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# Self-Perceptions of Disability and Impairment in an Indian Prosthetic Population using Jaipur Foot Technology

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Self-Perceptions of Disability and Impairment in an Indian Prosthetic Population  
using Jaipur Foot Technology

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Fall 2016

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## **Abstract**

Twenty-nine first time and repeat prosthetic users were interviewed over a period of three weeks to determine how they perceived their own disability at Bhagwan Mahaveer Viklang Sahayata Samiti, or Jaipur Foot, located in Jaipur, India. The questions delineated different aspects of people's disabilities and impairment, and asked a multitude of questions regarding social, economic, political, and other contexts, influenced by the conceptual framework of the International Classification of Functioning (ICF). The study analyzed all of the factors as specified by the questionnaire and found that many varying trends over all types of prosthetic users. The study also used the ICF to determine whether or not it can be used in the scope of this study. Notable trends found few differences between the support a person had and whether or not the person was a first time or repeat prosthetic user, as well as a general struggle due to political factors. Overall, the study found that since there were no distinct trends, it was consistent with the changes in the perception of disability in India. Current needs call for increased support for progressive disability-related legislative policy, resource centers, more accessible buildings and transportation, and increased awareness of people with disabilities in general.

## Glossary of Terms and Acronyms

UL= Upper Limb Prosthetic

LL= Lower Limb Prosthetic

BK= Below the Knee Prosthetic

AK= Above the Knee Prosthetic

C= Caliper

ICF= International Classification of Functioning

WHO= World Health Organization

PWD= Persons with Disabilities Act of 1995

BMVSS= Bhagwan Mahaveer Viklang Sahayata Samiti/ Jaipur Foot

NGO= Non-Governmental Organization

Loco-motor Impairment= Any impairment relating to the inability to move or walk

Caliper= A prosthetic device used to support a person's leg for walking; usually for polio patients

Congenital disability= i.e. a person born with a disability

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## **Introduction**

### *Research Question and Overview*

The study applied ideas about disability, impairment, and the International Classification of Functioning (ICF) model to a patient population of prosthetic users in India. People who used different types of prosthetics were compared, as well as comparing first time prosthetic users to repeat users. The main categories of prosthetic types were divided into upper limb, lower limb, and calipers. The ICF model was also applied to determine whether it contributed to answering the main objective the study.

The study sought to answer the question: In an adult population of first time recipients and repeat users of prosthetics, what is the impact of receiving a prosthetic on the person's self-perception of disability and impairment, based on environmental and personal factors (social, economic, political, and "other")?

### *Disability in India: Overview & Definition*

As a myriad of ideals, perceptions, attitudes, and environment, disability can be said to affect almost any person either directly or indirectly. Regardless of whether or not a person is considered disabled, almost every person in society contributes to the mindset and the environment that affects those who are.

In India, a 1991 survey estimated 19 million people experienced disabilities related to physical or sensory disabilities (Dugal & Gangolli, 2005). This number has increased as recent 2011 census data reports 26.8 million to have disability

(Government of India, 2015). However, other reports state that 40 million people have disability in India (Mehrotra, 2011).

The World Health Organization (WHO) defines disability as an all-encompassing term that includes “impairments, activity limitations and participation restrictions,” as well as the interplay between the person’s environmental and personal factors (World Report on Disability, 2011). This definition is broad in contrast to the Persons with Disabilities Act (PWD) of 1995 in India. The PWD defines a person to have a disability if they are considered 40% or more disabled in the following categories: “loco-motor disability, blindness, low vision, hearing impairment, leprosy affected, mental illness and mental retardation” (Kothari, 2010).

### *Amputees, Polio, and Disability*

Despite increasing prevalence and recognition of limb loss and prosthetic use, the experience of disability in this particular population has been relatively unexplored. Approximately 10 million people who experience loco-motor impairment, with one million who have lost limbs and 4 million who have been affected by polio of the whole population of people with disabilities (Jaipur foot knee/limb, n.d.).

The shift since the 1980s from the causes of limb loss may have been a potential catalyst in how disability is seen in Indian society today. Primarily the highest cause of limb loss was due to infection. Since then, accidents have currently become the primary cause of limb loss, followed by non-communicable diseases (i.e.

diabetes), and then by infection (R. Arole, personal communication, 2016). Polio, eradicated in India in 2011, still has affected many in loco-motor function or paralysis (Government of India, 2015), leaving a significant portion of the population to seek calipers.

Other notable factors that affect limb loss and disability in India include high rates of poverty, increasing urbanization, caste, varied government roles in healthcare, and more. Trends demonstrate worldwide that higher rates of poverty lead to higher rates of disability (World Report on Disability, 2011). This is reflected in India, as about 69.5 percent of persons living with disabilities are in rural areas (Government of India, 2015). Despite this, the rampant increase of urbanization of India has led to a different change in how society may respond to those with physical impairments. For example, more urbanization may equate to increased use of technology, which in turn may lead to more accidents related to technology. The government is said to invest approximately 3.68% of its fiscal budget to healthcare (Grover, 2015). Of this expenditure, specific amounts of funding towards disability-related pensions and benefits were not explicitly stated. The Persons with Disability Act of 1995 (PWD) is a policy created to help disabled people but failed to give the full dignity, accessibility, and resources that disabled persons require (Kothari, 2010). Policy infrastructure helps at helping this population especially in education and employment, but implementation of this is still lacking (Sarin, 2013).

Other factors like caste and gender are significant in shaping the perception of disability as well. Those in scheduled castes or lower castes already have a disadvantage in accessing proper healthcare (Ahuja, 2016). Most likely, persons

with disabilities may have less equity within this population of people. The role of women in the household, especially in rural areas is still a common problem Indian society faces (Khan, 2016). Reports by the Indian government have shown that more men are disabled compared to women, 1.5 crore of men to 1.18 crore of women (Government of India, 2015). However that may not be the case when looking at disability from a holistic perspective and due to the marginalization of women in society. If a woman has a congenital disability, they may grow up believing they “cannot expect to have a relationship with a partner...” and are then “deprived of the role of childbearing” (Dawn, 2013, p. 192). If a woman acquires impairment, she could face divorce or be outcast if her impairment is too costly or too burdensome. All of these factors will be taken into account throughout the whole study.

