people that were experiencing similar situations as they were. These individuals had a support system that provided them with the opportunity to come together. Mateo felt the same with his online support group even when his family had abandoned him. He still had the drive to want to progress and document that journey.

In our research project we had individuals who had been living as a person that had experienced limb loss for a longer amount of time than others. Nine people in this study had been

living with limb loss for more than 10 years. In the case of two individuals, they had been amputees since they were babies. Having lived longer with the social identity of being a person with a disability may have influenced their experiences within social groups. Adapting to a new social identity happens over time, and in the case of many people in this study, not “enough” time had passed for them to adapt to this identity. Likewise, their families and friends also needed time to process participants' new identity as a person with a disability (Amiot et al. 2010).

This stresses the importance of the social in the process of becoming a person with a disability. In the case of the emotional impact of receiving a prosthesis, the majority of the participants in this study had a change in experiences once they had access to the prosthetic limb and became prosthetic limb users. The prosthesis brought a positive change into the lives of those who have experienced limb loss. In agreement with Webster et al. (2012), participants who were using their prostheses were less likely to have depressive episodes. Participants spoke about how the prosthesis brought a positive light to their life, but for those who did not have a prosthesis in their life or had lived without a prosthesis for a while, they seemed to have been managing just fine. It seems as if the prosthetic limb was having more of an impact on those who were “new” to living as an amputee.

The “in-between” period that Norlyk et al. (2016) researched was apparent in the case of the participants in my study. There was a severance in the lives of people when they were amputated and receiving their prosthesis. Some saw it as a state of “emptiness” while others were in dark period of depression. During this period, participants “lost” their former life as a person without a disability and now had to “re-conquer” their life as a prosthetic limb user. The “in-between” period that Norlyk et al. (2016) studied, where the individual lives in a state of

“standby,” was clearly felt by those who were still trying to learn to be a prosthetic limb user. Some people were in the process of “mastering” the use of the prosthetic limb and this may have been the reason as to why they were still experiencing issues related to sadness and depression. Along with the loss of limb due to complications from diabetes, as described by Coffey et al. (2009), the loss of a limb through a chronic illness, like diabetes, is followed by periods of depressive episodes. Our findings show that people still stress the importance of following up with them after receiving their prostheses. Issues of blame and stigma were common ideas that participants had and, for this reason, they may have been able to benefit from emotional support services.

An interesting finding of this study was the sense of pride that people felt in having a prosthesis. In the case of Murray (2005), participants were trying to pass as someone who did not have a prosthetic limb. These participants would use clothing and the “mastering” of the prosthesis as a way of concealing the loss of a limb. In my work, I find that some participants were empowered by exposing their prosthesis and looked forward to the responses by members of the community. The opportunity to expose their prosthesis served as a point of empowerment. This may be attributed to the limited access to prosthetic technology for those seeking them. Similar to Bigelow et al. (2004), having the economic means to purchase a prosthetic limb was out of reach for most of the participants. Among the participants that were employed and chose to share their income the average annual salary was \$44,408 pesos. This roughly translates to \$2,300 U.S. dollars. These economic situations are important to address as some of the most prevalent issues affecting people living in countries in the global South. People’s income is supposed to cover the cost of living expenses including rent, food, utilities and any other costs that happen throughout a year. Without having access to a low-cost prosthetic limb, many of the

participants of this study would have not been able to afford a prosthesis in the first place. The uncertainty of the replacement of prostheses was an important topic that individuals wanted to address. Some people were just happy to have something and this may have led to the pride that people reported. As documented in field notes, and in informal conversations, there were many people who had a disability (specifically physical disabilities) that were on corners asking for money and prostheses are technologies that do have a cost to them. Respondents were “*en la gloria,*” as stated by Mateo compared to other people.

Therefore, the pride that participants had about their prosthetic limbs and the want to show it to others could derive from this. To be able to have access to a prosthetic limb could be a source of empowerment that they wish to show to others in their community, especially since it is something that not all people with amputated limbs have access to.