### *Views of Disability*

The social and medical models of disability are determined to help understand how disability may be viewed by individuals and by society. These models are used to explain disability in a particular way of thinking created by society (Sandahl, 2016). These models present varying levels of influence in perceptions of disability, and will vary everywhere. The social model explains that attitudes and behaviors of society towards certain individuals is what “disables” a person, and not necessarily by their physical or mental variation. A person may be disabled by societal attitudes because of their physical impairment. On the other hand, a person may have a physical impairment but not be disabled because society

does not treat them differently than those without a physical impairment. In comparison to the medical model of disability, disability is seen as something that must be fixed as cured via surgery, medication, etc. A person is disabled because they deviate from what is medically considered “normal,” and should be cured in order to make them able.

Although current views are changing, Indian society approached disability with the medical model and utilized charity, pity, and karma as a way to treat disabled individuals (Mehrotra, 2011). In other words, disability is still seen as a “social welfare issue” (Thomas, n.d.). Charity and pity generally meant that people with disability were treated overtly nice. Actions a person in a community would do towards a disabled person would have motives behind charity and pity (Plattner, 2011). Karma, in particular, was used as an excuse to describe why a person was disabled, relating to bad actions in a past life (Olivelle, 2009). This could underlie why disability has been so stigmatized in Indian society.

### *Impairment*

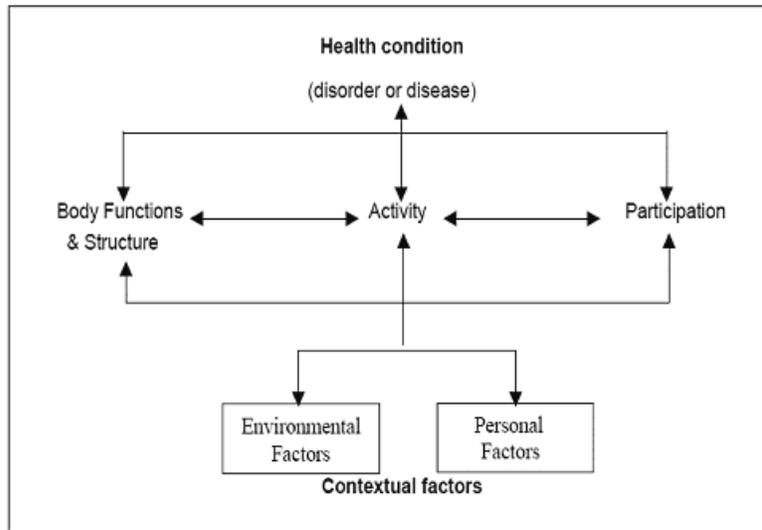
The WHO includes impairments as a term to help define disability, but for the purpose of this study, it is important to distinguish disability from impairment to understand how one may be affected by disability. The PWD (1995) legislation has little differentiation between these terms (Kothari, 2010).

Impairment can be defined as the anatomical difference in body function or structure from what is seen as a normal, functioning body. Impairment has a multitude of variations: physical, psychosocial, or intellectual. Examples of

impairment can range from limb loss or paralysis to severe depression or autism. In the spectrum of this study, impairment will generally refer to limb loss, paralysis, or anything related to loco-motor function. In contrast, disability will be looked at more conceptually and as an idea, mindset, or attitude created by society in response to a person's impairment.

### *International Classification of Functioning*

To further understand how disability can affect individuals, the WHO's International Classification of Functioning, or ICF model, will be utilized (WHO, 2001). The ICF is a model used to help assess and evaluate disability by looking at environmental and personal factors that either contribute or hinder a person's ability to participate in certain activities in combination with their health condition and body functions (World Report on Disability, 2011). The importance of ICF is that it combines a multitude of factors that looks holistically at factors contributing to a person's disability (WHO, 2001). It can even be used to integrate the social and medical models explained earlier.



**Figure 1. (World Report on Disability, 2011)**

#### Explanation of the ICF Components

**Health condition:** the disease, disorder, or injury affecting a person, which may affect what is defined as impairment

**Body Functions & Structure:** bodily functions reflect physiological aspects that run the body systems while structure is the anatomical aspect of the body; a dysfunction of either of these is called impairment

**Activity:** an individual's ability to perform a certain action or type of work

**Participation:** an individual's engagement in an activity or scenario

**Environmental Factors:** "barriers to or facilitators" of a person's ability to participate in activities; factors related to: social, economic, political, and "other" ideas

**Personal Factors:** not concretely defined, but may include basic information that influences a person's motivation and self-confidence like gender, age, education level marital status, occupation type, salary, etc.

(World Health Organization, 2001)

#### *ICF application*

The environmental and personal factors of the ICF were used as a theoretical basis for developing and analyzing this study. Because the ICF is extensive in its coding classification, only the chart (figure 1) was utilized. The contextual factors,

environment and personal, were separated into three categories: social, economic, political, and “other” to help formulate questions around disability and impairment. Examples of interviewees were applied to test whether it can help answer the research question.

*Setting: Jaipur Foot*

Non-governmental organizations (NGOs) have aimed to fulfill the needs of communities that have not been addressed completely by the Indian government and by society itself. In particular, Bhagwan Mahaveer Viklang Sahayata Samiti (BMVSS), also known as Jaipur Foot, has been instrumental in helping those in need, especially due to the increase and prevalence in limb loss and prosthetic use. The NGO has provided free prosthetic limbs to anyone who requires one since 1975 (Jaipur foot/ knee limb, n.d.). A team of skilled laborers, technicians, and healthcare providers work in the center to ensure that each person who comes is properly fitted with a customizable prosthetic with proper treatment and respect, and not as a charity (n.d.).