The SRM of disability allows us to recognize the impact that living with an impairment had in the lives of the participants. The physical impairment of losing a limb limited access to places and the ability to do certain things that people were able to do prior to amputation. The use of a prosthesis also had its own effects on individuals as they dealt with pain, cuts, bruising, swelling, to name a few, that occur to the stump through use of a prosthesis. This separation of life before limb loss, post-limb loss, before receiving a prosthesis, and post-prosthesis is apparent in the previous cases. While still being able to see the social construction of disability, the SRM of disability is rooted in understanding the experiences of the impairment and disability through the narrative of the individual. The lived experiences of the participants are the center of this study and their stories are used as a way to view the collective experiences of living with limb loss and as a prosthetic limb user in México.

## **Conclusion**

It is important not only for sociological studies, but for rehabilitative science and other disciplines to study and expand the conversation on the functionalities of prosthetic limbs for those who seek and use them. Through the Social Relational Model of Disability, we can gain an understanding of the experience of living with an impairment and the effect that the social construction of disability has on the life experiences of people with them. I still sit and reflect on some of the conversations I had with people in México. I met such beautiful people that were going through such difficult situations and wondered if they would ever receive the help they asked for and required when it came to medical and psychological help. I would like to think that these services were provided to them. The reality is sometimes starker.

With the limited social science literature on the subject of physical disability (Lucas et al. 2018) and the experiences of people living with disabilities in the global South (Connell 2011; Meekosha 2011), this study shows the importance of continuing this kind of work. Where there are the most individuals with disabilities and most vulnerable to their effects, there is the least amount of research examining the lived-experiences of people with disabilities. In reflection, most of these individuals would not have had access to a prosthetic limb without the service of the non-profit sector (Bigelow et. al. 2004). If these organizations were not available to the participants in my study, these people may not have had access to a prosthesis. As a result, this may have limited their life chances and opportunities. Many of the people in this study had not had enough time to learn how to walk with the limb “independently,” but they were reaching different sets of milestones and goals every day.

In the end, people’s independence meant an ability to regain employment, the ability to financially support themselves and their family, and offered hope for their future. Many of them

mentioned that there is a lack of understanding and *cultura* by society about disabilities and that people in society should learn to be open about all abilities. This study is an attempt to inform and fill that gap.



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## Appendix

TABLE 1: CAUSES OF AMPUTATION

	Frequency	Percent
Trauma	16	35.6%
Birth	2	4.4%
Diabetes	17	37.8%
Other Illness	3	6.7%
Infection	7	15.6%

TABLE 2: PARTICIPANT DEMOGRAPHICS

Participants	Sex	Age	Income (Pesos)	Location	Marital Status	Education
Kevin	M	64	52,000	Oaxaca	Married	Elementary School
María	F	51	52,000	Oaxaca	Married	Elementary School
Martin	M	41	90,000	Oaxaca	Married	Middle School
Ramón	M	30	Not provided	Oaxaca	Single	High School
Antonio	M	68	36,000	Oaxaca	Union Libre	Elementary
Darío	M	20	Unemployed	Oaxaca	Single	High School
Juan	M	39	14,000	Oaxaca	Married	Middle School
Joan	M	61	24,000	Oaxaca	Single	Elementary
Rafael	M	35	Unemployed	Oaxaca	Single	High School
Oscar	M	66	14,400	Oaxaca	Union Libre	Middle School
Arturo	M	41	Unemployed	Guadalajara	Married	Elementary School
Augusto	M	65	Unemployed	Guadalajara	Married	Elementary School
Irving	M	23	36,000	Guadalajara	Single	College
Jacobo	M	39	60,000	Guadalajara	Married	No formal schooling
Jeremías	M	60	36,000	Guadalajara	Widowed	Elementary School
Lucas	M	36	Unemployed	Guadalajara	Married	Middle School
Mario	M	53	Unemployed	Guadalajara	Married	Elementary School
Roberto	M	55	104,000	Guadalajara	Married	College Degree
Tobías	M	45	Not provided	Guadalajara	Divorced	College Degree
David	M	69	25,500	Guadalajara	Married	College Degree
Hernando	M	62	Unemployed	Guadalajara	Married	College Degree
Iván	M	63	24,000	Guadalajara	Single	High School
Jaime	M	42	Not provided	Guadalajara	Divorced	Elementary School
Mateo	M	53	30,000	Guadalajara	Separated	Middle School
Milagro	M	26	19,100	Guadalajara	Single	Middle School
Francisco	M	57	Not provided	Guadalajara	Separated	High School
Andrés	M	53	Not provided	Guadalajara	Married	No formal education
Lucero	F	53	36,000	Guadalajara	Union Libre	High School
Pepe	M	64	60,000	Guadalajara	Married	Middle School
Armando	M	42	14,400	Guadalajara	Married	Middle School
Irene	F	59	54,000	Guadalajara	Married	Technical School
Dennis	M	44	Not provided	Mexico City	Divorced	Middle School
Javier	M	19	Not provided	Mexico City	Single	High School
Martin	M	39	Not provided	Mexico City	Married	High School
Pablo	M	44	Not provided	Mexico City	Married	Elementary School
Fernando	M	56	Unemployed	Mexico City	Separated	Elementary School
Luis	M	60	Unemployed	Mexico City	Married	No formal education
Alfredo	M	73	Unemployed	Mexico City	Widowed	Elementary
Karla	F	38	60,000	Mexico City	Married	High School
Silvia	F	39	54,000	Mexico City	Single	Technical School
Patty	F	54	14,400	Mexico City	Single	Elementary School
Julián	M	61	120,000	Cuernavaca	Married	Middle School
Leónidas	M	52	Unemployed	Cuernavaca	Married	College Degree
Manuel	M	44	36,000	Cuernavaca	Union Libre	Middle School
Alfredo	M	25	Not provided	Cuernavaca	Single	Middle School