The Jaipur foot and Stanford-Jaipur knee technology has also been internationally acclaimed and recognized by many due to its durability, function, low-cost, and ability to help people integrate back into the community (n.d.). The Jaipur Foot (Figure 2) itself has the ability to mimic the different plane movements of a human foot, via dorsi-flexion, inversion and eversion, and transverse rotation (n.d.). The Stanford-Jaipur knee on the above the knee (AK) prosthetic (Figure 3) allows for activities like squatting and sitting crossed-legged, which is a common

activity done especially in Asian countries. This, along with the ability to create the limbs in a short period of time, has attracted people across India, leading to the establishment of other BMVSS centers and camps nationally and internationally. The main center is located in Jaipur, and hosts approximately 80-100 people per day from all over the country (S. Bhansali, personal communication, 2016). This, along with the reputation for being the “World’s largest organization for the disabled,” seems fitting that the study was conducted here.



**Figure 2<sup>1</sup>**



**Figure 3<sup>2</sup>**

### *Significance and Related Studies*

The application of the ICF model is still emerging when it comes to applying it solely for prosthetic and limb loss patients in research studies. The use of the ICF is feasible on a prosthetic patient population, but it is also tedious, and must be more specific towards the health condition (Burger, 2011). Other related studies similar to this one used concept indicators said by patients during interviews to

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<sup>1</sup> This is the Jaipur foot placed on all lower artificial limbs (Jaipur foot, n.d.).

<sup>2</sup> This is the above the knee lower limb including the Stanford-Jaipur knee (Jaipur foot, n.d.)

classify any facilitators or barriers in their environment, functioning, and participation (Xu, Kohler & Dickson, 2011). Instead, this study identified its own indicators and created it into a questionnaire to test how effective or ineffective each indicator is. This was done due to limitations in time and communication.

## **Methods**

### *Overview*

A proposal was sent and reviewed by the Local Review Board (LRB) before the study was conducted. Certain protocol, as specified by the LRB, was set to ensure that each participant in this study is treated according to proper ethical standards.

Twenty-nine primary interviews were conducted over a period of three weeks. Most of the interviews were spoken in Hindi through the help of a translator. Twenty-nine individuals with upper limb, lower limb, or caliper prosthetics were interviewed. These interviewees were considered the primary population sample. A few supplementary interviews were conducted to help gain additional perspective of disability. This included two technicians with a prosthetic and orthotics degree, as well as the founder and chief patron of BMVSS. In addition, two schools for children with disabilities, Disha and Umang, were also visited in Jaipur. Although they were not included in data analysis, the discussions held at these schools were instrumental in helping gain insight to the perception of disability in India.

The patient population, as per ethical standards, were required to be ages 18 and over, and not considered a part of a vulnerable population in order to be

interviewed. The study also required that the person to have lost a limb (upper or lower) or have an affected loco-motor function. Those with an affected loco-motor function previously had polio early in their life. The study also specified that the persons interviewed were at Jaipur Foot were first time or repeat prosthetic users. They have already received or were about to receive an upper limb, lower limb (AK and BK), or caliper (C). The criteria did not specify against caste, ethnicity, gender, location, income, or employment status, and rather encouraged diversity in these factors.

#### *Questionnaire Development*

Preliminary interviews at BMVSS were conducted in order to develop a questionnaire that was relevant, comprehensible, concise, and specific towards Indian prosthetic patients. Each question was developed and aimed towards a social, economic, political or “other” factor. For example, the question “Do you go with your family to visit relatives?” was asked as part of the social category. In the Indian context, many people go to visit family during festivals or holidays. Answering either yes or no could indicate social stigmas that the person faces with their family. It also serves as an effective way of comparing patients who are first-time or repeat prosthetic users. If a first time prosthetic user says “no” to the question above and a repeat user says “yes,” then possible indications could determine that the impact of the prosthetic creates inclusiveness for the person in their family. A question classified under “other” asked: “After your accident, did you feel more sad because you lost your limb OR because you were unable to work?” If a

person answered that they lost their limb, it could indicate how they were thinking more about having their impairment as opposed to thinking about the consequences that may come in society with having lost a limb. If a person required a caliper and had not lost a limb, each question would be worded appropriately to say “did you feel more sad because it was difficult walk from polio...” instead.

Creating the questions to have either “yes” or “no” answers were more effective than open-ended questions because it obtained information without losing translation from Hindi to English. Other questions were also closed-ended, giving a few options for certain emotions, such as ashamed, sad, supportive, or surprised/shocked. If a person added an additional emotion to what was on the list, it would help gather more ideas about what types of emotions a person may associate about their impairment.

### *Primary Interviews*

As stated, approximately 29 primary interviews were conducted with persons over the age of 18 requiring or using a prosthetic (BK, AK, UL, C) with the help of a translator from Hindi to English. Each day, around 4-5 people were interviewed. Generally each person interviewed per day used a different type of prosthetic. A majority of the interviewees were also men, as there were rarely any women available.

The beginning of the interview asked for personal information: name, age, gender, marital status, state, educational level, type of employment, type of prosthetic required, cause of impairment, and if it was their first time at BMVSS.

Then, eighteen questions surrounding their disability and impairment were asked, divided into the social, economic, political, and “other” categories (Appendix A). To keep up with each question asked, a simple numbering system was assigned to each question. Any information translated into English was written down. This allowed for a quick interview process, lasting no more than 10 minutes per person.

### *Supplementary Interviews*

Two people who worked at BMVSS with a degree in prosthetics and orthotics were interviewed in English. They were interviewed with a set of separate questions developed at gaining additional insight on how disability and impairment were viewed (Appendix B). These questions asked topics as a general overview about how they perceive the prosthetic users they work with daily, and their general opinions on working in an organization for the disabled. This was also necessary as they are the primary contact between the patient and prosthetic, since they are involved in creating a customized prosthetic and ensuring correct fitting and comfort for the patient. The founder of BMVSS, Dr. DR Mehta, was interviewed as well. Questions for him surrounded his ideas on disability, as well as learning more about the organization itself (Appendix B).

## **Data**

### *Understanding the Primary Interview Population*

Based on the personal information collected, brief analysis was applied in order to learn more about twenty-nine interviewees. Almost everyone came from a

variety of states around India, including Uttar Pradesh, Rajasthan, Matar Pradesh, Tamil Nadu, Maharashtra, Jharkhand, and Bihar. Fourteen people were receiving their prosthetic device for the first time and fifteen others have come to the center multiple times either for readjustment or for another limb. A majority of these people were in the age range of 18-30 years old. Nine BK, eight AK, four UL, and 8 C patients were taken into account. Every type of prosthetic user was in the age range of 18-30. Every type of prosthetic user except UL was in the age range of 30-45, and only 1 AK and 1 UL person was 45-60+ years old. The types of employment varied for this population as well. Approximately 38% were unemployed, consistent with the 2011 Census data (Government of India). 17% were students, 17% were employed with a degree, and 17% had other types of jobs (i.e. electrician, shop worker, etc.). The smallest category worked in agriculture, at 10%. The amount of education ranged from illiterate up to a post-graduate degree. Many people considered illiterate had some schooling, usually until 4th or 5th grade. A large portion of the people had attended school up until 8th grade, and quite a few attended or graduated from high school. Most of the other students were working towards a degree in college. Approximately 80% of the people interviewed were unmarried, with only one person indicating that they were separated from their spouse post-accident. Lastly, 50% of the causes of limb loss were due to a bus, truck, train, or machine accident. Around 28% of the cases were due to polio, and 21% was due to another cause, mainly diabetes, gangrene, or electric shock. Graphs displaying this information are located in Appendix C.

## Results

### *Social*

- Question: “How did your family react to when you lost your limb/had polio?

(Answer choices: ashamed, sad supportive, shocked, other)

Many said a mix of these emotions. In particular, polio patients were more likely to say supportive, while the limb amputees said that their families were sad and/or shocked more frequently. Others amputees added in additional emotions, such as angry, hopeless, or sympathetic.

- Question: “Do you go with family to visit your relatives?”

Neither group had any distinguishing answer that indicated a higher likelihood of saying yes or no to coming to visit their relatives.

- Question: “How did your community react when they saw you post-amputation?” (Answer choices: stared, did nothing, treated nicely, treated worse)

Polio patients said answers that were all across the board: their community reaction to their illness/the effects of their illness went from worse to no change to nice treatment. Most of the UL amputees said that no change was perceived in how the community reacted to their amputation. Many of the BK and AK patients indicated higher tallies of nice, sympathetic, or supportive reactions.

- Question: (If applicable) “Did your classmates treat you differently in school than other people?”

Almost everyone said that they were treated like everyone else or had very supportive classmates. Only two people stated that they felt like they were treated differently.

### *Economic*

- Question: "What is your family income?"

The range of yearly family income went from 12,000 to 12 lakh.

- Question: "Are you dependent financially on your family or is your family dependent on you?"

Most of the first time patients said yes. Comparatively, more repeat prosthetic patients reported that they were self-dependent. Many still replied that they were dependent. One person said that "we do not depend on each other, we support each other."

- Question: "What did you do before you lost your limb? What did you do right after the accident (If applicable)? What will you do with your new prosthetic?"

First timers reported that they were a student, farmer, driver, or unemployed. Almost everyone said that they did nothing after their accident (with the exception of people affected by polio, as all of them were affected during childhood). Only a few said they continued to study, and one person said they went back to work. This group also said a few things that once they receive their prosthetic, they would "find a new, normal life," "work easily," "find a government

job”, or “find new hope.” Most of them also said they would find work, study, or try to continue their previous work.

Compared to the repeat patients, all said similar but more specific answers. For example, a person with a BK prosthesis said that they were first a student, afterwards a typist, and with their new prosthesis, a teacher. One of the women said that they used to work as a laborer, but then used their prosthetic to stay at home and do house work.

### *Political*

- Question: “Do you have any government help or pensions? How did you find the help?”

Most of the people who answered yes had a government pension and were repeat prosthetic users. Only two out of the fourteen first time interviewees indicated having any government pension. People who received pension found this because of a neighbor, friend, or village panchayat (local village council). One person notably described that he found a pension because his village organized a camp to contact a local politician who eventually helped him find a pension from the government. Everyone who replied no to having a government pension said that they tried with no response or that they will try finding help.

- Question: “Is it hard for you to go inside buildings because of stairs?”

With the exception of upper limb prosthetic patients, most of the people said they have difficulty with using stairs in buildings in general. While more people in

the repeat prosthetic user group said that they found no difficulty using stairs, half of this group still reported difficulty with stairs.

- Question: “What type of transportation did you use to get here? Is it hard for you to use this transportation?”

People either used train, bus, or car. Trains were the most difficult to use, while little problems were said about using a car or a bus.

- Question: “Do you vote? Is it hard for you to get to the voting place?”

Everyone in the repeat prosthetic group said that they voted, and with the exception of two people, said there was no trouble getting to the voting poll. Half of the first time patients said that they did vote and had no trouble getting to the location. The other half said they did not vote.

- Question: “Where do you go when you are sick?”

Everyone answered they either went to their school, clinic, or hospital. Five people in total of both groups said that they went nowhere to receive healthcare.

### *Other*

- Question: “Do people call you disabled?”

Most of the people said yes. Those who said no were a majority of the BK prosthetic users.

- Question: “Do you think you should be called disabled with your prosthetic?”

The biggest distinction found was that first time prosthetic users said yes, they should continue to be called disabled, whereas more repeat prosthetic users

were likely to say no, they do not consider themselves disabled. One person said they should not be called disabled “if you are working.”

- Question: “Are you religious? Did you become more religious after your accident/illness?”

Everyone except one person said they were not religious. Almost half of the first time interviewees said yes, they became more religious. The others either replied no, or that they became less religious because it was “hopeless.” Those in the repeat prosthetic user group had similar results.

- Question: “Were you affected more by losing your limb/the effects of polio or because of your inability to work?”

The results were had little distinction between groups. Almost half of the people said they were more affected by limb loss. Three people chose both options. Three people in the repeat prosthetic group said neither or that they did not “feel anything.”