TABLE 3: AMPUTATION/PROSTHESES INFORMATION

Participants	Year of Amputation	Year received prosthesis from LIMBS, Intl.	Years living with limb loss	Cause of leg Amputation
Kevin	1995	2017	23	Trauma
María	1981	2016	37	Trauma
Martin	2016	2017	2	Trauma
Ramón	1988	2016	30	Birth
Antonio	1991	2017	27	Trauma
Darío	1998	2017	20	Birth
Juan	2011	2017	7	Diabetes
Joan	2015	2017	3	Infection
Rafael	2015	2017	3	Diabetes
Oscar	2002	2017	16	Trauma
Arturo	2011	2017	7	Illness
Augusto	2012	2018	6	Diabetes
Irving	2017	2017	1	Infection
Jacobo	2016	2017	2	Trauma
Jeremías	2015	2017	3	Trauma
Lucas	2016	2017	2	Trauma
Mario	1982	2016	36	Infection
Roberto	2017	2018	1	Trauma
Tobías	2016	2017	2	Diabetes
David	2012	2015	6	Diabetes
Hernando	2016	2016	2	Trauma
Iván	2016	2017	2	Infection
Jaime	2016	2016	2	Infection
Mateo	2015	2017	3	Diabetes
Milagro	2015	2017	3	Trauma
Francisco	2015	2018	3	Diabetes
Andrés	2017	2017	1	Diabetes
Lucero	1981	2017	37	Illness
Pepe	2017	2017	1	Infection
Armando	2015	2016	3	Diabetes
Irene	2016	2017	2	Diabetes
Dennis	2016	2017	2	Trauma
Javier	2017	2018	1	Infection
Martin	2016	2017	2	Diabetes
Pablo	2017	2018	1	Trauma
Fernando	2017	2017	1	Trauma
Luis	2016	2017	2	Trauma
Alfredo	2017	2017	1	Diabetes
Karla	2017	2018	1	Illness
Silvia	2016	2018	2	Diabetes
Patty	2007	N/A	11	Diabetes
Julián	2017	N/A	1	Diabetes
Leónidas	2017	N/A	1	Diabetes
Manuel	2016	2016	2	Trauma
Alfredo	2016	2017	2	Diabetes



## **Vita**

Roger Andrew Renteria was raised in the working-class community of Socorro, Texas. Renteria started his college career as a high school student of Mission Early College High School. In the fall semester of 2016, Roger received his B.A. in Sociology with a minor in Biology from the University of Texas at El Paso (UTEP). After graduating with his Bachelors, he began the Master's program in sociology at UTEP in the spring of 2017. As a graduate student, Roger was a research assistant for Dr. Jayajit Chakraborty and Dr. Aurelia Lorena Murga. He also was employed through the NIH funded BUILDing SCHOLARS program as a mentor for a group of first and second-year students. In fall 2019, Roger will continue his education and enroll as a doctoral student in sociology at the University of Utah.

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