## **Analysis**

### *General Result Analysis*

Social perception of family and community is most different between polio-affected patients and amputees. Post-polio patients were more likely to say that their family was supportive most likely because they and their family had a longer period of adjustment time to comprehend their impairment. A family who has a child facing polio could have the expectation that the child may become paralyzed or have loco-motor dysfunction as opposed to a family that would suddenly learn or

limb loss due to accident. This could describe why the emotions the amputee patients said were more negative, like sad, angry, hopeless, etc. However, there is little distinction for other questions in the social category. One may expect that post-prosthesis, almost everyone would say that they went along for family visits, but there was no pattern between any of the groups that demonstrated that having a prosthetic increased family inclusion.

It is also difficult to understand whether people were dependent financially on their family because of their disability or because they were dependent due to how family is structured in India. The same goes when asked what the family did for the person with a disability. With or without disability, families are co-dependent of each other; many times, children earn income that goes back to the family, and a family will take care of everyone regardless of whether or not they are not disabled. It can also be speculated that since such a large number of persons are unemployed, they have to rely on their family financially. There are a few that have said they are self-dependent or said no to being dependent on their family, however these were scattered responses in all of the groups.

Responses in the political category weigh heavily on the lack of government implementation for handicap pensions and accessibility (buildings and transportation). Those who did receive pensions were found to have a lot of help from their community. This could equate to earning positive impact from the community in response to a prosthetic. Trains were noted as more difficult to use than buses or cars. Many trains that travel long distances have a high stair entryway and narrow passageways, which is a possible reason why this had higher difficulty,

especially if a person uses crutches. Entry into buildings via stairs has continuously been an issue, and not much urgency has been made in creating additional accommodations. The use of a prosthetic may help a person use the stairs, however only half of the people who are repeat prosthetic users have said yes to having little difficulty using stairs.

The higher incidence of BK prosthetic patients stating that others did not call them disabled exhibited an inclination towards appearing “normal” to others. A BK patient can adjust the quickest with their artificial limb and mimic the most natural gait compared to all of the other artificial limb patients (Observation, 2016). It is also significant that almost everyone said that they did not consider themselves disabled, regardless of whether or not they received the prosthetic yet. The expectation of receiving a prosthetic may be enough to make a person think they had no need to be called disabled. The cosmetic appearance of having a prosthetic also allows for passing off as normal and has no need to make a person have the name. The stigma of disability or other association people think of with disability (i.e. psycho-social or intellectual disabilities) may make people believe it to be an unnecessary label.

The use of religion as a means of coping towards a person’s impairment indicated a few key speculations. One is that becoming more religious could be related to karma. Becoming more religious could help restore a balance of previous action. A person may think of turning to religion as repentance. Becoming more religious may also allow a person to rely on something besides family and friends to help their situation. On the other hand, becoming less religious meant the person

became discouraged by religion, or saw it as redundant in helping a “hopeless situation,” as reiterated by some amputees. Others who said they did not become more religious have indicated religion as a constant in their life, and it did not relate to why or how they were disabled. Since all of the results were mixed on this, one can only guess the possible reasoning behind their answers.

Lastly, more people were likely to think of the health condition or physical anatomical loss as more influential than the consequences that follow, like a lower inability to work, higher dependency on family, or even social consequences. It was more confusing to understand why a person had felt nothing towards an inability to work or limb loss. The people that said “neither” had contradictory factors that do not back up the answer, such as unemployment, worse treatment in the community, and one even said that they go nowhere for healthcare. Since these were all repeat prosthetic patients, the impact of the prosthetic on these people could have been desensitization or acceptance towards their impairment.

#### *ICF: Focus Analysis*

The answers of three individuals were utilized into the ICF chart model to exemplify the results (figures 4, 5, & 6). Aside from demonstrating the usefulness and application of the ICF theoretical components into the study, it allows for a comparison between patients. These people were chosen to show differences and similarities between age, gender, education, income, and almost all other environmental and personal factors.

Comparatively analyzing these three charts have led to various conclusions on the impact of prosthetics. Effects on a person's disability can be looked at by looking at their age, level of education, gender, support system, incidence of accident or health condition, and facilitators or barriers in their environment because of this model. A brief insight can be made on their self-perception of their disability itself even if all of the factors mentioned above are contradictory and show little commonality between each other. While the ICF can help understand the scope of disability, it cannot help understand the scope of impact of the prosthetic itself on a person's disability in the context of this study. This is because there are no baseline measurements that effectively compare a person's disability before and after receiving a prosthetic to determine its full impact. Looking at first time versus repeat prosthetic users with this model will only allow for comparison between factors between these people.

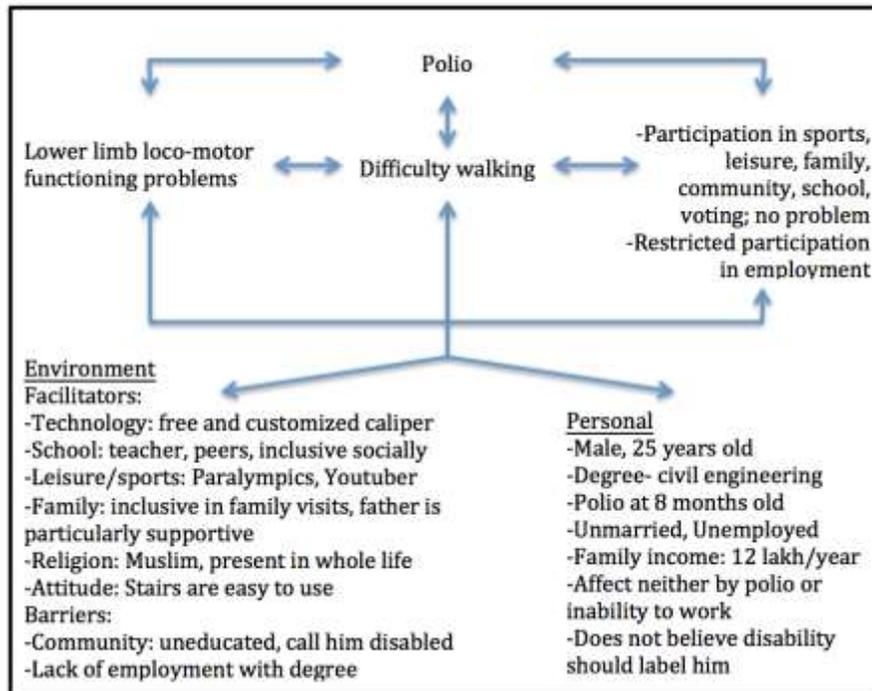


Figure 4

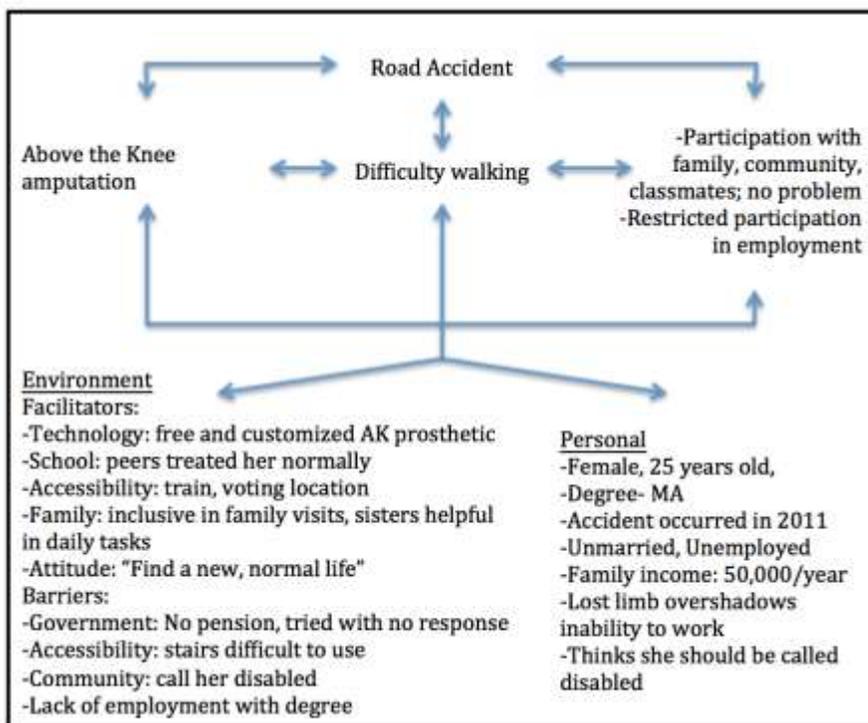


Figure 5

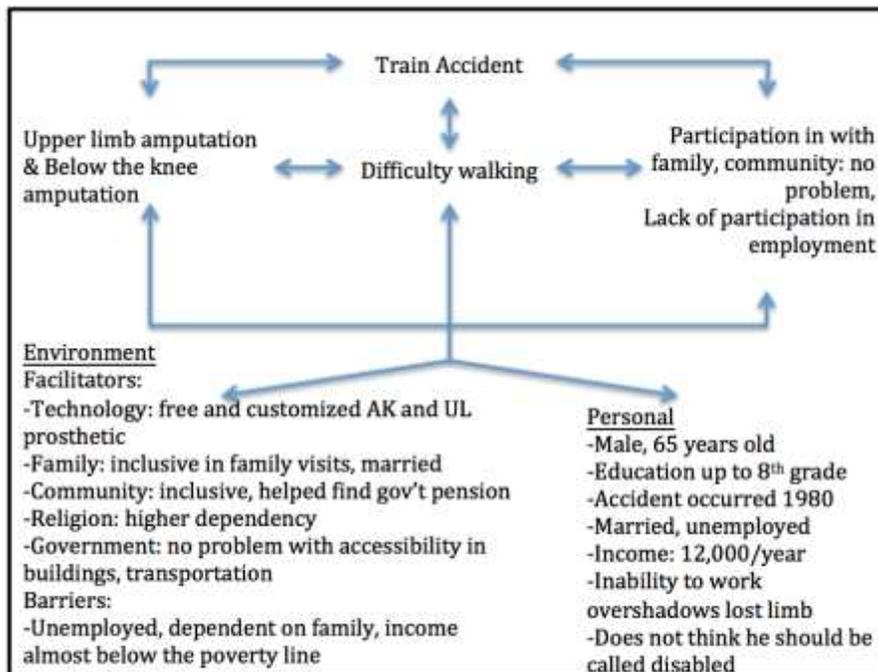


Figure 6

## Discussion

Overall, it can be seen that the results were mixed and had no distinct trend that favored one group (first time versus repeat prosthetic user or between different types of prosthetic types) over another in all or most of the categories. The ICF has been helpful in determining this.

These results are consistent with current trend of disability in India today. Perhaps 20-30 years ago, this study could have been conducted and more conclusive trends could have been seen. There may have been a huge difference in improving a person's life between the first time and repeat patients in almost all of the categories. However, after conducting supplementary interviews and facilitating discussions with professionals in the working with people with disabilities, one

thing has been repeated multiple times: disability is an attitude and has been changing, especially in the last ten years. The biggest disability in a person's life is their mindset towards an inability to do something, rather than an actual impairment itself. "Disabled" can be considered more as a label than an actual condition of being. Other people have defined also disability according to the WHO definition of disability, according to personal experience in the field, or according to the government definition of disability.

Indian society has come to a crossroad of change in how everyone, not just by the individual or the health professional, perceives disability. In the past, disability would previously have been defined as the actual impairment itself. Increasing numbers of people have begun to realize that disability can be looked at differently, as something in the mind rather than in the person's impairment. The current PWD act of India definition does not account for this change in definition and re-conceptualization of disability, which is why there is still critique on this act.

As seen with the ICF examples and other results described, community and family support systems are present in one way or another for Indian prosthetic users. Even in cases where big support systems have fallen, individuals have described of others that have built up in its place. A person may be more overcome by limb loss over the inability to work because there are people that are there to help them financially. Another may be more overcome by their inability to work because unemployment rates for persons with disabilities are still high. Age also factors into this reasoning. A person who lost their limb during adolescence would respond differently than adults who have families depending on them financially.

Even with this reasoning, the amount of a person's salary is not always exhibiting trends of self-recognizing disability. A lower salary does not always mean a person is always likely going to face more disability. Although poverty has the potential to create disability, it does not equate to the potential to perceive disability.

Some of the biggest environmental barriers of the Indian prosthetic user's experience with disability this study has found has been linked more to political factors over everything else. While the prosthetic technology is wonderful in enabling an individual's independence and self-confidence, physical barriers still remain. Inaccessible buildings and transportations are problems that continue to remain. When whether a person had government help most commonly was answered "tried, no response."

Every person interviewed for this study has acquired impairment at different times in their lives and are experiencing different changes in how society may affect their own perception. For example, people that had polio or lost their limb prior to 1995, when the Persons with Disability Act was established, would have been affected most by old societal views on disability. They especially would have faced more inaccessible buildings and transportation, as well as policy pre-PWD act of 1995, designed more towards helping people with disabilities. These people would also have experienced the change in how disability may have been before versus what it is currently becoming to be seen as. Seeing political change as well as societal change towards an attitude would mix a person's self-perception of their old and new views of disability. Those who lost a limb or grew up with the effects of polio in the last ten years have experienced disability in a time where it is changing

and where policy does exist to help them. These people are still affected by older views of disability anywhere they go.

## **Conclusion**

Many of the interviews, discussions, and conversations have taken place over the course of three weeks has illustrated mixed and changing trends of society's viewpoints towards disability. The impact of a prosthetic has not changed current support systems as those have been in place long before impairment. A prosthetic has not always changed the employment status, ability to obtain government help, accessible infrastructure, religiousness, nor voting tendencies. The impact of this technology is thus an ability to facilitate change if a person warrants it. The self-confidence and independence that a person gains from a prosthetic empowers them to decide to choose whether or not any of these factors will enable or disable them. People may see their amputation or polio as a "challenge or an end" (P. Mukul, personal communication, 2016) and it is up to the person to make the choice of what to do with it, regardless of their environmental and personal factors. This is consistent with definition of disability equating to an attitude.

Although the ICF model was unnecessary in helping answer the research question, it was helpful in developing the study, as well as trying to look at patients holistically rather than just as a polio patient or amputee. The ICF, as useful as it is, is limited in understanding the impact unless an initial assessment is made with it. This calls for future study to focus on creating a baseline measurement with the ICF and then reevaluating right after fitting and after period of time of usage. The ICF

can be utilized in further finding that a person's attitude gained from receiving a prosthetic is what will influence their environmental factors more heavily than any other thing.

Many attitudes are changing in a trend that displays society as more inclusive and accepting of differences more than before. Technology, like the Stanford-Jaipur knee, has continued to progress and further enhances a person's self-reliance and inclusion into society. Schools like Disha and Umang in Jaipur are helping address a population of people with cerebral palsy, autism, intellectual disabilities, and multiple disabilities, in both education and employment. NGOs across the country have similar initiatives and are resource centers to . A pending bill in the Indian government, the Right of Persons with Disabilities Bill (2014), seeks to address the current discrepancies of the PWD act of 1995.

With these changes is a continual call for recognition, attention, and respect for people with disabilities. Government advocacy, more resources and support centers, and integration into the community can help do this. Perhaps then more people will be seen, not as disabled, but rather as people with normal differences.

### *Limitations*

Some limitations of this study must be further recognized. The biggest limitation of this study was the language barrier even with the help of a translator. The additional information and insight gained from the interviewees could have been more beneficial to the study if such a language barrier was not an issue. More women available for interview were unavailable, leading towards a gender

discrepancy in analyzing the data. More time at other centers and schools for disability, such as Disha and Umang, would have been beneficial in obtaining a additional comprehensive understanding of other disabilities in India at different ages.

#### *Additional Recommendations for Future Studies*

Aside from the recommended study with ICF mentioned above, more research should be done to study other subpopulations of prosthetic users, based on the outlined limitations. This could include women, children, and elderly people. Looking at disability and religion should be explored in depth as well, as religion is still a prominent aspect of many people's lives and can better understand the psychology of the family and person with a disability.

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## Appendix A

### Questionnaire:

- Name
- Age/Gender
- District/State
- Occupation
- Education Level
- Family members/Marital status
- Type of prosthetic required
- Cause of accident/health condition
- 1<sup>st</sup> time at the center?
  
- Social
  1. How did your family feel when you lost your limb?  
-Options: Ashamed, sad, surprised, became supportive
  2. What did your family do when you had no limb?  
-Options: Cook, clean, bathed, worked, or provided everything
  3. Do you go with your family to visit relatives?
  4. What did people in your village do when they saw you after your accident?  
-Did they stare? Did they treat you nice? Badly? Or nothing?
  5. (If applicable) Do your classmates in school treat you differently than other people?
  
- Economic
  6. What is your family income?
  7. a) What did you do for work before the accident?  
b) What did you do for work after the accident?  
c) What work will you do with your prosthesis?
  8. Are you dependent on your family? Is your family dependent on you?
  
- Political
  9. Do you have government help? How did you apply for the help?
  10. Is it hard for you to go into buildings because of the stairs?
  11. What type of transportation did you take to get here? (Auto, bus, train, etc.) Is it hard for you to use this transportation?
  12. Where do you go if you are sick?

13. Do you vote? Is it hard to get to a voting place?

- Other

14. Do people call you disabled?

15. Do you think you should be called disabled even with the new limb?

16. Are you religious?

17. Did you become **more** religious after your accident?

18. After your accident, did you feel more sad because you lost your limb **or** because you were unable to work?

## Appendix B

### Technician Questions

1. What is your definition of disability?

2. How do you see people change before/after they receive prosthesis?

3. What influenced you to work here? How did you get this job?

4. What is the difference between men and women's response to receiving an artificial limb?

5. What is your experience with disability?

6. Does a person receiving an artificial limb make them seem normal?

7. What is your favorite part of your job?

### Questions for Dr. DR Mehta

1. What is your definition of disability?

2. What are the biggest challenges you have faced in this organization?

3. How do you see people change before and after they receive prosthesis?

4. Please tell me more about your mother and her influence on you.

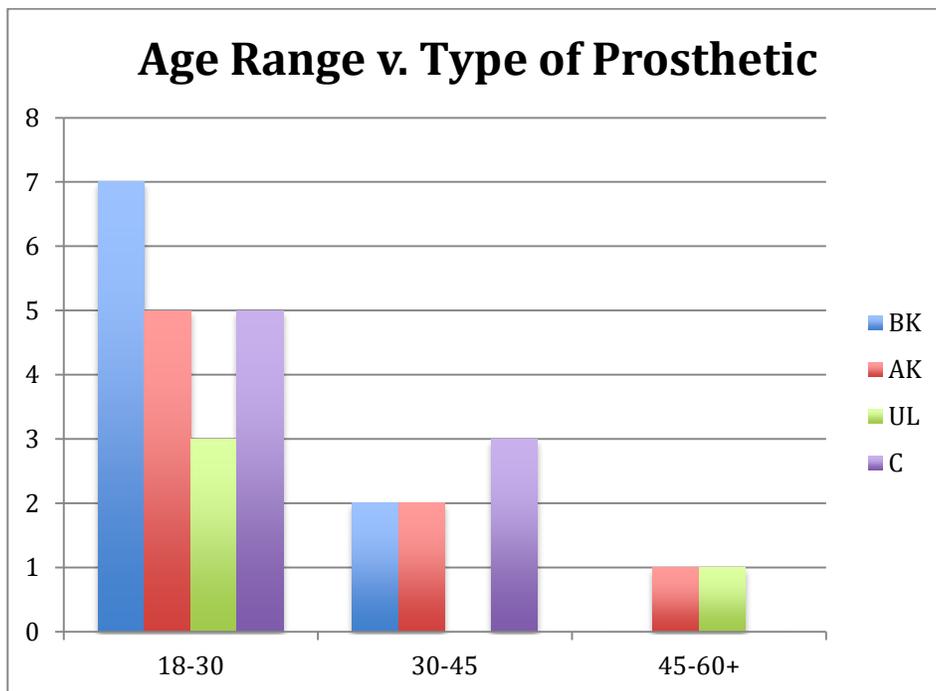
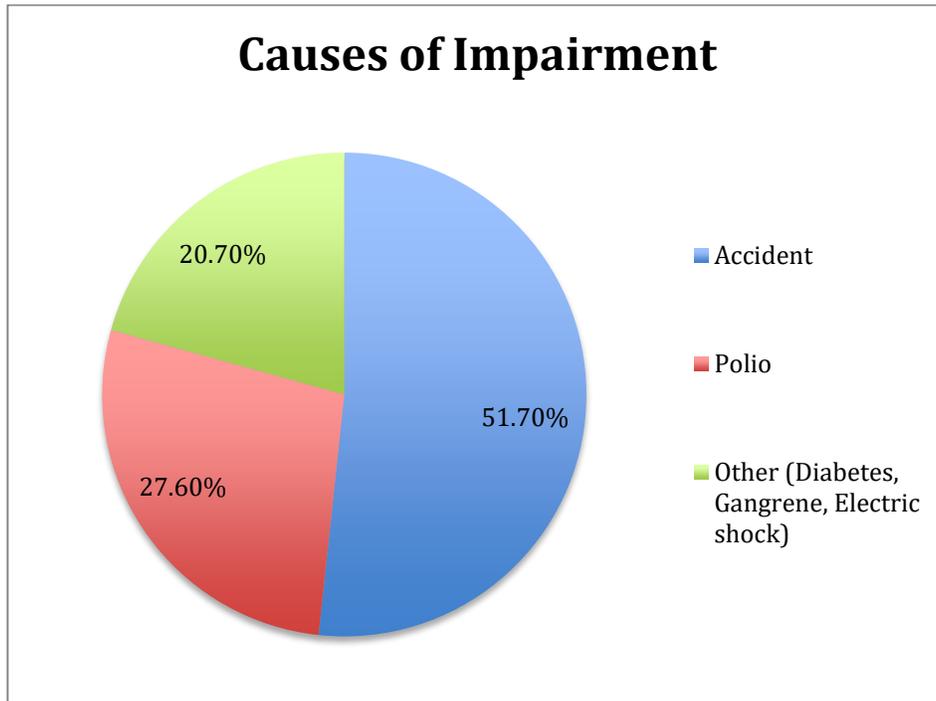
5. What other experience have you had with disability outside of this organization?

6. Please tell me more about the international camps BMVSS holds.

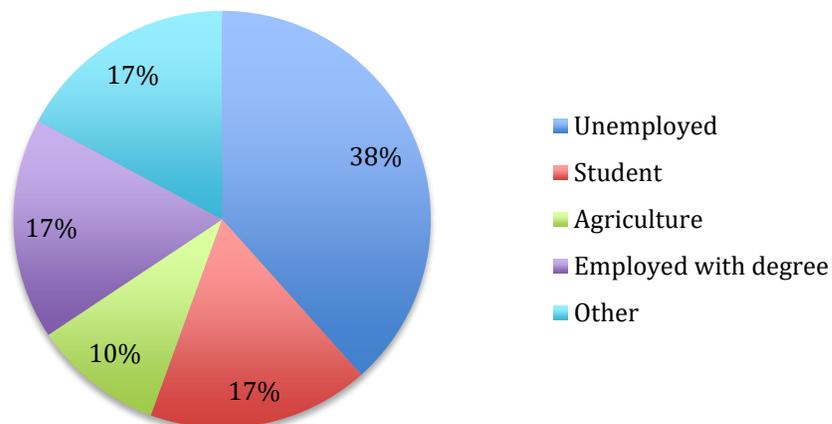
7. Many NGOS have good intent and mission but have been subject to the desires of their donors to further carry out initiatives they may not want to do. How has BMVSS been able to maintain their current vision and mission without being subject to its donors' own agenda?

8. What is something you would like to say to this upcoming generation?

### Appendix C



## Types of Employment



## First and Repeat Prosthetic Users v. Job Type

